What's Love Got to Do with it?
A Qualitative Study Addressing the Unmet Needs of Older LGBTQ+ Individuals Caring for a Spouse or Partner with a Chronic Medical Condition

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Abstract

Caregiving for an older spouse or partner with a chronic medical condition has become a prominent role in Western society as individuals are living longer and requiring more care. Most in-home care is provided through informal means by family members and friends. Spouses provide care longer than other informal caregivers and may suffer stress, burnout, and other physical and psychological challenges if they have unmet needs, such as lack of support and resources. Due to the events, encounters, and history experienced by older LGBTQ+ caregivers, they face a unique set of challenges and needs when caring for a spouse or partner with a chronic medical condition. The purpose of this qualitative study with an interpretive phenomenological design was to explore the perceptions and lived experiences of the unmet needs of older LGBTQ+ individuals caring for a spouse or partner with a chronic condition. Six spousal/partner caregivers participated in semi-structured interviews to explore their experiences and whether they led to any unmet needs. Findings of the data analysis with an idiosyncratic approach suggested that the participants did not currently experience significant discrimination from medical professionals, but this had not always been the case. There were several challenges that were unique to LGBTQ+ older adults, as well as remarkable ways they have developed resilience and created methods to minimize challenges. Some of the challenges included an increase in chronic conditions experienced by caregivers, lack of advance directives, stress, and unique family relations. To minimize these challenges, the participants formed chosen families and developed strategies for choosing medical professionals. Practical recommendations include cultural competency training for medical practitioners to improve wellbeing and outcomes for both the caregiver and care recipient. Further research can expand upon the background and demographics of the participants, specifically, the impact of race, location, and socio-economic status of individual participants.

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Chapter 1: Introduction

Caregiving for an older spouse or partner with a chronic medical condition has become a prominent role in society as individuals are living longer with more complex diagnoses (Bai et al., 2018). Informal caregivers are non-paid family members or friends who provide the bulk of assistance with activities of daily living (bathing, dressing, grooming) and/or instrumental activities of daily living (managing finances, shopping, cooking) (Amankwaa, 2017). Nearly 75% of care for impaired older adults in the community is provided through informal means (Amankwaa, 2017). Current research shows there are 41 million informal caregivers in the US, providing over 15 billion hours of care and assistance to loved ones (Cohen et al., 2021), typically older adults.

As advances in medical treatments are progressing, the percentage of individuals living past the age of 80 and requiring a caregiver has been increasing (Bai et al., 2018); however, this unpaid work does not come without a cost to the caregiver. According to Amankwaa (2017), caregiving can be a challenging experience as it not only includes day-to-day tasks (e.g., bathing, dressing, and grooming) but also larger tasks, such as medical decision-making. This work may lead to great physical and psychological stress to the caregiver (Amankwaa, 2017; Hawkley et al., 2020; Kim et al., 2021). When this physical and psychological stress is severe, it is referred to as caregiver burnout (Amankwaa, 2017; Hawkley et al., 2020; Kim et al., 2021).

Caregiver burnout can manifest as depression, anxiety, or isolation of the caregiver (Kim et al., 2017). Caregiver stress and burnout can cause physical issues to the caregiving spouse or partner, exacerbating debilities such as arthritis, high blood pressure, and other chronic diseases (Amankwaa, 2017). Spousal caregivers are more likely to maintain the role longer than other types of informal caregivers (Kim et al., 2021), thus increasing the potential for burnout and

long-term impacts. The closer the relationship between the caregiver and recipient, the greater the degree of stress—caregiving can even "increase the risk of mortality" for spousal caregivers (Amankwaa, 2017, p.2). Caregiving can reduce the caregiver's ability to engage in self-care activities such as exercise, mental health care and addressing their own medical needs (Amankwaa, 2017).

Older lesbian, gay, bisexual, transgender, and questioning or queer (LGBTQ+) individuals face a higher risk of chronic medical conditions than their heterosexual counterparts (Holcomb et al., 2021). There are currently 3 million adults over the age of 50 who identify as LGBTQ+, and this number is expected to grow to 20 million by 2060 (Fredriksen-Goldsen et al., 2019). Up to 45% of LGBTQ+ adults over the age of 50 are already caregivers to a partner or spouse compared to 23% of the overall population in that age group (Hawkley et al., 2020). (Anderson & Flatt, 2018). Caring for a spouse or partner living with a chronic medical condition in the LGBTQ+ community can present a unique set of challenges (Holcomb et al., 2021), which can in turn lead to a greater degree of unmet needs (Capistrant et al., 2020; Jones et al., 2018). Such challenges include higher prevalence of chronic medical conditions (Holcomb et al., 2021) and fear of discrimination by healthcare providers (Alba et al., 2020). Fear of discrimination may also lead to a reluctance or inability to advocate for their own or their spouse/partner's needs, as they may feel that there is still a stigma towards LGBTQ+ individuals within the medical community and society (Alba et al., 2020).

Caregivers of spouses or partners with a chronic medical condition may face longer and more difficult challenges than other informal caregivers, as their demands increase throughout the process (Gibson et al., 2019; Park, 2017). The caregiver may feel that they are losing their partner and begin the grieving process, long before death occurs (Gibson et al., 2019; Liew et al.,

2019). In the case of dementia, the caregiver may lose the social and emotional partnership they had with the other person (Hellstrom et al., 2005). If the chronic medical condition is debilitating, the caregiving partner may now be faced with taking on, and even learning, the tasks once completed by their partner, to keep the household running. However, due to fear of discrimination, older LGBTQ+ individuals may avoid sharing their sexual orientation with medical professionals (Anderson & Flatt, 2018; Furlotte et al., 2016), thus not receiving the support or resources other caregivers may garner. Candrian and Cloyes (2021) report that 40% of 60–75-year-old LGBTQ+ individuals have not disclosed their sexual orientation to their health care provider. These challenges lead to a greater degree of unmet needs (Capistrant et al., 2020; Jones et al., 2018).

Unmet needs may encompass a lack of advance directive documents that are necessary for the partner or spouse to direct care (de Vries & Gutman, 2016), a lack of understanding from the medical community (Anderson & Flatt, 2018; Furlotte et al., 2016), and a lack of social support (Holcomb et al., 2021; Jones et al., 2018). Social support would encompass friends and family who provide informal assistance to the older individual and their caregiver but may be diminished in the LGBTQ+ community due to discrimination and stigmatization, separation from family, and fewer biological relations (Holcomb et al., 2021). Through their research on the topic of support systems, Holcomb et al. (2021) found that older, LGBTQ+ individuals had higher rates of HIV, diabetes, other physical debilities and more instances of depression, anxiety, and suicidal thoughts.

For older, LGBTQ+ individuals, the additional challenges they face, such as discrimination and health disparities (Furlotte et al., 2016; Holcomb et al., 2021), can lead to a unique set of unmet needs, therefore research that specifically addresses the needs of LGBTQ+

older adult caregivers is needed to offer better support for the caregiver to provide adequate and dignified care to their spouse or partner. This is especially important for a group that already faces health disparities (Holcomb et al., 2021).

LGBTQ+ individuals may feel that there is a stigma towards them by homophobic or transphobic members the medical community and society (Alba et al., 2020; McCarron, 2020) and may not have the necessary support system set up to alleviate their responsibilities (Capistrant et al., 2020; Jones et al., 2018). Prior research has shown that this subgroup of caregivers already faces discrimination and health disparities when compared to heterosexual caregivers (Furlotte et al., 2016; Holcomb et al., 2021). They also may not have the necessary advance directives documents (de Vries & Gutman, 2016) in place when their partner becomes unable to make decisions on their own. This may be incredibly impactful, as laws around marriage equality have only changed within the last few years, and many older LGBTQ+ couples may remain unmarried. Older LGBTQ+ individuals may also be reluctant to disclose their relationship status for all of the above reasons (Toze et al., 2020).

To thrive in this role, caregivers need a support system (Silva de Sousa et al., 2021). Research has shown that resources and support directed to caregivers will benefit both the caregiver and recipient (Amankwaa, 2017; Hawkley et al., 2020; Kim et al., 2017). This is especially important for spouses who provide the bulk of caregiving duties for the greatest length of time (Amankwaa, 2017, Kim et al.; 2021). However, as LGBTQ+ adults age, a support system becomes less prominent (Holcomb et al., 2021). LGBTQ+ individuals have traditionally had smaller support networks due to stigma, discrimination, and laws that historically did not support gay marriage (Holcomb et al, 2021); as LGBTQ+ individuals age, they may feel the need to “go back into the closet” (McCarron, 2020, p.108), thus shrinking their support network even further.

A better support system will provide better outcomes for the caregiver (Hawkley et al., 2020) and thus, potentially better outcomes for the spouse or partner they are caring for. Better knowledge of how the lack of outside assistance and resources can lead to worsening psychosocial outcomes, which in turn lead to a great burden for the caregiver, can improve the medical system for LGBTQ+ older adults living with a chronic medical condition and their caregivers. A better support system and better information for practitioners will provide better outcomes (Hawkley et al., 2020) for both the caregiver and the care recipient.

The goal of this research was to understand the extent of the unmet needs and increased challenges LGBTQ+ caregivers face. The practicality of this research is to better inform future policies and the development of resources that are geared towards this group. Cultural competency training will be helpful to ensuring some of these disparities are tackled (Fredriksen-Goldsen et al., 2018), but the unmet needs of this population need to be studied before they can be addressed in practice, as more individuals are faced with the task of caring for their loved ones.

Statement of the Problem

The problem to be addressed in this study is that older, LGBTQ+ individuals face a unique set of challenges and needs when caring for a spouse or partner with a chronic medical condition (Furlotte et al., 2016; Holcomb et al., 2020). The ramifications of not addressing the unmet needs of this group of caregivers is that they may not be fully prepared or supported to care for their spouse or partner, leading to poorer outcomes for both the caregiver and the care recipient (Amankwaa, 2017; Kim et al., 2017); this is particularly salient as older LGBTQ+ individuals already have higher rates of disability and psychological concerns (de Vries & Gutman, 2016; Holcomb et al., 2021, McCarron et al., 2020) than their heterosexual

counterparts.

Older LGBTQ+ individuals face a distinctive set of circumstances when caring for a spouse or partner. The challenges LGBTQ+ individuals face, such as discrimination and health disparities, can lead to a unique set of unmet needs (Furlotte et al., 2016; Holcomb et al., 2021). They may be reluctant to disclose their relationship status (Toze et al., 2020) if they feel there is a stigma towards LGBTQ+ individuals within the medical community (Alba et al., 2020).

Previous research has shown that caregiving can be a challenging experience that causes great physical and psychological stress to the caregiver (Amankwaa, 2017), often expressed as depression, anxiety, and isolation of the caregiver (Kim et al., 2017). This research was needed to inform future policies and the development of resources that are geared towards this group, as the number of older, LGBTQ+ individuals is expected to grow to 20 million by 2060 (Fredriksen-Goldsen et al., 2018).

Purpose of the Study

The purpose of this qualitative phenomenological design study was to explore the perceptions and lived experiences of the unmet needs of older LGBTQ+ individuals caring for a spouse or partner with a chronic condition. This study is a logical, explicit research response to the problem of unmet needs of older LGBTQ+ caregivers through three basic concepts—lack of social support (Holcomb et al, 2021), lack of advance directives and other necessary documents (de Vries & Gutman, 2016), and fear of discrimination by medical and other professionals (Anderson & Flatt, 2018; Furlotte et al., 2016). The percentage of individuals who require a caregiver has been rising (Bai et al., 2018), and this often puts great strain on spousal caregivers. In the coming decades, the number of LGBTQ+ older adults aged 50 and over providing care to a spouse or partner will increase by 15% (Anderson & Flatt, 2018; Fredriksen-Goldsen et al.,

2019), based on current projections.

I recruited six LGBTQ+ individuals 50 years or older, caring for a spouse or partner with a chronic condition living in the US through online social media platforms such as Facebook, Instagram, and LinkedIn. Sample size in qualitative research is determined by the richness of the data being collected from participants and the point saturation may be reached (Guest et al., 2020) but should also remain small due to the detailed work that goes into each interview (Anderson, 2010). The data were collected through oral interviews via Zoom with participants; the researcher requested that participants allow the conversations to be recorded for accuracy and transcribed by Zoom for analysis.

Introduction to the Theoretical Framework

The Iridescent Life Course framework was developed by Fredriksen-Goldsen (2019a) as a more in-depth approach to the Life Course framework, specific to LGBTQ+ older adults. This framework was developed after extensive research and literature reviews to examine the intersectionality of all facets of LGBTQ+ aging – psychological, biological, social, behavioral, etc. (Frederiksen-Goldsen et al., 2019a). While most studies into LGBTQ+ older adult unmet needs around caregiver issues, rely on the Life Course framework, the Iridescent Life Course framework was the most appropriate for this work.

While the Life Course framework addresses the shared experiences of a cohort over their lifespan, the Iridescent Life Course framework specifically proposes that the unique history encountered by the LGBTQ+ community (trauma, inequities, marginalization, etcetera) forms the distinct challenges and accomplishments this group faces as they age (Frederiksen-Goldsen, 2020). This theory encompasses the risk factors that may lead to a unique set of unmet needs for older, LGBTQ+ individuals. Some of these factors include a lack of social support (Holcomb et

al., 2021; Jones et al., 2018) or advance directives documents (de Vries & Gutman, 2016) in place and fear of discrimination if they come out to medical providers or others (Albaet al., 2020; Toze et al., 2020). The intersectionality of these challenges, as well as greater health disparities than their heterosexual counterparts (Holcomb et al., 2021), put LGBTQ+ older adults at greater risk of having unmet needs.

The Iridescent Life Course framework guided the development of the problem and purpose statements as it focuses in on the unique history and challenges historically faced by the LGBTQ+ population, and how this history may inform the unmet needs of older LGBTQ+ caregivers. The Iridescent Life Course framework directed the development of the research questions which were posed to uncover the unmet needs of older LGBTQ+ caregivers of a spouse or partner with a chronic medical condition.

Introduction to Research Method and Design

This study utilized a qualitative methodology with an interpretive phenomenological design to capture the descriptions of the experiences of LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition. Qualitative research is descriptive and relies on non-numerical data to explore participants' perspectives and draw inferences (Chalmers & Cowdell, 2021; Husserl, 2012). Specifically, the phenomenological approach allows the participants to share their lived experiences (Korstjens & Moser, 2017; Smith & Osborn, 2015) from their own vantage point. This approach permits the participants the space to share their own, subjective accounts of how they have experienced the phenomenon being studied. Experiences with caregiving are unique to each individual and are best shared through storytelling by the person living with the day-to-day challenges, encounters, and victories (Andrews, 2020; Ford, 2020). This study relied on a phenomenological approach to collect data through semi-structured in-

depth interviews. This method compiles each individual's experience into a collective archive of the concept being studied (Clandinin et al., 2017) and the information garnered can eventually affect the way professionals interact with such individuals and improve practices.

The data from the study were analyzed using an idiographic, case analysis approach (Alase, 2017; Smith & Osborn, 1999), allowing the researcher to interpret all data from the interviewees' perspectives. The process of data analysis included transcribing the data with Zoom, organizing the data into general themes, coding the data, deducing the categories or themes, and then writing up findings (Alase, 2017; Moser & Korstjens, 2018).

I used deductive and latent approaches when analyzing the data, as these methods best fit the study. Deductive approaches are theory driven (Braun & Clarke, 2021); the starting point for this study is the prior research that shows LGBTQ+ older adults may already be at a disadvantage compared to their heterosexual counterparts due to discrimination, health disparities (Furlotte et al., 2016; Holcomb et al., 2021), and a deeper array of unmet needs (Capistrant et al., 2020; Jones et al., 2018). The latent approach to data analysis helped to uncover hidden meaning in the participants' language (Braun & Clarke, 2021). Transparency in data collection and analysis is presented in detail throughout the study to ensure that the research can be duplicated.

Building on previous research, the study added to this body of research by pulling together how these various issues, as well as others, lead to unmet needs of LGBTQ+ caregivers. Having the comfort and ability to disclose LGBTQ+ status will help to ensure that the caregiver receives the resources, support, and tools necessary for their own health and wellbeing.

Research Questions

RQ1

What are the lived experiences of the unmet needs of LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition?

RQ2

What is the perceived impact of the unmet needs of LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition?

Significance of the Study

The significance of this study is that it contributes to the field of psychology and gerontology by providing evidence of the unmet needs of LGBTQ+ older adult caregivers and how these needs may differ from that of their heterosexual counterparts. This information may impact the way professionals relate to LGBTQ+ patients and caregivers through a deeper understanding of their unmet needs. This deeper understanding will include the factors that contribute to these unmet needs (Furlotte et al., 2016; Holcomb et al., 2021) and how addressing such unmet needs may impact the caregiver's ability to provide care for their spouse or partner (Amankwaa, 2017, Kim et al., 2017).

There is currently a deficit in the area of services that reflect the needs or understanding of LGBTQ+ caregivers (Anderson & Flatt, 2018). This deficit of understanding and information has also led to a lesser number of formal caregiving to older LGBTQ+ individuals (Anderson & Flatt, 2018), placing more of the onus on informal caregivers. The implications of this research into the unmet needs of older LGBTQ+ caregivers may provide vital information for improving outcomes for these caregivers and the spouses or partners with chronic medical conditions they

care for, such as better physiological and psychological health (Amankwaa, 2017; Kim et al., 2017).

LGBTQ+ older adults face a higher prevalence of discrimination and health disparities when compared to heterosexual caregivers, as reported by previous studies (Furlotte et al., 2016; Holcomb et al., 2021). The unique unmet needs of this particular population must be studied in order to overcome the challenges and disparities they face. Findings will inform the professionals who work with this distinct group of caregivers and allow them to better assist the LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition.

Definitions of Key Terms

Caregiver

A caregiver is "a person who attends to the needs of and provides assistance to someone else who is not fully independent, such as an infant or an ill adult. A person who does the majority of the work is called the primary caregiver" (American Psychological Association, n.d., para. 1).

Caregiver Burden

Caregiver burden refers to the physical and psychological symptoms faced by individuals who are caring for another with mental or physical conditions, diseases, or disorders (American Psychological Association, n.d.).

Caregiver Burnout

Caregiver burnout is extreme physiological and/or psychological stress that can manifest itself as depression, anxiety, and isolation of the caregiver (Kim et al., 2017).

Caregiver Stress

Caregiver stress refers to the negative effects often felt by caregivers, such as "muscle

strain, skeletal injury, aggravation of chronic illness such as arthritis, or other sources of physical discomfort and pain" (Amankwaa, 2017, p.93).

Chronic Medical Condition

A chronic medical condition is a physical or psychological disorder that lasts for more than 12 months and affects an individual's functional capacity or requires routine healthcare (Raghupathi & Raghupathi, 2018).

Discrimination

Discrimination is the "differential treatment of the members of different ethnic, religious, national, or other groups. Discrimination is usually the behavioral manifestation of prejudice and therefore involves negative, hostile, and injurious treatment of the members of rejected groups" (American Psychological Association, n.d.).

Informal Caregiver

Informal caregivers are family members and friends that provide unpaid care, such as assistance with bathing, dressing, grooming, and medication administration to an older or disabled individual (Amankwaa, 2017).

LGBTQ+

According to the American Psychological Association (n.d., para. 1) LGBTQ is defined as the:

> abbreviation for lesbian, gay, bisexual, transgender, and questioning or queer: an inclusive term used to refer to the homosexual population in all of its diverse forms, to those with both homosexual and heterosexual preferences, and to those whose gender identity differs from the culturally determined gender roles for their birth sex.

Stigma

Stigma is defined by the American Psychological Association (n.d., para. 1) as "the negative social attitude attached to a characteristic of an individual that may be regarded as a mental, physical, or social deficiency. A stigma implies social disapproval and can lead unfairly to discrimination against and exclusion of the individual."

Summary

Older adults face many challenges when providing constant care to a spouse or partner living with a chronic condition (Amankwaa, 2017). They are at a greater risk for developing their own physical and psychological conditions (Amankwaa, 2017; Hawkley et al., 2020; Kim et al., 2021) that may impact their own health due to caregiver stress and burnout (Amankwaa, 2017; Kim et al., 2021). Caregivers must obtain social support and help from professionals to deal with this burnout. For LGBTQ+ individuals, there are additional issues that may lead to a greater level of unmet needs (Capistrant et al., 2020; Jones et al., 2018), as they are already facing health disparities (Furlotte et al., 2016; Holcomb et al., 2021) and a higher prevalence of chronic conditions (Holcomb et al., 2021) when compared to heterosexual individuals of the same age group.

Fear from decades of discrimination may prevent LGBTQ+ individuals from disclosing their relationship status with medical professionals (Anderson & Flatt, 2018; Furlotte et al., 2016). As these individuals may not have the necessary advance directive documents to make decisions on behalf of their loved one (de Vries & Gutman, 2016), they may be met with a smaller network of social support to assist them (Holcomb et al., 2021; Jones et al., 2018).

The problem addressed is that LGBTQ+ older adults face a unique set of challenges when caring for a spouse or partner with a chronic medical condition (Furlotte et al., 2016; Holcomb et

al., 2020). More information about this phenomenon is needed as the population of older LGBTQ+ individuals increase (Anderson & Flatt, 2018; Fredriksen-Goldsen et al., 2019), as this information will help to ensure better outcomes for both caregivers and care recipients (Amankwaa, 2017; Kim et al., 2017). The purpose of implementing this qualitative phenomenological study was to explore the perceptions and lived experiences of the unmet needs of older LGBTQ+ individuals caring for a spouse or partner with a chronic condition (Furlotte et al., 2016; Holcomb et al., 2020) and further implement the need for more information and education. The Iridescent Life Course framework has helped shape this study as it specifically addresses the intersectionality of the challenges of the LGBTQ+ community, with the challenges of aging and caregiving (Frederiksen-Goldsen et al., 2020).

The data were collected from five participants through interviews using a virtual format (Zoom). The participants were LGBTQ+ individuals aged 50 years or older, caring for a spouse or partner with a chronic condition in the US, recruited through Facebook, Instagram, and LinkedIn social media platforms as well as a presentation at a church group. Using deductive and latent approaches, a phenomenological analysis of the data was completed. This study relied on phenomenological research to delve further into this issue and obtain data to be analyzed and used to inform future policies and the development of better resources for older LGBTQ+ individuals caring for a loved one or spouse with a chronic condition. Chapter 1 included an outline of the study's nature and significance, along with key definitions that would be used throughout. Chapter 2 will commence with a literature review, detailing prior research into this issue.

Chapter 2: Literature Review

The purpose of this qualitative phenomenological design study was to explore the perceptions and lived experiences of the unmet needs of older LGBTQ+ individuals caring for a spouse or partner with a chronic condition. The general problem was that older, LGBTQ+ individuals face a unique set of challenges and needs when caring for a spouse or partner with a chronic medical condition (Furlotte et al., 2016; Holcomb et al., 2020). Specific to the LGBTQ+ community, older adults caring for a spouse or partner may lack advance directive documents (de Vries & Gutman, 2016), understanding from the medical community (Anderson & Flatt, 2018; Furlotte et al., 2016), and social support (Holcomb et al., 2021; Jones et al., 2018).

Previous research has focused on the challenges that arise for individuals who are caring for a spouse or partner with a chronic condition. Caregiving can cause physical and psychological stress to the caregiver (Amankwaa, 2017), as well as depression, anxiety, and isolation (Kim et al., 2017). Spouses are more likely to remain caregivers for a longer period (Kim et al., 2017), leading to greater degrees of stress and burnout. Studies have also shown that interventions, resources, and supports geared toward the caregiver are beneficial to both parties (Amankwaa, 2017, Hawkley et al., 2020, Kim et al., 2017). The additional challenges faced by LGBTQ+ individuals, such as discrimination and health disparities (Furlotte et al., 2016; Holcomb et al., 2021), coupled with a higher risk of chronic medical conditions (Holcomb et al., 2021), may lead to a unique set of unmet caregiver needs. The totality of the challenges of being an older LGBTQ+ caregiver to a spouse or partner with a chronic condition (Furlotte et al., 2016; Holcomb et al., 2021) may be increased depression and anxiety, greater health disparities (Fredriksen-Goldsen et al., 2013) longer time in the caregiver role (Gibson et al., 2019; Kim et

al., 2017; Park, 2017)., discrimination (Alba et al., 2020)., and a higher risk of chronic medical conditions themselves (Holcomb et al., 2021).

The literature review consists of a critical analysis of empirical and theoretical sources covering topics related to older LGBTQ+ caregivers and the needs they face when taking on this challenge. The review begins broadly, presenting information regarding all LGBTQ+ caregivers, then concentrating on spousal or partner caregivers. This review into the unmet needs of older LGBTQ+ caregivers was completed through the Northcentral University library through the Roadrunner search engine. Databases searched included EBSCOhost and Google Scholar, and the search for peer-reviewed, full-text, scholarly sources went back seven years (2018–2025). The search did include older works that were seminal or were still able to contribute to this study. All works used were published in the English language. Keywords for this search included *caregiver*, *caregiver stress*, *LGBTQ+*, *LGBTQ+ caregivers*, *older LGBTQ+ caregivers*, *spousal caregivers*, and *unmet needs of caregivers*. The reference lists of key articles also helped to find seminal sources.

Theoretical Framework

Fredriksen-Goldsen et al., (2019a) developed the Iridescent Life Course framework as a more in-depth approach to the Life Course framework, specific to LGBTQ+ older adults. This framework was developed after extensive research and literature reviews to examine the intersectionality of all facets of LGBTQ+ aging; psychological, biological, social, behavioral, etcetera. (Frederiksen-Goldsen et al., 2019a). This framework also addresses the inequities and trauma historically encountered by the LGBTQ+ community. Before delving into the specifics of the framework developed by Fredriksen-Goldsen et al., an in-depth examination of the Life

Course framework (Elder, 1998) will be reviewed, as it led to the development of the Iridescent Life Course framework.

Life Course Framework

Glen Elder was one of the pioneers of the Life Course theory after performing a great deal of research involving individuals from childhood through adulthood. In *The Life Course as Developmental Theory* (1998), Elder described reviewing longitudinal studies in the 1960s and how this helped inform his work. These longitudinal studies, from the late 1920s and early 1930s, were some of the first of their kind to follow individuals from childhood through adulthood. Through his research, Elder determined that even within a cohort, the pathway of an individual's lifetime guided the trajectory of who they were to become (Elder, 1998). Elder developed four basic principles that played a role in this trajectory: time and place one is living, timing of major life transitions, relationships or interconnectedness, and personal choices or human agency (Elder, 1975, 1998).

Throughout his career, Elder researched the way various historical events impacted the individuals who lived through them. Some of the major events he focused on were the Great Depression (Elder, 1999) and World War II (Elder, 1987). Elder determined that the principles he established through the Life Course theory impact the way an individual's behavior may develop or change as they live major experiences (Elder, 1994, 1998). For example, living through the Great Depression was not the sole determinant for the trajectory an individual's life would follow; rather, their age during the event, the age they hit major milestones, relationships before and after the event, and choices they made based on opportunities available are all fundamental in framing the individual's Life Course.

By examining prior research and through his own studies of life across a spectrum of time, Glen Elder (1998) saw how these intersecting factors played a role in later life, terming this the Life Course theory. Elder theorized that all of these events, together, are what determined the trajectory and transitions (Alwin, 2012) of an individual's life. Elder (1998) suggested that none of these factors occurred in a "social vacuum" (p. 2), therefore they must all be looked at as they intersect with and impact each other. Life Course is the result of aging, along with the cultural context and historical events experienced by a specific cohort (Elder, 1975). Life Course can be viewed as the outcome of the aforementioned intersections (Alwin, 2012).

Iridescent Life Course Framework

The Life Course framework addresses the shared experiences of a cohort, and the Iridescent Life Course framework goes one step further by specifically addressing the history encountered by LGBTQ+ individuals and how it has impacted the older segment of that population (Frederiksen-Goldsen, 2020). Elder (1998) wrote that "historical time and place: that the Life Course of individuals is embedded in and shaped by the historical times and places they experience over their lifetime" (p. 3) as part of his first principle. Fredriksen-Goldsen et al. (2013) noted the Life Course framework addresses how culture, social context, time period, and location impact aging—but this perspective does not include sexual orientation, which they found to be a significant factor in determining health disparities and outcomes. Fredriksen-Goldsen et al. (2019b) noted that the Iridescent Life Course framework "illuminates the intersectionality of demographic characteristics and the social construction and power dynamics within the interplay of history, cultural location and meaning, and structural location affecting LGBTQ older adults" (p. 3). Thus, it is not just the interplay of time and place as the Life Course

theory posits, but also those events that are distinct to the older LGBTQ+ segment of the population (Frederiksen Goldsen et al., 2019a).

Events such as Stonewall (Varga, et. al., 2019) and the fact that homosexuality was once considered a mental illness (Margolin, 2021) support the notion that LGBTQ+ individuals have a unique history that shaped where this 50+ cohort is today. Fredriksen-Goldsen et al. (2019a) suggested that the discrimination, inequities, and injustices older LGBTQ+ individuals faced throughout their lifetime could translate to poorer health outcomes in later life (Fredriksen-Goldsen & Muraco, 2010; Fredriksen-Goldsen et al., 2013; Fredriksen-Goldsen et al., 2014). A lifetime of such inequities can lead to poorer mental and physical health and higher rates of debility, and a "cumulative disadvantage" (Fredriksen-Goldsen et al., 2019a, p. 7). That study also found that on average, older LGBTQ+ individuals reported 6.5 occurrences of discrimination or victimization over the course of their lifetime due to their sexual identity or the perception of their sexual identity (Fredriksen-Goldsen et al., 2019a). Characteristics such as being male, transgender, or of lower socioeconomic status increase the risk of being victimized, with 57–69% of transgender participants reporting having been victimized (Fredriksen-Goldsen et al., 2019a).

Due to the evolutionary nature of changes and experiences that occur over time, Fredriksen-Goldsen et al. (2020) further explored three generations of older adults through the Iridescent Life Course framework, finding there were some significant differences between them. That 2020 study examined the Pride Generation (born 1950-1964), the Silenced Generation (born 1935-1949), and the Invisible Generation (born 1934 or earlier). They reported that the Invisible Generation, who lived through the Great Depression and World War II, had the lowest levels of *visibility*, or disclosure of their sexual orientation due to the significant risks they

would have faced. This led to this group experiencing fewer incidences of bias and discrimination but also put them at a greater risk of isolation, secrecy, and loneliness (Fredriksen-Goldsen et al., 2020).

The Silenced Generation came of age during the Lavender Scare of the 1950s, which linked homosexuality to "susceptibility to Communism" (Fredriksen-Goldsen et al., 2020, p. 7), and caused many individuals suspected of non-heterosexual orientation to lose federal and state jobs. This significant experience, along with homosexuality being described as a "medical or psychiatric affliction" Fredriksen-Goldsen et al., 2020, p. 8) during this same time period led to the Silenced Generation being *silenced*. Many did not identify as LGBTQ+ until later in life than the following generation, and physical and mental health issues are higher among this group Fredriksen-Goldsen et al., 2020). While the Pride Generation has come of age through a time of greater visibility, this also means vulnerability to discrimination, bias, and victimization. This cohort grew up fighting for Civil Rights, Women's Rights, and LGBTQ+ rights, and were also more likely to face discrimination in the workplace and bias, in general. When the AIDS epidemic hit, this group was severely discriminated against and lost many of the friends and networks they had come to rely on (Fredriksen-Goldsen et al., 2020).

In one 2019 study, Fredriksen-Goldsen et al. (2019a) noted that the Institute of Medicine identifies LGBTQ+ older adults as an understudied and underserved population, although it is expected that by 2060, there will be more than 5 million older adults who identify as LGBTQ+. The fastest growing segment of older adults is those who are 80+ years old, yet 80+ LGBTQ+ individuals are the least visible and most likely to be underserved and underrepresented (Fredriksen-Goldsen et al., 2019b). The current group of 80+ individuals came of age while there was the greatest reticence to self-identify as LGBTQ+ due to taboos, stigma, and discrimination

(Fredriksen-Goldsen et al., 2019b; Fredriksen-Goldsen et al., 2020). Older LGBTQ+ individuals still face discrimination in in-home care and healthcare settings, and requiring caregiver assistance yields higher rates of poor health for LGBTQ+ individuals than for their heterosexual counterparts (Fredriksen-Goldsen et al., 2019a).

These unique patterns and experiences have had a significant impact on where older LGBTQ+ individuals are today, their willingness to be *visible*, and their overall life trajectory that brought them here. This is why the intersectionality of sexual identity on these factors is important to consider (Fredriksen-Goldsen et al., 2019a; Fredriksen-Goldsen et al., 2019b; Fredriksen-Goldsen et al., 2020) during this research study. While there has been some changing context for the LGBTQ+ population, such as Obergefell v. Hodges legalizing same-sex marriage across the United States in 2015 (Fredriksen-Goldsen et al., 2019a), there is still a long way to go before disclosure becomes the norm, without fear of discrimination. Fredriksen-Goldsen et al. (2019a) reported that only 48% of older lesbians were out to their healthcare providers, and there are lower rates of disclosure for those in rural areas or with small informal networks. Part of this lack of disclosure is due to the direct discrimination experienced over a lifetime, and part can also be attributed to internalized stigma (Bower et al., 2021; Fredriksen-Goldsen et al., 2019a) due to the historical context in which LGBTQ+ individuals have been perceived.

Visibility is critical for individuals on a personal and societal level, yet many older LGBTQ+ individuals will "camouflage" (Fredriksen-Goldsen et al., 2020, p. 4) their identities to keep from being vulnerable to the discourse that may result from disclosing. Without visibility, it is harder to find partners, a chosen family, a support network, and health practitioners who are supportive. A positive sense of one's identity leads to a better quality of life (Fredriksen-Goldsen et al., 2019a).

The authors depict the Iridescent Life Course as a fluid and ever-changing interaction between the environment and illumination (Fredriksen-Goldsen et al., 2019b) – similar to the way we would define iridescent in terms of light and appearance. As an object moves and shifts, so does the way that light reflects off it and is interpreted by the viewer. Neither the light nor the object creates this phenomenon on their own; the interplay of the two produces vibrant iridescence. In this same way, the unique history of LGBTQ+ individuals has influenced this cohort and may impact their interactions and encounters as caregivers to older partners. All cohorts experience changes and progression over time, but the older LGBTQ+ population has experienced a unique set of occurrences that have impacted them in a distinct manner. According to Fredriksen-Goldsen et al. (2020, p. 3), "Iridescent Life Course extends earlier Life Course work as it addresses both evolutionary and ecological forces and how these intersect with historical and social context as they change over time." These experiences vary depending on the viewpoint of the observer and the individual experiencing the phenomena (Fredriksen-Goldsen et al., 2019b).

Origins of the Iridescent Life Course Framework. In 2010, Fredriksen-Goldsen and Muraco (2010) published a literature review of 58 articles published between 1984 and 2008, applying the Life Course framework to study the intersections of the factors noted by Glen Elder in relation to LGBTQ+ older adults. The research conducted by Frederiksen-Goldsen and Muraco (2010) found that the criminalization and stigmatization of LGBTQ+ sexual orientation throughout life created experiences that are unique to this population. They also found that although earlier studies examined higher rates of mental health conditions of LGBTQ+ individuals, they did not look at them in the context of the experiences they had lived through (Frederiksen-Goldsen & Muraco, 2010). Their research through a Life Course

lens acknowledged that this framework did not include the uniqueness of the LGBTQ+ population; these experiences need to be considered in order to understand the LGBTQ+ perspective and the cultural context that has shaped their lives in elderhood.

In concluding their 2010 study, Frederiksen-Goldsen and Muraco wrote that a blueprint for future studies should take the LGBTQ+ perspective into account and focus on this population. In 2013, Fredriksen-Goldsen et al. published research analyzing data from the 2003–2010 Washington State Behavioral Risk Factor Surveillance System. That analysis was designed to uncover the health disparities specific to the LGBTQ+ population to determine how to enable better outcomes. Health disparities among other key demographics (socio-income status, age, race, etcetera) had already been studied in older adults, but Fredriksen-Goldsen et al. (2013) specifically focused their research on sexual orientation, as they saw this as a gap in the research (Fredriksen-Goldsen et al., 2013). The authors noted that there has been research into health disparities of LGBTQ+ individuals between the ages of 18 and 64, but previous research into the disparities of LGBTQ+ older adults was "glaringly sparse" (Fredriksen-Goldsen et al., 2013, p. 1802).

The State Behavioral Risk Factor Surveillance System is a telephone survey that randomly dials community-dwelling individuals meeting the age criteria. This survey is done in all states, but Washington added sexual orientation as a demographic in 2003, which is why it was chosen by Fredriksen-Goldsen et al. (2013). They studied the data available from 2003-2010, which included 1,531 individuals 50 years old or older, who identify as LGBTQ+. That study looked at poor mental health, poor physical health, and disability as factors that affect outcomes, and also delved into unhealthy behaviors such as smoking and unhealthy drinking that affect overall wellbeing. Their findings reveal "significant" health disparities between LGBTQ+

older adults and their heterosexual counterparts (Fredriksen-Goldsen et al., 2013, p. 1805), determining that there is a need for interventions that address the unique disparities and needs of older LGBTQ+ individuals. Their study also concluded that as this is an at-risk population, more "research across the Life Course is needed to better understand health disparities by sexual orientation and age" (Fredriksen-Goldsen et al., 2013, p. 1802).

The authors of that study noted that historical events such as Stonewall (Fredriksen-Goldsen & Muraco, 2010; Varga et al., 2019) impacted LGBTQ+ individuals and would affect how they age. On June 28, 1969, police aggressively raided the Stonewall Inn, in Greenwich Village, NYC, NY, which was an LGBTQ+ friendly establishment that served food and drinks. At this time, it was not uncommon for police to raid LGBTQ+ friendly establishments, but this was the first time there was a large response from the LGBTQ+ community and its allies (Varga et al., 2019). Over the course of the next few days, protests against discrimination of LGBTQ+ individuals by police occurred around Stonewall, calling for equal rights and better treatment. This became known as the Stonewall Riots and was a decisive event in the Gay Rights Movement (Varga et al., 2019).

Fredriksen-Goldsen et al. (2019a) later conducted another literature review of 66 articles published between 2009 and 2015 that focused on LGBTQ+ individuals aged 50 years and older. They found a wider research pool than was available for the 2010 study with varied designs and research methods utilized, but very few studies examined the subgroups of the LGBTQ+ population. From that research, the Iridescent Life Course framework was born. "Highlighting the interplay of rainbow like colors, the Iridescent Life Course highlights *queering* and *transforming* the Life Course, encompassing intersectionality and fluidity over time" (Fredriksen-Goldsen et al., 2019a, p. 1). This framework incorporated the historical

significance of the LGBTQ+ experience with the rest of the components found in the Life Course theory (Elder, 1975).

Fredricksen-Goldsen et al. (2019a) acknowledge that while the last two decades had brought positive change to the social and cultural context of sexual orientation (such as legalizing gay marriage), the older generation had lived through very harsh experiences that still colored their current perspective. These negative past experiences impact their sense of self-identity, willingness to be open about their orientation, and the way they utilize care and services (Fredriksen-Goldsen et al., 2019a). That study found that a lifetime of adverse experiences would correlate to poorer health outcomes, barriers to care, and a higher prevalence of unhealthy behaviors. In follow-up studies, Frederiksen-Goldsen, along with other researchers, examined subgroups of LGBTQ+ individuals through the perspective of the Iridescent Life Course.

Using data collected through Aging with Pride: National Health, Aging, and Sexuality/Gender Study, Fredriksen-Goldsen et al. (2019b) focused on the health of 200 LGBTQ+ individuals 80 years or older. They wrote that they focused on the 80+ LGBTQ+ participants as this group is often understudied and underserved. In particular, this cohort has lived through a time when many LGBTQ+ individuals felt it safer to remain quiet about their sexuality due to stigma, criminality, and discrimination. That study found that many of the participants hid their sexual identity at various points in their lives; 80% of participants reported being the victim of microaggressions and 25% reported receiving threats to be *outed* (Fredriksen-Goldsen et al., 2019b). Social supports were lower for this group than their heterosexual counterparts, leading to higher levels of isolation and depression (Fredriksen-Goldsen et al., 2019b).

Existing research using Iridescent Life Course Framework. A later study used data collected through Aging with Pride: National Health, Aging, and Sexuality/Gender Study to focus on the health of bisexual older adults through the perspective of the Iridescent Life Course (Fredriksen-Goldsen et al., 2020). That study evaluated responses from 216 participants and compared them by generation. Their findings include information related to biases reported, feeling the need to hide their orientation, and less social support for the oldest age group surveyed (those born in 1934 or earlier) (Fredriksen-Goldsen et al., 2020). Those two studies show that there is a need to examine the Life Course of older LGBTQ+ individuals through a unique, iridescent scope that includes the historical events, occurrences, and experiences that are specific to them.

Lam and Campbell (2023) used the Iridescent Life Course framework to explore social supports, loneliness, and health disparities among older LGBTQ+ individuals. Using data from the Household, Income and Labour Dynamics in Australia Survey, which included 5,500 participants, Lam & Campbell compared the responses between heterosexual individuals and LGBTQ+ individuals. That survey data were collected between 2001 and 2019, and all participants were aged 50 or older. They examined the impact that sexual identity, intersected with time, location, and social context, had on health and loneliness. Their study found that bisexual men 50 years old or older reported the highest prevalence of loneliness, and the degree of loneliness increased as they age due to lower levels of social supports (Lam & Campbell, 2023). That same year, Fredriksen-Goldsen et al. (2023) published a study using the Iridescent Life Course that examined the responses recorded from 2,079 participants of the 2014 wave of Aging with Pride: National Health, Aging, and Sexuality/Gender Study. They found there were generational differences in the prevalence of disclosing orientation, determined by the lived

events of each. They found that older adults in the Pride Generation (born 1950-1964) were most likely to disclose their sexual orientation earlier in life, but also most commonly experienced discrimination and victimization (Fredriksen-Goldsen et al., 2023).

Waling et al. (2023) utilized the Iridescent Life Course framework to explore the 60+ cohort of gay men and lesbian women in Australia, as the perceived this group to come of age during times of great societal changes towards LGBTQ+ individuals. Through qualitative interviews with 33 LGBTQ+ individuals, that study found that this portion of the LGBTQ+ population has faced significant challenges over their lifetime – such as discrimination, bias, and losses due to HIV/AIDS – yet, they have also come into elderhood resilient, strong, and grateful for being able to age on their own terms (Waling et al., 2023). Jung et al. (2020, p. 735) described a lifetime of discrimination, bias, and other negative factors as "Allostatic load (AL), the net effect of 'wear and tear.'" Using data from the longitudinal National Health, Aging, and Sexuality/Gender Study, Jung et al. (2020) studied the responses of 205 transgender participants through the Iridescent Life Course framework and found that even within this subgroup of older adults, each generation's experiences impact their aging.

While the study conducted by Waling et al. (2023) highlights the positive attributes that older LGBTQ+ have developed, it also acknowledges the harsh reality that this group experienced earlier on, "when homosexual behaviours were criminalised, when homosexuality was treated as a mental illness, and forced gay conversion therapy was commonly practiced as a 'cure'" (p. 250). They also note that lesbian women often experience a trifecta of discrimination – homophobia, ageism, and sexism. Jung et al. (2020) reported that LGBTQ+ individuals who did not disclose their orientation showed a *higher allostatic load* than their counterparts who did disclose this information. The studies mentioned underscore the need to include sexual

orientation along with the other Life Course factors when examining the lives of older LGBTQ+ individuals.

Iridescent Life Course Framework and the unmet needs of LGBTQ+ caregivers.

This theory encompasses the risk factors that may lead to a unique set of unmet needs for older, LGBTQ+ individuals. Some of these factors include a lack of social support (Holcomb et al., 2021; Jones et al., 2018) or advance directives documents (de Vries & Gutman, 2016) in place and fear of discrimination if they come out to medical providers or others (Alba et al., 2020; Toze et al., 2020). Older LGBTQ+ individuals have higher rates of HIV, diabetes, other physical debilities, and more instances of depression, anxiety, and suicidal thoughts than their heterosexual counterparts (Holcomb et al., 2021), and are caregivers to a spouse or partner at higher rates (Anderson & Flatt, 2018; Hawkley et al., 2020). The intersectionality of these challenges, as well as greater health disparities than their heterosexual counterparts (Holcomb et al., 2021), have led to the theory proposed by this study that LGBTQ+ older adults are at a greater risk of having unmet needs.

Minority Stress Theory

Minority Stress Theory and the Health Equity Promotion Model are two other frameworks that were considered but did not fit the needs of this study as well as the Iridescent Life Course theory. Meyer first used the term *Minority Stress Theory* in a quantitative study published in 1995. The minority stress model posits that groups who face long-term discrimination, bias, and stigmatization will experience chronic stress, which will in turn cause an increase in mental health conditions. Prior to that study, there was a focus on the prevalence of mental health disorders among gay men, but not necessarily on the cause (Meyer, 1995). This issue of a focus on mental health disorders among gay men, without exploring the cause, was

likely compounded by the inclusion of homosexuality as a mental health disorder until 1973 (Margolin, 2021; Meyer, 2003). Meyer conducted a study of three stressors: internalized homophobia, stigma, and discrimination/violence, on 741 gay men in New York City. His findings support the hypothesis that minority stress can lead to mental health disorders, concluding that gay men who experience minority stress are two-to-three times more likely to suffer from mental distress or disorders than men who do not (Meyer, 1995).

A later study by Meyer (2003) included lesbian women and bisexual individuals within the context of the minority stress model. That quantitative study still utilized three stressors: internalized homophobia, stigma, and discrimination/violence. In that study, Meyer (2003) also discusses the negative effects LGBTQ+ individuals incur when they feel they need to hide their orientation. Meyer used a meta-analysis prove his hypothesis that the stress felt by LGBTQ+ individuals increased the prevalence of them having a mental health disorder and suggested this be a guiding factor for future research. Hendrix and Testa (2012) took the minority stress model one step further and applied it to transgender individuals in their study. They found that a history of discrimination, and fear of more discrimination, along with other adverse events realized by trans individuals did in fact lead to negative psychological outcomes and higher rates of suicide (Hendrix & Testa, 2012).

Lacking from the studies that developed and applied Minority Stress Theory is the construct of age, for the purpose of this study. The studies mentioned show that there is a negative outcome to the mental health of LGBTQ+ individuals who have experienced minority stress, but they do not account for age in the intersection of historical events. Pereira and Banerjee (2021) noted in their recent publication that the minority stress model may not be adequate to address the experience of LGBTQ+ aging.

Health Equity Promotion Model

This model was developed to examine the intersectionality of LGBTQ+ communities, the environment, and positive and negative health behaviors (Fredricksen-Goldsen et al., 2014). The goal of that research was to develop a framework geared toward LGBTQ+ individuals reaching their highest level of well-being, both mentally and physically. This model combines Life Course with health promotion to reduce disparities experienced by LGBTQ+ individuals, as they have been identified as an at-risk population (Fredricksen-Goldsen et al., 2014). That study indicated that LGBTQ+ individuals develop disabilities and health conditions at greater rates than their heterosexual counterparts, yet there have been few studies on the ways that a history of stigma and discrimination can impact mental and physical well-being.

In 2017, Jabson Tree et al. used the Health Equity Promotion Model to show how disparities can lead to food insecurity among LGBTQ+ individuals. Their research indicated that stigma, exclusion, and institutional heterosexism all lead to barriers for LGBTQ+ individuals to earn livable wages, secure steady employment, and access community resources, which in turn may lead to food insecurity. Their study findings show that LGBTQ+ individuals are at a higher risk of food insecurity than their heterosexual counterparts. (Jabson Tree et al., 2017).

While both of those studies show the potential impact the Health Equity Promotion Model may have on research and outcomes for LGBTQ+ individuals, they do not address age as a specific factor within the context of the framework. Lifelong discrimination, bias, fear of disclosure, and negative external factors all influence the way LGBTQ+ individuals move through elderhood (Fredricksen-Goldsen et al., 2019a; Frederiksen-Goldsen & Muraco, 2010; Waling et al., 2023) While most studies into LGBTQ+ older adult unmet needs around caregiver issues rely on the Life Course framework, the Iridescent Life Course framework, developed by

Frederiksen-Goldsen et al., is the most appropriate for this study. This history of discrimination and maltreatment may lead to a unique set of unmet needs for older LGBTQ+ caregivers, particularly if they are hesitant to disclose their relationship status to medical and other professionals (Alba et al., 2020; Toze et al., 2020). As LGBTQ+ older adults already face greater health disparities than their heterosexual counterparts (Holcomb et al., 2021), and many lack the necessary social supports for caring for a spouse or partner (Holcomb et al., 2021; Jones et al., 2018), these issues may compound the unmet needs they face.

Caregivers

The term caregiver refers to an individual who provides for the needs of another person who is unable to care for themselves (American Psychological Association, n.d.). The other person may be a child or an incapacitated or disabled adult. As the population of the US is aging exponentially and individuals are living longer with chronic medical conditions (Bai et al., 2018), there is a greater need for informal or familial caregivers (Amankwaa, 2017). The bulk of this informal caregiving is provided by spouses, typically alone and for longer periods than other types of familial caregivers (Kim et al., 2017). The caregivers may also be older themselves, with their own health concerns. According to an AARP report published in 2020 (AARP, 2020), 11% of the nearly 42 million caregivers over 50 years old are caring for a spouse or partner. Together, these studies show that as our population is aging (Bai et al., 2018), there will be a greater need for spousal caregivers who will also be aging themselves (AARP, 2020; Kim et al., 2017).

Caregivers provide an estimated 15 billion hours of support to loved ones in the United States each year (Cohen et al., 2021), through assistance with activities such as bathing, dressing, grooming, paying bills, and arranging medical appointments (Amankwaa, 2017). Caring for a

spouse or partner can have a drastic impact on this dyadic relationship (Gallagher & Rickenbach, 2020), as the balance, dynamic, marital roles, and intimate connection may change (Andréasson et al., 2021; Stockwell-Smith et al., 2018). Employing an ethnographic approach, Andréasson et al. (2021) studied the various ways in which a relationship changes and evolves when an older spouse becomes a caregiver to their partner. They conducted nine semi-structured interviews with spousal caregivers and also documented informal communication and observations as part of their research.

That study applied Morgan's perspective on family life and Hochschild's analysis of emotional work to demonstrate how becoming a caregiver to a spouse can drastically change the couple's relationship (Andréasson et al., 2021). They found that this role can impact the health and social well-being of the caregiver. During their interviews, they found that both the caregiver and care recipient reflected on changes to their relationship. The main limitations of that study were its size (nine participants), and it only included heterosexual couples. Although the study conducted by Andréasson et al. (2021) had its limitations due to size, other studies have also shown that simply being a caregiver to a spouse can dramatically alter the relationship (Gallagher & Rickenbach, 2020; Stockwell-Smith et al., 2018).

Hellstrom et al. (2005) conducted a larger study into the effects of spousal relationships several years earlier and concluded that it is possible to maintain couplehood and a sense of reciprocity through the dementia journey, as the care recipient "hands over" (p.383). responsibilities to the caregiving spouse. That research consisted of 152 interviews with 20 Swedish couples over a five-year period; each couple consisted of one individual living with dementia and a spousal caregiver. After collecting the data, they applied a constructivist grounded theory to analyze the data (Hellstrom et al., 2005). The higher number of participants

interviewed over a series of many years helps to solidify the results they have reported. While Hellstrom et al. (2005) note that a sense of couplehood may be maintained, their findings do suggest that the nature of the relation still shifts when the care recipient *hands over* responsibilities to their partner, as the later studies also found (Andréasson et al., 2021; (Gallagher & Rickenbach, 2020; Stockwell-Smith et al., 2018).

Better outcomes for the caregiver lead to better outcomes for the patient (Amankwaa, 2017, Hawkley et al., 2020, Kim et al., 2017; Stockwell-Smith et al., 2018). One way to help ensure better outcomes for the caregiver is to provide support and resources (Silva de Sousa et al., 2021) as they progress through their journey. Stockwell-Smith et al. (2018) used a mixed-method design to study the dyadic relationship between caregivers and care recipients living with dementia. They employed quantitative data collection at three points during the study and qualitative data collected through questionnaires and semi-structured interviews. That study looked at 88 dyads, which is a much larger sample than others in this realm. That study focused on four regions of Australia with high percentages of residents that are 65 years or older (Stockwell-Smith et al., 2018). Participants were dyads that included a community-dwelling care recipient with a diagnosis of dementia or Alzheimer's disease. They were able to conclude that psychosocial interventions early on yielded better outcomes for both caregivers and care recipients. Together, those studies show that providing support and resources to caregivers (Silva de Sousa et al., 2021) throughout their journey will lead to better outcomes for the caregiver (Amankwaa, 2017, Hawkley et al., 2020, Kim et al., 2017; Stockwell-Smith et al., 2018) and the partners they are caring for (Stockwell-Smith et al., 2018).

This journey may prove to be especially difficult and challenging for an individual caring for their spouse or partner (Gallagher & Rickenbach, 2020; Gibson et al., 2019), as the

caregiving trajectory in this scenario may be longer and more stressful than for those of other relationships (Gallagher & Rickenbach, 2020; Gibson et al., 2019; Park, 2017). The caregiver may also be tasked with completing the activities their partner once did if that partner's condition is debilitating, as there may be a "redistribution" of roles (Happich et al., 2022, p. 110) that were previously performed by the other spouse, such as housework or finances (Andréasson et al., 2021). These new tasks would be on top of any caregiving activities that need to be accomplished, as well. While a burden to both the caregiver and recipient can be seen, the physical and mental exertions of the caregiver will increase (Happich et al., 2022). Those studies together reinforce the need for support and resources for individuals who take on the often long and challenging (Gallagher & Rickenbach, 2020; Gibson et al., 2019; Happich et al., 2022; Park, 2017) role of caregiver to a spouse or partner with a chronic condition.

The caregiver may start to feel the effects of grief and loss during the caregiving journey (Gibson et al., 2019; Liew et al., 2019), as their relationship and partnership dynamics begin to change. Gibson et al. (2019) conducted a qualitative study with a thematic analysis approach to determine how spousal caregivers experience grief throughout their partner's dementia diagnosis and caregiving journey. That study included interviews with 10 participants who were older adults, considered themselves to be in good health, and cared for their partner up until their partner's death. Participants were recruited from a small Canadian city. They found that caregivers experienced grief while their partner was still alive (Gibson et al., 2019); these studies solidify the need for caregivers to have support, resources, and assistance through this journey, as there is an ongoing loss of their partner (Gibson et al., 2019; Liew et al., 2019).

One partner's need for personal care may also impact the overall relationship of the couple and potentially their feelings toward each other (Andréasson et al., 2021). With a change

in physical abilities, there may also be a decrease in autonomy and independence and disruption to the couple's normal balance of power. These changes may cause struggles with intimacy and sexuality. The closer the relationship, the greater the degree of stress to the caregiver (Amankwaa, 2017; Happich et al., 2022). Using grounded theory methods, Gallagher & Rickenbach (2020) studied the relationship changes that occur later in life when one spouse begins caring for their partner. That research relied on semi-structured interviews of 13 caregivers between the ages of 53 and 85 to realize the experience of a changing spousal relationship from the perspective of the caregiver. The researchers found that four main themes emerged ("couplehood, positive mindset, later life roles and transitions, and looking towards the future") when analyzing their data (Gallagher & Rickenbach, 2020, p. 1429). A limitation of that research was sample size, but the study did find that the nature of the relationship before the caregiving experience affected how it changed or evolved. As those studies show that the relationship will likely change throughout the caregiving experience (Amankwaa, 2017; Andréasson et al., 2021; Happich et al., 2022), it is important to ensure that the needs of the caregiver are met to ensure positive outcomes.

Using data from 4573 participants of the fifth (2014) and sixth (2017) waves of the longitudinal German Ageing Survey, Happich et al. (2022) studied the effect that caregiving had on both spouses (caregiver and care recipient) and how they felt about their partnership. Structured interviews and written questionnaires employing Likert-like scales were used to collect data from participants. Their quantitative research included a linear fixed effects regression analysis (Happich et al. 2022). That study did not find any significance in differences in overall satisfaction of the partnership between male and female participants but did find significant differences between caregivers and care recipients. Happich et al. (2022) found that

the caregiver typically saw a decrease in satisfaction in their partner relationship, while the care recipient saw an increase in this satisfaction. This data underscores the challenges spousal caregivers face while in this role. The sample size of this study allows for greater generalization than many smaller studies, but it did not account for demographics such as race or sexual orientation in its findings. The large size of the study performed by Happich et al. (2022) reinforces the findings of other studies (Amankwaa, 2017; Andréasson et al., 2021; Happich et al., 2022) that concluded caregiving impacts the dyadic relationship of a partnered couple.

When caregivers are overwhelmed or not receiving the support they need, they may be faced with stress, burden, or even burnout. Caregiver stress or burden is viewed as the negative effects on the caregiver. These can be physical, emotional, or psychological effects (Amankwaa, 2017; American Psychological Association, n.d.) that impact the caregiver and their own wellbeing. Caregiver burnout is severe stress that leads to depression, anxiety, (Amankwaa, 2017; Hawkley et al., 2020; Kim et al., 2021) and an array of other health issues to the caregiver. Isolation is also a negative effect on both caregivers and the spouse/partner with a chronic condition. Caregivers play a pivotal role in keeping their spouse at the highest practicable level of well-being; therefore, those studies show we must ensure caregivers are provided all of the support and tools they need to reduce stress and burnout (Amankwaa, 2017; Hawkley et al., 2020; Kim et al., 2021).

LGBTQ+ Older Adults

The official American Psychological Association (n.d.) definition of LGBTQ is the "abbreviation for lesbian, gay, bisexual, transgender, and questioning or queer: an inclusive term used to refer to the homosexual population in all of its diverse forms, to those with both homosexual and heterosexual preferences, and to those whose gender identity differs from the

culturally determined gender roles for their birth sex." In the US, approximately 3 million older adults (over the age of 50) identify as LGBTQ+, and it is expected that this number will grow to over 5 million by 2060 (Fredriksen-Goldsen et al., 2019a).

The LGBTQ+ community has a history of adverse experiences that have shaped the way this population may relate to the medical and legal community. Although the DSM officially removed homosexuality as a diagnostic code in its 1973 edition, Margolin (2021) argues that the manual continued to publish casebooks through 2002 that contained harmful stereotypes of the LGBTQ+ community. Meyer (2003) suggests that after the DSM removed this diagnostic code, LGBTQ+ -affirming perspectives were pitted against conservative perspectives that wanted homosexuality to remain a mental health diagnosis. Together, those studies show that the history of mistreatment experienced by LGBTQ+ individuals has an impact on how they move through elderhood (Margolin, 2021; Meyer, 2003). Although the DSM removed this diagnostic code, those studies show the everlasting effects this message had regarding the treatment of older adults in the LGBTQ+ community.

This harsh reality may leave individuals afraid of disclosing their own LGBTQ+ status as they fear discrimination from the medical community (Alba et al., 2020; McCarron, 2020). One study (Candrian & Cloyes, 2021) found that only 60% of 60 –75-year-old LGBTQ+ individuals have disclosed their sexual orientation to their healthcare provider. Drawing insight from in-depth interviews with 31 LGBTQ+ individuals, Candrian & Cloyes (2021) reported that the wishes of LGBTQ+ individuals are ignored, their chosen family is not included in care decisions, and 43% of 865 hospice professionals reported witnessing discrimination towards LGBTQ+ individuals. Combined, those studies all support the discrimination and fear of discrimination (Alba et al., 2020; Candrian & Cloyes, 2021; McCarron, 2020) felt by LGBTQ+ individuals.

Fear of disclosing orientation or relationship status is unique to the LGBTQ+ experience. As heterosexuality is typically deemed the default, LGBTQ+ individuals need to actively disclose their status to inform medical professionals but may be reluctant to do so as past trauma, inequities, and prejudice impact visibility (Fredriksen-Goldsen et al., 2019a).

LGBTQ+ older adults may have faced a lifetime of compounding victimization, but also likely suffer from microaggressions on a much more regular basis. Negative effects of microaggressions have also been shown to worsen physical impairments as individuals age (Bower et al., 2021; Fredriksen-Goldsen et al., 2019b), thus leaving older LGBTQ+ individuals more vulnerable to poor treatment and the feeling that they need to camouflage who they are (Fredriksen-Goldsen et al., 2020). LGBTQ+ individuals face more discrimination in the workplace than non-LGBTQ+ individuals, and experience greater rates of isolation (NAC, AARP, 2020). Dakin et al. (2020) reported that many older LGBTQ+ individuals in their study reported that neighbors were tolerant, so long as they "did not openly display" (p. 781) their sexuality. Again, this concept is unique to LGBTQ+ individuals, as heterosexuals typically do not feel this same type of discourse from society over their perceived sexuality.

Many individuals across the sexual spectrum may have what they call a "chosen family," but this concept is much more prevalent with LGBTQ+ individuals, as one study found that all of their participants reported having a family of choice that offered a network and support (Dakin et al., 2020). LGBTQ+ older adults are twice as likely to live alone and four times less likely to have children (Perone et al., 2019) than their heterosexual counterparts, often requiring them to build their own familial support system. Dakin et al. (2020) reported that participants told them they just use the word *family*, rather than *family of choice*, as that is how they view their network. Older LGBTQ+ individuals with a strong network of support fare better than those without a

network, as they report overall better health and less loneliness (Dakin et al., 2020). LGBTQ+ older adults are at a greater risk of social isolation, which can greatly impact overall health and well-being (Perone et al., 2019). Citing a study that included 2,560 LGBTQ+ older adults, Perone et al. (2019) reported that 60% of the respondents did not have a partner or companion, and roughly 50% felt isolated.

While it is becoming more common for LGBTQ+ individuals to be out in rural areas, many are still more cautious about disclosure here than they would be in urban areas (Comerford et al., 2004; Dakin et al., 2020). Individuals in rural areas also have less access to formal supports and resources (Dakin et al., 2020; Frederiksen Goldsen et al., 2019a) and may rely on the social service system for transportation, personal care, and homemaker tasks (Comerford et al., 2004) than those in more urban areas. Individuals in rural areas also face higher rates of poverty and less mental health care (Comerford et al., 2004). Women comprise more than 60% of the over-age 65 population (Comerford et al., 2004), yet lesbian women in rural areas may be even more marginalized than other LGBTQ+ individuals in this setting, as they may be victims of sexism (Comerford et al., 2004), as well as discriminated against for their orientation.

Another subgroup of the LGBTQ+ older population that needs to be examined is those who are ethnic minorities and may face significant differences in care and treatment, and an even deeper history of discrimination than their White counterparts (Chen et al., 2022). LGBTQ+ ethnic minorities have significantly lower rates of positive sense of self (Chen et al., 2022), due to the multiple stigmas and greater challenges they have endured. Black and Hispanic gay males report the greatest cumulative experience of discrimination and bias (Chenet al., 2022), leading to lower levels of disclosure and visibility. Friedman et al. (2017) found that bisexual Black men experience even higher rates of health disparities than their Black gay counterparts, including

higher rates of depression, physical assault, and drug use. This group is also less likely to disclose their sexual orientation, leading to less support and other resources (Friedman et al., 2017). Even within these subgroups, there is further demonstration of how the intersectionality of race/age/sexual orientation can affect an individual's overall psychological well-being.

Stigma

Older LGBTQ+ individuals may face multiple stigmas, as these are still more socially acceptable than other overt forms of discrimination (Bower et al., 2021). According to the American Psychological Association (n.d.), stigma is negative social attitudes about a group of individuals, while discrimination is exhibited negative behaviors towards a group. Stigma may lead to discrimination, and both are felt in different ways by the individual being targeted. LGBTQ+ individuals may face overt experiences such as laws and policies that negatively impact their lives, as well as violence and hate (Bower et al., 2021) directed at them because of their orientation. Microaggressions, such as viewing heterosexuality as the norm and anything else as *other,* can impact individuals already affected by vulnerabilities (Bower et al., 2021).

Older adults face discrimination in the form of ageism, which may be felt in the workforce and even in healthcare. Stigma towards LGBTQ+ individuals may come in the form of overt acts, such as hostility and violence, or microaggressions, such as the use of stereotypes (Bower et al., 2021). That study further differentiates between external stigma and internalized stigma. External stigma is the treatment by other individuals that have led to a history of poor treatment of LGBTQ+ individuals (Bower et al., 2021). Some examples are the HIV/AIDS crisis, Stonewall, and the Lavender Scare. Internalized stigma, which is turning these outside pressures into themselves, may result in individuals changing appearances or not disclosing orientation (Bower et al., 2021). Stigma may be one unifying factor that can help build one's support

network (Bower et al., 2021) as individuals come together to fight against inequities and structural boundaries that impact the needs (Perone et al., 2019) of LGBTQ+ older adults.

Resilience

A factor to consider regarding LGBTQ+ older adults is that of resilience (Allen & Lavender-Stott, 2020; Bower et al, 2021; Chen et al., 2022). It is especially important for many LGBTQ+ older adults to feel like they are making their mark and leaving a legacy for future generations (Bower et al., 2021) due to past adversity and negative experiences. While researching volunteers of a Friendly Caller Program, Perone et al. (2019) found that younger LGBTQ+ individuals wanted to show support for older LGBTQ+ individuals for the work and sacrifices they have endured. Social engagement, participation, and support were shown to help counteract stigma and the negative experiences encountered by older LGBTQ+ individuals (Perone et al., 2019). Social support can also help counteract bias, stigma, and discrimination (Dakin et al., 2020) and lead to successful aging (Allen & Lavender-Stott, 2022).

LGBTQ+ Caregivers of Spouses or Partners with a Chronic Medical Condition

In 2020, one study produced findings that demonstrated there is stigma and discrimination for both the caregiver and care recipient when either or both parties are LGBTQ+ (Alba et al., 2020). That quantitative research included surveys of 218 lesbian and gay caregivers in Australia who were 60 years of age or older, and the analysis compared caregivers to non-caregivers and LGBTQ+ caregivers to heterosexual caregivers. That research established that LGBTQ+ caregivers are in poorer health than their non-caregiving counterparts, and individuals providing care to an LGBTQ+ individual receive less support and more psychological distress than caregivers caring for heterosexual persons (Alba et al., 2020). Although that research was limited by its length, the sample size yielded strong results. They reported that LGBTQ+ partners

may be excluded from the decision-making process of the individual they are caring for. That research also found that LGBTQ+ individuals are more likely to be caregivers than their heterosexual counterparts, potentially due to the marginalization this group experiences (Alba et al., 2020), leading to a lack of professional and informal supports. LGBTQ+ individuals may also apply a "group solidarity and cohesiveness that protect minority members from the adverse mental health effects of minority stress" (Meyer, 2003, p. 6). Together, those studies show that LGBTQ+ individuals may often find more support in their *chosen* families (Alba et al., 2020, Meyer, 2003), rather than family through blood or marriage.

Alba et al. (2020) found that feeling supported as a caregiver led to better outcomes for the care recipient, yet stigma and discrimination caused many not to divulge this information. This ongoing discrimination and fear of discrimination can lead to chronic stress and worsening overall health, according to the Minority Stress Theory (Alba et al., 2020; Hoy-Ellis, 2023; Meyer, 1995; Meyer, 2003). Ongoing stigma, discrimination, and prejudice can lead to higher rates of substance abuse, mental health disorders, and even suicide (Meyer, 1995; Meyer, 2003) among LGBTQ+ individuals. The Minority Stress Theory posits that LGBTQ+ face additional stressors that other groups or individuals may not. A limitation of Meyer's research and writing regarding the Minority Stress Theory is that his conclusions are in opposition to previous research, although he reviewed multiple published studies to solidify his views. Later research did support the Minority Stress Theory (Alba et al., 2020; Hoy-Ellis, 2023) and the impact it may have on LGBTQ+ individuals. The totality of that research is that although chronic stress can lead to a decline in health for LGBTQ+ individuals (Alba et al., 2020; Hoy-Ellis, 2023; Meyer, 1995; Meyer, 2003), feeling supported in their role as caregivers can lead to better outcomes for

them (Alba et al., 2020), and thus, would improve caregivers' health if they are comfortable disclosing their relationship status.

Hoy-Ellis (2023) conducted a literature review of the Minority Stress Theory that goes back 20 years. One of the topics Hoy-Ellis emphasized is the historical treatment of gay men surrounding the HIV/AIDS crisis, leading up to present-day treatment. The stigma surrounding AIDS could lead many LGBTQ+ individuals fearful of poor medical treatment and reluctant to seek care for all conditions. Individuals who hide their orientation as a protective measure may develop long-term psychological distress because of this (Hoy-Ellis, 2023). That literature review suggested that age may also be a factor in Minority Stress Theory as certain cohorts have shared similar negative experiences (Hoy-Ellis, 2023). Shared experiences such as Stonewall and the historical treatment of LGBTQ+ individuals would be prominent factors for current older adults who lived through these events. Understanding health disparities and additional stressors of LGBTQ+ individuals will help improve the quality of life for caregivers and care recipients within this group.

Alba et al. (2020) found that caring for an LGBTQ+ individual can cause additional distress than caring for a heterosexual individual. When both the caregiver and recipient are LGBTQ+, higher rates of mental health conditions are attributed to Minority Stress Theory, as "Care-givers would need to be able to address and support the care-receiver's concerns and experiences, as well as coping with their own concerns or experiences" (Alba et al., 2020, P.5). The health disparities and inequities felt by diverse populations is also experienced by their caregivers, as well (Tan et al., 2023). Social support can help combat the additional stressors felt by the LGBTQ+ population (Savage & Barringer, 2021).

As older LGBTQ+ individuals are at a higher risk of developing a chronic condition and requiring care than heterosexuals in their age group (Holcomb et al., 2021), it is imperative that they are comfortable disclosing and sharing this information with medical providers. Savage and Barringer (2021) conducted a qualitative study utilizing the minority stress model to evaluate the data collected from 1,762 LGBTQ+ participants of a 2018 nationwide AARP survey. Their study found that many LGBTQ+ older adults are hesitant to disclose their orientation due to discrimination and stigma. This group is expected to grow to 20 million by 2060 (Fredriksen-Goldsen et al., 2019a), and will require medical staff who are compassionate, caring, and understanding of their needs. Together, those studies show that although LGBTQ+ individuals are at a greater risk of health issues (Holcomb et al., 2021) this growing group (Fredriksen-Goldsen et al., 2019a) is also likely not to disclose this information (Savage and Barringer, 2021), although it would benefit them to do so.

As previously mentioned, caregiving can be most strenuous for spouses or partners of the older adult with a chronic condition (Gibson et al., 2019; Park, 2017), and almost twice as many older LGBTQ+ individuals are caring for a spouse or partner with a chronic condition, as compared to their heterosexual counterparts (Hawkley et al., 2020). On average, LGBTQ+ caregivers have lower income and socioeconomic status than heterosexual caregivers (Boehmer, 2018; Tan et al., 2023), which can pose challenges, as well. They also report on the great financial burden in caregiving, as compared to their heterosexual counterparts (Boehmer, 2018). If the spouse or partner is afraid to disclose this status to medical professionals (Alba et al., 2020; McCarron, 2020), this may lead to a greater lack of support and resources needed to provide adequate care. Yet, Candrian and Cloyes (2021) reported that 40% of older LGBTQ+ individuals (aged 60-75) did not disclose their sexual orientation to physicians. In order to

properly care for a partner or spouse, a caregiver needs resources, support (Amankwaa, 2017; Hawkley et al., 2020; Kim et al., 2017; Silva de Sousa et al., 2021), and compassion.

Unmet Needs of Caregivers

"Unmet needs are defined as the differences between the services perceived by the informal caregiver to be necessary to manage both the health condition of the patient and the caregiver, and the services actually received" (Denham et al., 2020, p. 2). Unmet needs may be a lack of compassion from the medical community, a lack of support and resources for the caregiver, and a lack of legal documents to direct care. Caregivers of spouses or partners tend to have a longer time in this role, the demands on them often increase through the trajectory of the disease process, and the relationship with their partner may be affected (Gibson et al, 2019; Park, 2017). Tan et al. (2023) found that LGBTQ+ individuals caring for an older adult with cancer take on more home nursing duties than their heterosexual counterparts. The individual providing care may begin the grieving process while their partner is still living, as their dyadic relationship shifts and changes (Gibson et al., 2019; Liew et al., 2019). The emotional and physical toll of caregiving often leads to more stress and potential burnout to the caregiver (Amankwaa, 2017; Hawkley et al., 2020; Kim et al., 2021). This makes it imperative that the caregiver has support from medical professionals, friends, and family to ensure that their own needs are met. Caregivers may be reluctant to discuss unmet needs in front of the individual they are caring for (Sharpe et al., 2005), for fear of causing them additional stress or worry. It is beneficial to the caregiver for medical professionals to encourage the caregiver to open up about their unmet needs (Sharpe et al., 2005), but if the caregiver is reluctant to disclose their relationship status, the medical professional may not know to ask about this.

Due to adverse experiences endured by LGBTQ+ older adults, many are positioned to experience a set of unmet needs that is unique to them (Furlotte et al., 2016; Holcomb et al., 2020), due to stigma, discrimination, and prejudice felt throughout their lives. Based on current growth forecasts, we can expect there to be 9 million older LGBTQ+ individuals in a caregiving role by 2060 (Anderson & Flatt, 2018; Fredriksen-Goldsen et al., 2019a), and more needs to be done to address their unmet needs. A lack of understanding and compassion from the medical community may leave LGBTQ+ individuals reluctant to disclose their relationship status (Alba et al., 2020; McCarron, 2020) or even seek help for their physical or psychological needs. Due to a higher prevalence of chronic conditions (Holcomb et al., 2021), the same population who need medical professionals the most may be reluctant to seek help due to fear of discrimination and stigma (Anderson & Flatt, 2018; Furlotte et al., 2016), although they may have the greatest need for such assistance.

As the needs of the individual living with a chronic condition increase, so does the need for additional support for the caregiver. Worrell et al. (2022) examined the various ways that peers provide informal support to individuals experiencing mental health impairments within the LGBTQ+ community. Their findings include negative side effects to the peer providing informal support and caregiving, such as burnout. That study also found that the informal assistance provided may negatively impact the longevity of the relationship (Worrell at al., 2022) due to the stress of the caregiving relationship and caregiver role. Many in the LGBTQ+ community start off with a smaller support system than their heterosexual counterparts, and this system continues to diminish as the couple ages (Holcomb et al., 2021). For many, they are left to face the challenge of caregiving alone, just as they need help the most. This segment of the population may not have the necessary legal documents to direct care for their spouse or partner (deVries &

Gutman, 2016) if they were not comfortable disclosing their relationship status to legal professionals. Together, a higher prevalence of health conditions, diminishing social support (Holcomb et al., 2021), fear of discrimination and reluctance to disclose relationship status (Anderson & Flatt, 2018; Furlotte et al., 2016), and lack of legal documents (deVries & Gutman, 2016) may lead to a unique set of unmet needs for LGBTQ+ individuals caring for a spouse or partner with a chronic medical condition (Furlotte et al., 2016; Holcomb et al., 2020).

Summary

This chapter helps to highlight the demand for compassion, understanding, support, and resources for older LGBTQ+ individuals caring for a spouse or partner with a chronic condition. This population faces a set of challenges and unmet needs that are unique, understudied, and overlooked. These challenges include a higher prevalence of chronic medical conditions, fear of discrimination by healthcare providers, and lack of personal support in the community. The population of older adults is booming, and that includes the segment that is LGBTQ+. To effectively care for this population, this study explored the unique unmet needs of older LGBTQ+ individuals caring for a spouse or partner with a chronic condition. The Iridescent Life Course framework has helped shape this study as it focuses on the intersectionality of the challenges of the LGBTQ+ community, with the challenges of aging and caregiving. Chapter 3 will provide an in-depth look at the research methods used in this study.

Chapter 3: Research Method

The general problem is that older, LGBTQ+ individuals face a unique set of challenges and needs when caring for a spouse or partner with a chronic medical condition (Furlotte et al., 2016; Holcomb et al., 2020). The purpose of this qualitative phenomenological design study was to explore the perceptions and lived experiences of the unmet needs of older LGBTQ+ individuals caring for a spouse or partner with a chronic condition. Current research shows there are 41 million informal caregivers in the US (Amankwaa, 2017), as individuals live longer with more complex diagnoses (Bai et al., 2018). Nearly 75% of the care provided to older adults is completed through informal means (Amankwaa, 2017).

Alba et al. (2020) utilized qualitative methods to research the role of older LGBTQ+ individuals caring for a spouse or partner with a chronic condition and found that most participants reported stigma and discrimination in their experiences as a caregiver. Wardecker et al. (2021) recounted the daily discrimination that many LGBTQ+ individuals report through the common experience of slurs and offensive comments directed towards them and how this impacts their chronic stress level and physical well-being. That study found that a significant portion of LGBTQ+ individuals (60%) had reported this experience leading many to feel pressure to conceal their sexuality to prevent discrimination (Wardecker et al., 2021). This fear of discrimination may prevent couples from disclosing their relationship status, even though this information is crucial to caregivers receiving the support and resources they need to prevent declines to their own physical and mental health (Hawkley et al., 2020; Kim et al., 2021; Wardecker et al., 2021).

The general problem addressed in this study is that older LGBTQ+ individuals, caring for a spouse or partner living with a chronic medical condition face challenges that are not prevalent

with their heterosexual counterparts (Holcomb et al., 2021; Wardecker et al., 2021). Some of these challenges are a higher rate of chronic medical conditions (Holcomb et al., 2021), fear of discrimination by healthcare providers (Alba et al., 2020; Wardecker et al., 2021), and stigma towards LGBTQ+ individuals (Alba et al., 2020). The purpose of this qualitative phenomenological design study is to explore the perceptions and lived experiences of the unmet needs of older LGBTQ+ individuals caring for a spouse or partner with a chronic condition. This study will utilize a qualitative methodology with a phenomenological design to capture the narratives of LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition. This chapter will provide a detailed overview of the methodology utilized for this study, as well as an outline of the population and sample size.

It is important for the medical professionals working with the patient and their caregivers to understand their relationship, as a better support system relates to the medical outcomes of both parties (Hawkley et al., 2020). Spousal/partner caregivers face more difficult challenges related to caregiving than others in the caregiving role may face. Spousal/partner caregivers tend to provide care for a much longer time, and the demands will increase during this process (Gibson et al., 2019). This research was designed to understand the needs of LGBTQ+ older adult caregivers so medical professionals may offer better support for the caregiver, and in turn, the caregiver can provide better care to their spouse or partner.

Chapter 3 of this study presents the methodology and design used. The chapter will provide an outline of the population, sample size, and participant selection. The materials used for data collection, study procedures, and data analysis will be described. The chapter will detail the assumptions, limitations, delimitations, and ethical assurances of the study.

Research Methodology and Design

Utilizing a qualitative methodology with an interpretive phenomenological design, this study captured the narratives of LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition. This data will help inform future policies and the development of resources that are geared toward this group of caregivers and the medical professionals who support them.

Methodology

According to van Manen (2014), "The term method refers to the way or attitude of approaching a phenomenon" (p. 26). A qualitative method allows for a non-scientific, non-numeric approach to collecting data from participants and giving meaning to the data within the context of the participants' experiences. (Queirós et al., 2017; van Manen, 2014). Qualitative research is not designed to generalize the collected data (Austin & Sutton, 2014; Polit & Beck, 2017), rather the goal is to find deeper meaning in the phenomenon being studied (Queirós et al., 2017) in a multidimensional manner. The value of qualitative research is that it allows the researcher to explore the experiences studied through the participant's perspective (Austin & Sutton, 2014) and metaphorically walk in their shoes. Qualitative research allows for an intensive study (Polit & Beck, 2010) of each participant's responses and how their experience has shaped their thoughts and feelings about the phenomenon. It is the best choice for ambiguous and complex phenomena (Austin & Sutton, 2014; Smith & Osborn, 2015) that will vary based on the participants' experiences and historical encounters.

Some of the most common types of data collection within a qualitative study are observations, focus groups, and interviews (Austin & Sutton, 2014). As a stand-alone tool, researchers use their five senses to examine a phenomenon that is occurring and interpret the

participants' actions and behaviors (Austin & Sutton, 2014). Focus groups are unstructured interviews with multiple participants at one time, with a facilitator asking questions (Austin & Sutton, 2014). Because this is a group setting, participants may be reluctant to share personal details of their experiences. Interviews are one-on-one conversations that aim to yield in-depth, detailed responses to a set of questions (Austin & Sutton, 2014). Interviews were the best method of data collection within this qualitative study because they allowed the participants to freely share their experiences in a confidential setting.

Qualitative methods were the best choice to address the study problem because the goal of this type of research is to find an "improved understanding" (Aspers & Corte, 2019, p.145) of the significance of the lived experiences shared through the study (Husserl, 1977; Stahl & King, 2020; van Manen, 2014). Qualitative methods were the best choice to address the study purpose because semi-structured and conversational (Elhami & Khoshnevisan, 2022) interviews allowed me to compile these accounts into a collective archive regarding the unmet needs of older LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition. Qualitative methods were the best choice to address the study research questions because this type of data collection relies on participants' own perspectives and the words and language they use to convey their own lived experiences (Chalmers & Cowdell, 2021).

This study included semi-structured, one-on-one interviews to collect data related to the lived experiences (Husserl, 1977; Stahl & King, 2020; van Manen, 2014) of older LGBTQ+ individuals caring for a spouse or partner with a chronic medical condition. Using non-numerical data, this qualitative approach focused on each participant's account of caring for a spouse or partner through their own unique set of experiences through semi-structured interviews. Qualitative research, sometimes referred to as interpretive research, has been around as long as

the field of sociology (Aspers & Corte, 2019). It has historically been used in sociological and anthropological research to study behavior (Austin & Sutton, 2014). Juxtaposed to quantitative research, which is rooted in observation and scientific analysis, qualitative methodologies rely on getting to the core of the participants' experiences through informal conversations (Elhami & Khoshnevisan, 2022) and compiling them into a collective archive.

Design

The design for this study was an interpretive phenomenological approach (Nizza et al., 2021). The phenomenological design is rooted in the philosophy of Edmund Husserl, who is considered the father of the modern phenomenological approach (Grossoehme, 2014; Phillips-Pula et al., 2011; Shorey & Ng, 2022). Husserl developed his approach as a method of studying experiences and the meaning of experiences as individuals have lived and interpreted them (Husserl, 2012). His interpretive approach focused on deriving the meaning of the accounts provided by individuals. This meaning, when applied to research design, is deduced from a blending of the researcher's preexisting notions and the information provided by the participant (Phillips-Pula et al., 2011).

Martin Heidegger's philosophy was to apply phenomenology as a "concept of method" (Heidegger & Stambaugh, 1996, p.24) which describes how research is conducted. Heidegger proposed that the purpose of phenomenology was to have a better understanding of the phenomenon or experience being studied (Heidegger & Stambaugh, 1996). Heidegger's design was interpretive in nature, with the goal of deriving common meanings of experiences (Willis et al., 2016). Descriptive phenomenology was not chosen for this study, as this approach focuses on a depiction or portrayal of events (Williset al., 2016) but does not leave room for either the

participants or researcher to interpret the meaning behind the experience, feelings, or actions reported.

Specifically, the interpretive phenomenological design was used in this study, as it allowed participants to describe and "make meaning" (Willis et al., 2016, p. 1187) of their own lived experiences. Interpretive phenomenological design was the best choice to address the study problem because it allows the researcher space to use their own experience and knowledge within the study (Phillips-Pula et al., 2011). An interpretive phenomenological design was chosen to address the study purpose because it focuses on the meaning behind the words and language used by the participant (Shorey & Ng, 2022). This design approach allows the researcher to blend their preexisting notions and experiences with the participants' experiences to address the questions posed (Phillips-Pula et al., 2011). This type of design is quite common in qualitative research (Grossoehme, 2014; Shorey & Ng, 2022), as it focuses on the participants' words and their meaning and allows space for the researcher's perspectives.

An idiographic, case analysis approach analysis was conducted after data collection. Using this method, the researcher examined each participant's account separately, prior to combining the data and searching for common themes (Smith & Osborne, 2015). Interpretive phenomenological analysis was the best choice to address the study problem because this type of analysis is helpful when studying emotional subject matter (Smith & Osborne, 2015). Interpretive phenomenological design was the best choice to address the study purpose because its underlying aim is to conduct an in-depth analysis of the participants' views and words (Smith et al., 1999). Interpretive phenomenological analysis is the best choice to address the study research questions because it allows the researcher to try to "make sense of the participant trying

to make sense of what is happening to them" (Smith & Osborn, 2015, p. 41). This approach allows for a deeper understanding of the responses expressed by participants.

Alternative Methodology and Designs

Descriptive phenomenology was also considered for this study, as it actively removes the researcher from the study. The descriptive phenomenological analysis seeks to uncover the "universal essence" (Shorey & Ng, 2022, p. 1969) of an experience that the participants have lived. This theory also aims to remove any preconceived notions, ideas, or experiences from the equation (Shorey & Ng, 2022). An interpretive phenomenological analysis was the best approach for this study as it allows the researcher to participate in the research more actively and interpret the meaning behind the information provided by members of the population of interest (Grossoehme, 2014).

Because each caregiver has a distinct and meaningful story to tell (Andrews, 2020), this information cannot be obtained through quantitative methods. Each individual account added substance and a wealth of information to the overall data collected. Structured interviews do not allow for deviation from a set of interview questions (Elhami & Khoshnevisan, 2022), whereas semi-structured interviews allow for some variation based on the conversation.

Ethnographic and grounded theory research were also considered for this qualitative study. Ethnographic studies seek to determine what the experience is like from the inside-out, on behalf of the participants. They typically use purposive sampling techniques and collect data through a combination of methods (Grossoehme, 2014), often including observations of participants during the experience. As the study included participants throughout the United States, this approach would not be best suited for the research. Grounded theory employs an inductive approach that simultaneously collects and analyzes data until it is perceived that

saturation has occurred (Grossoehme, 2014). The investigator may alter questions, or the research direction based on their interpretation of the data collected throughout the collection/analysis process. The goal of grounded theory is to garner results that are grounded in the data and yield a new theory emerging from the data (Grossoehme, 2014).

Population and Sample

The population chosen for this study was LGBTQ+ individuals who are age 50 and older, caring for a spouse with a chronic medical condition in the United States. There are currently 41 million informal caregivers in the US (Cohen et al., 2021), and 3 million are individuals over the age of 50 who identify as LGBTQ+ (Fredriksen-Goldsen et al., 2019). The percentage of LGBTQ+ individuals caring for a spouse or partner is nearly double that of the percentage of the overall population who are caregivers in this same age group (Anderson & Flatt, 2018; Hawkley et al., 2020). LGBTQ+ individuals have higher rates of depression, chronic pain, and other mental and physical conditions (Holcomb et al., 2021; Wardecker et al., 2021) that may lead to a great set of unmet needs when caring for a spouse or partner with a chronic condition (Capistrant et al., 2020; Jones et al., 2018).

Transparency throughout the study process allows the reader to share a view of and truly understand (Vučković Juroš, 2022) my approach, design, and methodology, and leads to a greater sense of validity. The first step I took in the study was to recruit and interview six individuals (Anderson, 2010; Austin & Sutton, 2014; Guest et al., 2020) who meet the inclusion and exclusion criteria using a purposive sampling method, where participants are recruited based on their characteristics (Elhami & Khoshnevisan, 2022). The inclusion criteria, or key features of a chosen sample, evaluates how that sample is chosen, and impacts the validity of a study (Patino & Ferreira, 2018). For this study, inclusion criteria were LGBTQ+ individuals aged 50 and older,

living in the United States, and caring for a spouse or partner with a chronic medical condition. This population was appropriate for the study because this group of caregivers is expected to climb to 20 million by 2060 (Fredriksen-Goldsen et al., 2019), and it is important to research what their unmet needs may be (Capistrant et al., 2020; Jones et al., 2018).

Purposive sampling is most commonly used in qualitative research, as the goal is not generalization, but to obtain meaningful information that is relative to the study (Elhami & Khoshnevisan, 2022). For this study, purposive sampling involved following the inclusion criteria established for this research. These criteria yielded a sample of participants who have direct experience with the phenomenon of interest and were able to speak to the research questions. This technique was appropriate for the study because it allows for the selection of "information-rich cases related to the phenomenon of interest" (Palinkas et al., 2015, p. 1). The researcher must ensure that participants are recruited in a consistent and reliable manner (Garg, 2016). To ensure this, I posted a recruitment flier to several Facebook groups with eligibility criteria listed for the study, and had participants confirm eligibility via email. For this study, the inclusion criterion was LGBTQ+ individuals 50 or older, caring for a spouse or partner with a chronic condition living in the US.

A small sample size is appropriate for this type of research because the goal is to obtain as many unique experiences as possible, through detailed information about the unmet needs of this portion of the population (Cobern & Adams, 2020; Garg, 2016). I reached data saturation for the research with five participants. Data saturation is the point at which no new data is being discovered (Guest et al., 2020; Hayashi et al., 2019). In this instance, data saturation was achieved when I stopped obtaining differing or unique perspectives (Cobern & Adams, 2020) on

the experience of unmet needs of older LGBTQ+ individuals caring for a spouse or partner with a chronic condition.

I recruited participant caregivers through the online social media platforms Facebook, Instagram, and LinkedIn. I posted the recruitment flyer (see Appendix A) on my own Facebook, Instagram, and LinkedIn profiles, asking that others share the flyer as well, in an attempt to generate a "snowbell effect." I also received permission to post recruitment materials with a church and also posted fliers on The Elder Care Network LinkedIn page. As a member of this group, I am able to post questions, polls, and posts. These groups were the best choice for recruiting participants because some members of each group may be caring for a spouse or partner with a chronic condition and can address the study purpose. These groups were the best choice to recruit participants who can address the study research questions due to the potential for members who meet all of the study criteria. I expanded my search through other Facebook groups, as well as presenting my research to a church group.

The recruitment post (see Appendix A) asked interested parties who meet the study criteria to contact me at an email address set up for the study. I am the only individual who had access to this email address, and it was only used for this study. Interested parties were asked by email to confirm that they meet the eligibility criteria listed in the post and then asked via email to schedule a Zoom video call with me. Participants received an informed consent document to review. Participants were given the opportunity to email me with questions about the documents before the scheduled interview. Data collection did not begin until the participant acknowledged that they received and read the informed consent documents and provided verbal consent to proceed at the start of the interview.

Materials

The next step was to interview the participants using a semi-structured technique to get to the heart of the research questions posed in this study. As part of the process of demonstrating trustworthiness, I utilized several tiers of checks throughout the interviews (Stahl & King, 2020). As the researcher is also an instrument in qualitative studies, bracketing must be employed to ensure any inherent biases or preconceived notions do not impact data collection or interpretation (Stahl & King, 2020). Bracketing includes setting aside beliefs, values, ideals, and assumptions about the phenomena being studied based on experience and/or prior knowledge (Stahl & King, 2020; Tufford & Newman, 2012). This is a multifaceted process to uncover conscious and subconscious views applied to various stages of the research (Tufford & Newman, 2012), which will be employed throughout the study. I began bracketing through the literature review and proposal process, and utilized personal journaling as a form of bracketing, by writing down reflections during the data collection and analysis processes (Tufford & Newman, 2012). I was able to note any assumptions or preconceived notions along the way to prevent bias from impacting the interpretation of data.

Interviews

The primary data collection method used in this study was one-on-one semi-structured interviews. Qualitative interview questions should be designed to prompt an in-depth response from the participant on a specific issue (McGrath et al., 2019; Roberts, 2020) and should align with the problem, purpose, and research questions of the study. The questions should be easy to follow and understand by participants (McGrath et al., 2019) and invite them to freely share their thoughts and experiences (Roberts, 2020). Through the use of semi-structured questions, "the interviewer can encourage the subjects to let their stories unfold and also assist the subjects to

structure their stories" (Kavle, 2007, p. 10) in a manner that is meaningful to the research. This allows the interviewer the option of opening up further dialogue depending on the participant's response. These questions may be direct, indirect, or hypothetical. For the study, I chose direct questions to elicit the information needed for this study. An interview guide was developed (see Appendix B) and consisted of direct questions and potential probing questions if more detailed information was needed (Roberts, 2020). I utilized open-ended questions, and the interview was divided into three parts. The first part was to establish the relationship between the caregiver and care recipient; the second part was questions related to the factors believed to be unique due to their LGBTQ+ status; the third part of the interview was questions related to unmet needs. I developed original questions for the interviews.

The Interview Guide (see Appendix B) for the study was developed to elicit participants' perspectives and experiences in caring for a spouse or partner (Chalmers & Cowdell, 2021). The questions were designed to allow participants the space to open up and share their own lived experiences (Korstjens & Moser, 2017). Experiences with caregiving are unique to each individual and more information can be gleaned through the participants' stories through the use of open-ended questions (Andrews, 2020; Ford, 2020). I performed a checkback review (Andrews, 2020; Stahl & King, 2020) by repeating statements made by participants and summarizing the data obtained. This allowed the participants to confirm that I had interpreted their statements as intended, which also helps to increase credibility (Stahl & King, 2020). Interviews were audio and visually recorded, as allowed by participants, but I did ask the participants to remove their names from their image to support confidentiality.

The participant interviews were guided by open-ended questions, as described in the Interview Guide. The questions posed attempted to get to the heart of the issue of unmet needs of

older LGBTQ+ caregivers. Examples of questions that were asked are: “Are you comfortable sharing your relationship status with medical professionals?” and “Do you feel like you have developed depression, anxiety, or any other mental health conditions since becoming a caregiver?” (see Appendix B). When necessary to obtain more information, I asked neutral, probing, unbiased questions. Examples of neutral, probing questions are “Can you tell me more about that experience?”, “How did you feel about this situation?", and “What did you mean when you said…?”.

Field testers were asked to review the data collection questions prior to beginning the interviews. I had three field testers who were experts in the field of aging. I asked the field testers to review the Interview Guide for readability, easy understanding, and whether they thought the questions would yield answers to the research questions. I then compiled their answers and used this information to make any necessary changes to the Interview Guide. The final version of the Interview Guide is presented in Appendix B.

Member Checking

Member checking is the process of reviewing answers with the participant at the end of each call (Andrews, 2020; Stahl & King, 2020) to verify accuracy and credibility (Stahl & King, 2020). The researcher wants to ensure that any notes taken are precise, but also that any statements made are interpreted correctly. It is recommended that qualitative researchers keep field notes (Phillippi & Lauderdale, 2018) to enhance the information that they obtain from participants during interviews. In an informal interview, it is important to note the participant’s tone, and any hidden meaning that they are conveying (Braun & Clarke, 2021) through their language or message.

Researchers can jot down the tone in which the participant responds to questions, any hesitancy in their voice, or even enthusiasm when answering a question. All of these factors play a key role in interpreting the information provided during a semi-structured interview. These notes can help add context later in the research process. As I was conducting interviews via video chat, these notes were short during the interview to maintain the conversation, then longer field notes were drafted shortly after (Phillippi & Lauderdale, 2018), while reviewing the recording.

Study Procedures

After receiving approval from the Northcentral University Institutional Review Board, flyers were developed and shared on Facebook LGBTQ+ organizations to solicit participants (see Appendix A). The flyers included the criteria required for participants as well as an overview of the study. The flyer requested that interested parties contact me through email to discuss eligibility criteria further and schedule virtual interview sessions. Each participant let me know in their initial email that they met the study criteria. Upon receiving an email from the potential participants demonstrating interest in the study I emailed them the consent letter and to schedule a Zoom interview.

Data were collected through one-on-one semi-structured interviews, member checking, and field notes. The use of these tools together helped to demonstrate trustworthiness through triangulation. Triangulation is the process of using various methods to determine where data points converge (Farmer et al., 2006) and is important for both data collection and researcher perception (Stahl & King, 2020). I asked the participant all questions from the interview guide (see Appendix B). As I needed, I also asked probing questions to obtain more details and information. Throughout each interview I employed data verification, which consisted of

repeating the answers provided back to the participant (Andrews, 2020; Stahl & King, 2020) and allowing them time to confirm the statement or add any information for clarity. I was able to put aside any preconceived notions or beliefs during the interview phase and data interpretation process to safeguard against impacting findings and conclusions. This process is referred to as bracketing (Stahl & King, 2020). I was able to bracket by separating direct statements made by the participant, and my own interpretation of statements (Stahl & King, 2020). At the conclusion of the interview, I thanked the participants for their time and participation in the study and asked permission from the participant to contact them again if needed.

Data Analysis

The analysis of data began following the first interview and continued until all interviews were completed, the information was transcribed through the use of Zoom software, and the compilation was concluded. I listened to the recordings several times, making note of pauses, coughs, and tone of voice (Moser & Korstjens, 2018). Transcripts were then re-read to ensure accuracy. After interpreting each participant's responses (Smith et al., 1999), I then organized this data into general themes, keeping in mind the big picture of the information obtained. (Alase, 2017; Moser & Korstjens, 2018). The data were stored using Excel. After conducting interviews with half of the estimated number of participants (3), I did a preliminary review for saturation. As I was still obtaining unique information (Cobern & Adams, 2020) and new data were still being collected (Guest et al., 2020; Hayashi et al., 2019) I continued interviewing new participants.

As the researcher is also an instrument in qualitative studies (Stahl & King, 2020), I used bracketing to ensure that personal experience, beliefs, or biases did not affect findings (Alase, 2017). Bracketing encompasses setting aside the researcher's own preconceived notions and

identifying any inherent biases (Alase, 2017) to ensure that they do not impact the interpretation of data collected from participants (Converse, 2012). One method that was employed was the use of a journal throughout the study to keep track of my own thoughts, ideas, and assumptions (Tufford & Newman, 2012).

The data were analyzed using an interpretive phenomenological analysis approach (Alase, 2017), as this method is participant-centered and allowed the researcher space to interpret the data from the viewpoint of participants. Analysis began at the point of data saturation or after interviewing all participants. To best fit the nature of this study, I used deductive and latent approaches to analyze the data. Deductive approaches are theory-driven (Braun & Clarke, 2021), and the theory behind this study is that LGBTQ+ older adults have a deeper set of unmet needs when compared to their heterosexual counterparts (Capistrant et al., 2020; Jones et al., 2018). The latent approach allowed me to unravel any hidden meaning behind the words and language used by participants (Braun & Clark, 2021).

To demonstrate trustworthiness, I utilized interviews, multiple check-backs throughout the interviews, and also employed the use of field notes to aid in triangulation (Farmer et al., 2006; Stahl & King, 2020). As part of the bracketing process, I kept a journal (Tufford & Newman, 2012) of thoughts, notions, and assumptions to ensure they did not impact data collection or interpretation (Stahl & King, 2020). The four elements that demonstrate trustworthiness are credibility, transferability, dependability, and confirmability.

Credibility refers to the "truth-value" (Korstiens & Moser, 2018, p.121) in qualitative research. Four strategies described by Korstiens and Moser (2018) to ensure credibility are prolonged engagement, persistent observation, triangulation, and member-checking. I employed prolonged engagement by asking questions of participants that are directly related to the research

questions, along with follow-up and probing questions to obtain further, detailed information. I allowed the time and space to provide examples that relate to the questions. Persistent observation was conducted by reading and rereading the interview transcripts to ensure accuracy. Triangulation is the use of multiple approaches (Korstiens & Moser, 2018), which was the use of interviews, member-checking, and field notes (Andrews, 2020; Stahl & King, 2020).

Transferability is the process of ensuring that the study findings would be applicable to another setting or group of individuals with similar characteristics (Korstiens & Moser, 2018). I have ensured transferability by providing an in-depth description of the participants who contribute to the study. I have also included the eligibility criteria and the Interview Guide with the findings for readers. Dependability is shown through consistency and the use of customary and acceptable standards of design. The study shows dependability by using an interpretive phenomenological analysis approach (Alase, 2017). I am able to show confirmability by remaining neutral (Korstiens & Moser, 2018) throughout the participant interviews and when I was documenting transcriptions.

Assumptions

Assumptions must be addressed as part of the research process. Three underlying assumptions that are present in all qualitative research are ontological, epistemological, and methodological. Ontological assumptions suggest that this experience is unique from other experiences; epistemological focuses on knowledge, and methodological assumptions suggest the researcher bracket oneself to get to the essential meaning of the phenomena (Converse, 2012).

The first assumption specific to this study was that the participants would provide quality, rich information. The reality is that participants may struggle to tell their full story during the

interview. To mitigate this issue, I developed probing questions, such as “Can you tell me more about that experience?” that are meant to elicit a more thorough description of the experience. The second assumption was that the participants would be comfortable enough to open up and share their personal thoughts and experiences. If the participant does not appear comfortable with the questions being asked, the researcher will attempt to build rapport with them through additional conversation (Alase, 2017) and again, offer to continue the interview at another time if that would help the participant relay information more easily. This was not an issue in this study, as all participants readily answered the questions that I posed.

The third assumption is that I would be able to adhere to study procedures (such as timeline) and conduct this study with the technological tools available (Zoom interviews, data collection software). To mitigate any technological issues, the researcher was prepared to be flexible with the timeline, for example, if there are connectivity issues during a scheduled Zoom interview and it needs to be rescheduled. I also kept a backup of all data on a password-protected thumb drive, which remained in a locked drawer to protect against data loss.

Limitations

Some general limitations of qualitative phenomenological studies are that the researcher relies on the honesty and truthfulness of participants, there may be potential memory errors of the participants, and researcher bias may impact data. To mitigate any deception or memory errors on the part of the participant, I employed several techniques. The participants were provided with the interview guide in advance of the interview to prepare themselves for the questions to be asked and give them time to focus on and remember details. I asked in-depth questions during the interview and employed probing questions to elicit more detailed responses.

Another methodological limitation is that I might not have been able to bracket myself enough to keep personal biases and preconceived notions from impacting data collection and analysis. Data were collected through qualitative interviews and will therefore be subjective. This data needed to be analyzed using an interpretive phenomenological analysis approach (Alase, 2017), and potentially influenced by any researcher bias (Anderson, 2010), not necessarily present in a quantitative study. The practice of acknowledging these potential biases and the researcher bracketing themselves can help alleviate this problem (Stahl & King, 2020). I identified any potential biases that may have impacted the interpretation and conclusions of the study (Alase, 2017; Converse, 2012).

Delimitations

This had several delimitations related to the sample that has been chosen to study. I recruited caregivers of a spouse or partner with a chronic condition on the premise that this dynamic is different from other caregiver/care-recipient relationships (Amankwaa, 2017; Kim et al. 2021) and needs to be studied on its own. Older LGBTQ+ individuals were chosen because they are caregivers to a spouse or partner at a higher rate than their heterosexual counterparts (Anderson & Flatt, 2018; Hawkley et al., 2020) and face a higher risk of chronic conditions (Holcomb et al., 2021).

The sample size that was used for the study is also a delimitation. A large volume of participants and data can be time-consuming to collect and analyze (Anderson, 2010), therefore I focused on interviewing six participants unless saturation had been reached sooner (Guest et al., 2020). The participants were older LGBTQ+ individuals caring for a spouse or partner with a chronic medical condition in the United States, which will prevented generalizing the collected data to apply to the entire population.

Two further delimitations were the research questions chosen for the study and utilizing an online platform for interviews. In qualitative research, the research questions may yield gaps in the information needed to maximize data collection. In order to mitigate these gaps, I developed an Interview Guide that pinpointed the data needed to be collected, including probing questions to obtain more data when necessary. An online platform was chosen as the method of interviewing participants to recruit eligible individuals from across the country, but tone and non-verbal communication may be hard to read due to this format. To mitigate misinterpretation of non-verbal communication, I employed check-backs throughout the interview.

Ethical Assurances

This study received approval from Northcentral University's Institutional Review Board (IRB) prior to data collection (Alase, 2017). I completed online training through the Collaborative Institutional Training Initiative (CITI) program and attached obtained certificate prior to any data collection. To mitigate risk, participants received documents outlining privacy and confidentiality practices as well as an informed consent document read prior to any data collection (Alase, 2017). Expressed verbal permission was obtained at the start of the interview, after I discussed the study overview and informed consent document with participants to ensure a good understanding (Byrne, 2023). Participants were reminded that they may withdraw from the study at any time.

In accordance with IRB and The Belmont Report (1979) procedures, names of participants will not be published, and pseudonyms will be used when necessary. Names of participants and any identifying information were stored separately from data collection in a locked drawer. The laptop and thumb drive used were password-protected. Although anonymity is not possible in this study due to the use of one-on-one Zoom interviews, confidentiality will be

maintained. I requested that the participants refrain from using their name or the name of their partner during the Zoom interview and removed any names from the transcripts.

I maintained all ethical practices necessary to collect, compile, and publish any data obtained through this study. I established an email address for the sole purpose of this study, and only the researcher has the password and access to it. Any printed materials with identifying information have been stored in a locked drawer. All digital material with identifying information was stored on a password-protected thumb drive, which was maintained in a locked drawer when not in use (Alase, 2017). I ensured that participants were treated with respect and compassion throughout the process. There was minimal risk to participants. I included a list of sensitive topics that were to be discussed on the Social Media Flyer (see Appendix A). This was to ensure that participants were aware of any topics that may cause them psychological discourse during the interview and could use that knowledge when deciding whether to participate in the study (Byrne, 2023).

I have worked in the field of aging since 2000 but do not have any known personal or professional ties to individuals who meet the eligibility criteria for the study. Based on research into the phenomena of older LGBTQ+ individuals caring for a spouse or partner with a chronic medical condition, it was my belief that this group does face a unique set of unmet needs. I was able to bracket myself to ensure that personal biases did not impact the study data. I conducted a self-examination to practice reflexivity (Vučković Juroš, 2022), and separate factual statements from interpretations to bracket myself and ensure preconceived notions or experiences do not affect data (Stahl & King, 2020).

Reflexivity can be defined as the researcher reporting on their own biases and other factors such as “Statements on the positionality of the researcher, their epistemological

assumptions, relationships with the participants, and similar reflections" (Vučković Juroš, 2022, p.256) that may impact data analysis. I practiced reflexivity through the use of journaling throughout the research process (Tufford & Newman, 2012). To mitigate any impact that my preconceived notions or experiences may have had, I put aside all beliefs and prior knowledge of this subject (Chanet al., 2013) to accurately portray the participant's experiences. I was able to keep the notion of bracketing and separating personal thoughts from data in mind throughout the study. Chan et al. further go on to say that "If the researchers are unaware of their own preconceptions and beliefs, it is impossible for them to put these issues aside (p.3), therefore I looked closely at my own thoughts and experiences around this issue to support self-awareness of subjectivity.

Summary

Chapter 3 presented the research methodology and design used for this qualitative study. A qualitative approach allowed for the collection of data regarding LGBTQ+ older adults caring for a spouse or partner with a chronic condition through semi-structured interviews with five participants using a purposive sampling method (Elhami & Khoshnevisan, 2022). These interviews offered participants the opportunity to share their lived experiences in their own words (Andrews, 2020; Chalmers & Cowdell, 2021). Field notes and member checking aided in triangulation (Stahl & King, 2020) and the trustworthiness of data collected. An interpretive phenomenological analysis approach was utilized to focus on the meaning of the information presented by participants (Nizzaet al., 2021; Phillips-Pula et al., 2011).

Study assumptions, limitations, delimitations, and ethical assurances have been presented. After receiving IRB approval, participants were recruited and provided with informed consent documents prior to data collection. I ensured that all aspects of the study were respectful

of the lived experiences shared by the participants.

Chapter 4: Findings

The general problem is that older, LGBTQ+ individuals face a unique set of challenges and needs when caring for a spouse or partner with a chronic medical condition (Furlotte et al., 2016; Holcomb et al., 2020). The purpose of this qualitative phenomenological design study was to explore the perceptions and lived experiences of the unmet needs of older LGBTQ+ individuals caring for a spouse or partner with a chronic condition. Taking care of a loved one can be a daunting task that causes great physical and psychological stress to the caregiver (Amankwaa, 2017), often contributing to depression, anxiety, and isolation (Kim et al., 2017). While this true for many caregivers, older LGBTQ+ individuals encounter a unique set of conditions that may exacerbate the stress. Older LGBTQ+ individuals have often encountered discrimination and health disparities when compared to their heterosexual counterparts, which may pose a distinctive set of unmet needs (Furlotte et al., 2016; Holcomb et al., 2021). If older LGBTQ+ individuals fear discrimination within the medical community (Alba et al., 2020), they may be reluctant to disclosure their relationship status (Toze et al., 2020), thus, not receiving the support and resourced needed to provide adequate care to their partner.

The problem addressed in this study was that older, LGBTQ+ individuals face a unique set of challenges and needs when caring for a spouse or partner with a chronic medical condition (Furlotte et al., 2016; Holcomb et al., 2020). The purpose of this qualitative interpretive phenomenological design study was to explore the perceptions and lived experiences of the unmet needs of older LGBTQ+ individuals caring for a spouse or partner with a chronic condition.

The study addressed three concepts that may impact the unmet needs of LGBTQ+ older adults providing care to a partner or spouse: (a) lack of social support (Holcomb et al, 2021), (b)

lack of advance directives and other necessary documents (de Vries & Gutman, 2016), and (c) fear of discrimination by medical and other professionals (Anderson & Flatt, 2018; Furlotte et al., 2016).

Research conducted by Holcomb et al. (2021) and Jones et al. (2018) determined older LGBTQ+ individuals may not have a support system; support systems help individuals through challenges. These challenges, coupled with documented health disparities realized by LGBTQ+ individuals and access to healthcare may exacerbate health issues for the caregiver and care recipient as they age (Holcomb et al., 2021; Stinchcombe et al., 2017). This chapter provides a review of the trustworthiness of the data collected, results of the study, an evaluation of the findings, and a summary. Chapter 4 begins with an establishment of trustworthiness of data collected and analyzed in this study. The results are described next, in relation to the research questions. This study contained two research questions, and the participant responses developed into five superordinate themes or main concepts. An evaluation of the findings is presented next, and the chapter concludes with a summary.

Trustworthiness of the Data

The simplest definition of trustworthiness within the context of qualitative research is whether the data can be trusted to be accurate (Korstjens & Moser, 2018). Provided in this chapter is a demonstration of the trustworthiness of the study by describing methods used to document the credibility, dependability, transferability, and confirmability of the research. Lincoln and Guba (1985) described these four criteria as the method support trustworthiness in their seminal research.

According to Korstjens and Moser (2018), credibility is "concerned with the truth-value" (p.121) of the study, ensured by confidence in the research findings, and is achieved by linking

the research to the lived experiences of the participants through triangulation and member-checking. As part of the process of demonstrating credibility, I utilized several tiers of checks throughout the interviews (Stahl & King, 2020). I re-stated questions and participant responses to ensure a deeper understanding of the context of the participants' replies. I demonstrated triangulation through the practice of interviews, member-checking, and field notes (Andrews, 2020; Stahl & King, 2020). Field notes and reflections were documented throughout the literature review, data collection, and data analysis processes. After the participant interviews were conducted, Zoom was used for transcription. The five recorded participants were sent transcripts of their interview, and four responded and sent back approval. Two of the four approved the transcripts as is. Two participants had edits to the transcripts that included incorrect spelling of city and hospital names, as well as a few words that the transcription did not capture correctly. In one transcript, I inadvertently changed the use of the participant's partner's name to (my wife) for confidentiality purposes, and the participant reminded me that they were partners. None of the other changes noted affected the data that was collected.

Credibility is also expressed through the process of data saturation. Data saturation is the process of calculating sample size in qualitative studies and is described as the point at which no new data are being uncovered through the research (Guest et al., 2020). In qualitative research, data saturation is dependent on the context of the study and may vary depending on the components of the study (Rahimi & Khatooni, 2024). In this study, it was determined after the fifth recorded interview (Participant #6) that no new codes or superordinate themes were emerging. Each of the five recorded participants shared similar overall experiences when caring for their spouse or partner.

Dependability is defined as the "stability of findings over time" (Korstjens & Moser,

2018, p. 121). One way that dependability is conveyed is through the separation of data into observations and interpretations, also referred to as bracketing. I employed bracketing to ensure any inherent biases or preconceived notions did not impact data collection or interpretation (Stahl & King, 2020). This included noting assumptions about the phenomena being studied based on experience and/or prior knowledge, and setting them aside (Stahl & King, 2020; Tufford & Newman, 2012), and an attempt to uncover any conscious or subconscious biases present. Bracketing began during the literature review and proposal process, as well as journaling and writing down reflections throughout the data collection and analysis processes (Tufford & Newman, 2012). Dependability is achieved through documentation provided in Chapter 4 that displays the logical analysis process used to determine the study results.

According to Korstjens and Moser (2018), confirmability is related to the ability of other researchers to confirm the findings and is demonstrated by showing neutrality of the data captured through the study. The researcher's analysis should be drawn from the data, rather than any bias or researcher viewpoints. This is achieved through the process of coding, categorizing, and theming the participant responses. The researcher also needs to identify and address any potential bias that may be present at the onset of the study. To prevent my own biases from interfering with the results of the study, I kept a journal throughout the process to document my own expectations of the data, and how they differed from the information provided by participants. I began writing down my thoughts about the topic once my subject was approved and continued throughout the data analysis process. It was helpful to write down my thoughts on the subject because doing so allowed me to acknowledge any preconceived notions and then put them to the side. By acknowledging them plainly, I felt that they did not subconsciously creep into the data collection or interpretation processes.

Transferability is the degree to which the results of qualitative research can be transferred to other contexts or settings with other respondents" (Korstjens & Moser, 2018, p. 121) and is demonstrated through the details provided throughout Chapter 4, which would allow another researcher to duplicate the study. While a duplicative qualitative study may not yield the exact same results due to the expression of lived experiences by the participants, the patterns that emerged may be applicable to another group of similar participants (Stahl & King, 2020). I presented a thick description of the questions posed to the participants, as well as detailed participant responses, and non-identifying details of the participants, to demonstrate how the results could be transferred to another study.

Results

For this study, a purposive sampling method was used to recruit participants based on their characteristics (Elhami & Khoshnevisan, 2022) utilizing a snowball effect through social media. The inclusion criteria were LGBTQ+ individuals 50 or older, caring for a spouse or partner with a chronic condition living in the US. After receiving approval for the study from the National University Institutional Review Board, recruitment flyers (see Appendix A) were posted to Facebook, Instagram, and LinkedIn to find participants. In the flyer, I asked eligible participants to communicate interest in being interviewed for the study by sending an email to the address on the flyer. The first participant was provided information about the study by a family member, after she read the flyer on my own social media pages. One participant was provided with information about the study through a mutual friend who also viewed the flyer on my social media. I was invited to discuss my study with a church group in Atlanta, and this yielded the last four participants.

After receiving an email from potential participants, eligibility was reviewed to verify the

participant met the study criteria (age, LGBTQ+ status, caregiver), and each participant was sent a consent form (See Appendix C) via email. Each of the participants who responded met the criteria for the study. After the participant expressed interest in the study via email, I responded with more information about the purpose of the study, topics that would be discussed, and a copy of the consent form. The consent form, along with the email itself, noted that the interview would be recorded. The consent form was emailed to each participant as soon as eligibility was confirmed, and in the next contact, a Zoom interview was scheduled. Each participant received an emailed copy of the consent form. While a signature was not required of participants, I discussed the consent form at the start of each interview to ensure they had read it and ask whether they had questions. Each of the participants provided verbal consent at the start of their interview.

All five participants were LGBTQ+ individuals over 50 years of age, who were or had been a caregiver to their spouse or partner. As displayed in Table 1, participants were between the ages of 57 and 77 when they were interviewed. All participants and their spouses or partners lived in their own homes during the time that they were caregivers.

Table 1

Participant and Partner Ages at The Time of Interview

Participant ID	Participant's Age	Spouse or Partner's Age	Years in Relationship
Participant #2	57	71	35
Participant #3	71	67	44
Participant #4	79	86	20
Participant #5	67	71	44
Participant #6	77	81	50
Mean	70.2	75.2	38.6

Data were collected through Zoom interviews. Due to technical problems during the

interview with Participant #1, we had a phone call, which was not recorded and therefore not reflected in this study. We attempted to speak through Zoom, but the participant was not able to connect to the Zoom application. The participant tried to get on Zoom several times without success, and it was determined that we would continue speaking via phone, as this was the time we were both available. After conducting interviews with five more participants, I determined that the first participant did not provide information that was vastly different from the last five. Because I did not have a transcription of this interview, this participant's information was not included in the results of the study. Participants were coded by number from 2–6. The information obtained from Participant #2 was not included in the study. As demonstrated in Table 2, the five recorded interviews yielded a total of 4.26 hours and 235 transcribed pages.

Table 2

Interview and Transcript Details

Participant ID	Interview Length	Number of Transcribed pages
Participant #2	1:08	70
Participant #3	1:20	42
Participant #4	:20	25
Participant #5	:27	32
Participant #6	1:01	66
Mean	51	47

This study examined the caregiving duties, practices, and experiences of six older, LGBTQ+ individuals who have been a caregiver to a spouse or partner with a chronic condition. All participants reported being in long-term relationships with their partners, with most ranging from 20 to 50 years. All but one participant had wed their partner, though most had been together for decades before marrying. One couple wed when gay marriage was legalized in their home state, while the others waited until the Supreme Court ruling of Obergefell v. Hodges in 2015.

Two of the participants had been widowed prior to being interviewed for this study. One participant was widowed about four months before our interview and one participant about a year before. All participants were over 50 years of age and a member of the LGBTQ+ community. Two participants were female, and four participants were male. All the participants were White. Four of the participants identified as Christian, one stated that their religion was "not Christian," and the sixth participant did not discuss religious affiliation. While I did not ask questions about religious affiliation, five of the participants offered this information during the interview.

The study relied on an interpretive phenomenological approach to collect data through semi-structured in-depth interviews. Participants were asked a series of open-ended questions but were also encouraged to share any other information they felt was pertinent to the subject matter (see Appendix B). After the completion of each of the five recorded interviews, the Zoom recordings were transcribed into Word documents, using the participant code number assigned to them. The first participant interviewed by phone was allocated the ID Participant #1; I determined not to incorporate this participant's responses into the study, as there were no recorded transcripts of the call.

Data Analysis

I applied an idiosyncratic approach, as described by Smith and Osborn (2015), by first examining each participant's responses in detail before comparing them to the others. This method allows for a display of convergence–areas where superordinate themes developed that were shared by participants; and divergence–areas where superordinate themes are unique to some participants. Data analysis was conducted manually and stored in an Excel spreadsheet using an interpretive phenomenological approach. I listened to the recordings and took notes of

items that stood out (Moser & Korstjens, 2018). After listening to the interviews, the transcripts were read through for accuracy and to remove any identifying information. I substituted names with identifiers such as “my spouse” or “friend.” I took an idiographic, case analysis approach, as recommended by Smith and Osborn (1999), which entailed analyzing each transcript for emerging superordinate themes, before combining data from all of the transcripts. After analyzing each interview in its entirety, I then organized the data into superordinate themes and assigned them to the research questions posed in Chapter 1 (Alase, 2017; Moser & Korstjens, 2018).

Next, significant statements were developed through the participant responses, and through the coding process meaning units and then structural descriptions emerged. The first step taken was to look at the transcripts again, and without reading them for content, highlight the meaningful or key words in each sentence. This was completed for each of the five interviews transcribed and yielded a total of 221 words which were stored in an Excel spreadsheet.

Two new subjects of “chosen family” and strategies for choosing doctors were introduced in the second interview and thus became topics that were asked about in subsequent interviews. As the goal of qualitative research is to find deeper meaning in the lived experiences of the participants (Queirós et al., 2017), the value is that this method allows the researcher to further explore the participant’s perspective and information they have shared. Semi-structured, qualitative interviews were the best choice for the collection of personal experiences (Austin & Sutton, 2014; Smith & Osborn, 2015) as it allows the questions to evolve as information is obtained. After five recorded interviews, it was determined that no new data had been obtained, and no new superordinate themes emerged, and saturation was reached (Guest et al., 2020). This was determined through an analysis of the significant statements, meaning units, and structural

descriptions stored in Excel.

The first step I took was to pull out significant statements from the transcripts, without applying context to them. Smith et al. (1999) described noting the significant statements in the margins of the transcript, but I accomplished this by reviewing the transcript in a Word document and highlighting the significant words from each sentence. Once I finished highlighting these words in each transcript, I entered them into an Excel spreadsheet. From there, I clustered the significant statements into meaning units. The meaning units were then combined into structural descriptions and then superordinate themes. A total of 22 meaning units and 12 structural descriptions emerged. All of the significant statements were then entered into one spreadsheet and placed in a structural description or superordinate theme. The structural descriptions were color-coded for easier tracking. By comparing and contrasting this information for each participant, I was able to identify five superordinate themes and apply three of the superordinate themes to RQ1 and two superordinate themes to RQ2.

Table 3

Synthesis of Superordinate Themes

Superordinate Theme	Structural Descriptions	Participant				
1.1 Relationship Dynamics		2	3	4	5	6
	Relationships	X	X	X	X	X
	Family Relationships	X	X	X	X	X
	Support Systems	X	X	X	X	X
1.2 Additional Duties						
	ADLs	X		X		X
	Household Tasks	X	X	X	X	X
1.3 Legal Issues						
	Consent	X	X	X		X
	Advance Directive	X	X	X	X	X
2.1 Challenges						
	Stress	X			X	X
	Anxiety, Depression, Physical Impairments	X		X	X	X
2.2 Resiliency						
	Respect & Acceptance		X	X	X	X
	Friendships and Chosen Family	X	X		X	X
	Strategies for Choosing Doctors	X	X		X	X

Research Question 1

Research Question 1 was "What are the lived experiences of the unmet needs of LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition?" Seven structural descriptions emerged, and I identified three superordinate themes related to RQ1, as participants described and shared their lived experiences. There was no overlap of significant statements between different superordinate themes. Relationship dynamics emerged as a superordinate theme by combining the overarching messages of the myriad ways the participants described those closest to them. There were many statements and terms used in reference to

spouse/partner, family, and siblings, but all five participants discussed friends that they considered family or chosen family. All the different types of relationships were clustered into three structural description categories as part of the relationship dynamics superordinate theme.

When evaluating the participants' signature statements individually, a meaning unit of home and personal needs emerged, but these significant statements were later split between the structural description categories of ADLs and household tasks. Some of the recurring statements that were initially in the Home and Personal Needs meaning unit were yard work and exercise. Many significant statements regarding household tasks, such as cooking, laundry, paying bills, were reviewed independently when analyzing each participant's transcripts, but clustered together as a structural description category. When looking at household tasks as a whole, all five participants described taking on additional activities in that arena. I presented both household tasks and ADLs under the superordinate theme of additional duties.

The meaning unit legal issues remained consistent through all levels of coding and categorizing the significant statements made by participants. Some of the terms that were identified were legal/ly, benefits/insurance, consent, and advance directives. These terms were clustered into one meaning unit, then diverged into two structural description categories under the same superordinate theme. Table 3 displays the synthesis of superordinate themes and categories as they arose from the data analysis.

Table 4

RQ1 Superordinate Themes

Superordinate Theme	Structural Description
1.1 Relationship Dynamics	• Relationships • Family Dynamics • Support Systems
1.2 Additional Duties	• Household Tasks • Assistance with Activities of Daily Living
1.3 Legal Issues	• Advance Directive • Consent

Superordinate Theme 1.1 Relationship dynamics. Each participant discussed their relationship with parents and siblings, as well as relationships with their partner or spouse. While each participant demonstrated convergence of superordinate themes by describing positive relationships with their own parents, two of the male participants shared that they never officially "came out" to their parents, and their sexuality was not discussed. Each participant described having a strong network of support, both family and friends, who they were able to rely on during their caregiving journey. Participant #4 described a healthy relationship with their own biological child, as well as their partners.

Participant #2 did discuss the ways that her circle of support has diminished over time but still has some individuals who provide support in various ways. The other participants all described a larger support system. Support systems were also discussed in formal and informal terms. All the participants were in long-term relationships with the partner they were caring for, and one shared some of the difficulties that LGBTQ+ older adults often face after losing a life-long partner. A few of the participants shared some of the struggles they have had with their own biological families. Two discussed having never "officially" come out to their parents but

coming out to siblings later in life. Participant 3# stated that his mom told a sibling "She could never have a have a conversation about my being gay to me. yeah, my mother never once talked to me about being gay." Participant #5 shared that they had a brother close by while they were a caregiver to a spouse but stated they had an "estranged relationship." Participant #6 explained, "Our mothers were both very open and receptive fathers, not so much." This participant went on to say, "You might think about a little bit with gay couples, especially. You've got a lot of family issues, even if you've been together as long as (my partner) and I have been. By that I mean even the ones that are accepting." Many of the participants shared that their sisters, or sisters-in-law, were a source of help during the caregiving journey.

Participant #2 discussed attending different support groups and training sessions for caregivers, and the need for groups that are geared towards LGBTQ+ individuals:

> You know, I'm the only one. Okay, everyone. Yeah. Everyone here are women taking care of men. Okay. And but there, no one's been unkind to me. Okay. but no, I'm the only gay person there. And then, when I went to the powerful tools for caregivers. I was the only gay one there in that group.

The topic of what happens after losing your partner was discussed in-depth by Participant #6:

> You know, as long as you have your spouse living, and you're still able to get around and do everything. You know it's life is wonderful. What am I going to do on my own when I don't have my partner, because we rely so much on them, especially in long term relationships in the gay community. In a gay relationship especially. I mean, you just count on them. They're everything to you. So, I yeah, I think that it's that's the one difficulty. That we have is like, well, what do we do next? Where do we go? Where will we be? Do we have to go back in the closet?

Superordinate Theme 1.2 Additional duties. All five participants discussed the impact being a caregiver had on their own lives, as well as physical and mental wellbeing. They all shared that they had taken on new tasks in the household that they were not responsible for in the past, along with three participants assisting their partner with activities of daily living (ADLs). ADLs include activities such as bathing, dressing, and grooming. Participant #2 described ongoing ADL assistance she has been providing to her spouse, resulting in an injury that she has sustained. Participant #1 had been a caregiver to their partner for six years before they passed, and expressed that they took on all household tasks, including driving, navigating appointments, laundry, helping their partner with bathing, and ambulation.

Participant #2 is now working as much as she can (after retiring and rejoining the workforce) and has a teenage child while simultaneously caring for her spouse. She described the challenges a caregiver faces with unending tasks that need to be done:

> I just say it feels like invisible work. Well, I think I said earlier, that stuff is just invisible. Yeah, it's just like this case, things that need to happen just up and happen, and they don't… I was just about to crack with the load of it, and I when I crossed my 30-year mark (at work), I wouldn't have retired but for the caregiving.

Participant #6 discussed how he and his spouse had a pretty defined list of household tasks that they each fulfilled for many decades. When his spouse became sick and unable to perform these tasks, Participant #6 explained,

> (My partner) cooked really for the last 40 years. Then I kind of took it over and I was doing the best I can. But I was no match to his culinary expertise. I'm an outside person. So, I did all the outside work, and we had a really good working relationship. So, he'd be cooking inside. I'd be working outside, and I come in, he'd say, now everything's ready,

and I come in and always say what's cooking? Everything smells so good. You know we had a wonderful life. So yeah, I took over that. There were a lot of things I took over. He was the guy that did all our laundry. I had no idea how to even work the washing machine. I had never, never used it. The last time I used a washing machine was in college, where you put quarters in and you just push the button, and you know. He packed everything. I had no idea how to pack, and I had to learn how to do all that. So, all the things that he did that I never did. In the 50 years we were together I was all of a sudden doing. And then, to mention helping, you know, as it got worse and he couldn't really get up. I had to get him out of the tub, you know. I had to kind of get him out of the chair, you know. He did as best as he could, but a lot of times. It was you know, kind of a mutual effort. But there were a lot of times when I would say, Oh, God, I can't do this.

Participant #4 stated,

(My partner) started having back problems. Probably a little over a year ago she was in a lot a lot of pain. And so, it finally got maybe a year and a half or so it finally got so bad she'd been to pain clinics. And so, I would say, maybe for the last year and a half I've been sort of a caregiver, you know, helping her do stuff. She couldn't really walk. Her back would hurt. Going to the wound clinic every Monday and working on that. So that's been upsetting for her. And you know I'm the one that changes the dressing. So, (my partner) was always the cook. Okay, so that that part has suffered. I've been doing pretty much everything for (them), you know. Fix her breakfast, fix her lunch, fix her dinner. I help her take a shower. She has a really hard time. She doesn't have much strength in her legs. I did everything. Yeah. Now we have a housekeeper who comes and cleans every 2 weeks. But, but, everything else. You know, taking out the garbage. Yeah. Taking the dog.

> Yeah, taking the dog for a walk. Everything pretty much. Yeah. Washing clothes. The whole thing. Hadn't been able to do really anything.

Participants #3 and #5 both explained that very little cooking was happening during the time they were caregivers, as their partners were the usual cooks in the household.

Superordinate Theme 1.3 Legal issues. All five of the participants stated that they had advance directive documents in place at the time of the interview, as some of them had situations arise in the past when they did not. Five of the participants shared situations where consent for their partner's treatment was a topic, generally prior to legal marriage and/or advance directives documents put in place. Participant #5 shared a situation that occurred when his partner was in the hospital, and the hospital required his partner's immediate family members to make medical decisions for him:

> (My spouse) and I were not legally married at that point, and to have permission from one of his siblings who was his nearest relative and that worked out beautifully because we all have a great relationship, and they knew that I had (his) best interest at heart. So, you know, it was a a cog in the in the in the wheel. But it all worked out fine. May of 2012. We had been together for 32 years at that point. It was the surgery that they wanted his sisters. Yes, yes. There were a couple of procedures during that process that had to stop and get permission from them.

Participant #2 shared an experience that happened earlier on, before the couple was legally married. In that situation, the hospital would not share information about her partner, even though they had been together for two decades at that time. She went on to explain, "So, when you say, did it happen? Not in 2021, but it did happen in 2006. So, I'd say, the world is

changing. Yeah. So that stuff people tell about gay people in the hospital, it's true. but it's less true now. I think, at least in the city."

Participant #6 shared how the Obergefell case positively impacted their caregiving and decision-making experience:

> But when one gets sick like (my spouse) did I mean, all of a sudden. You know, I'm gonna be a little blunt, the shit kind of hits, the fan. And all of a sudden you realize, do I have everything in place? You know. Thank God, we were married, thank God! You know we had all that stuff done. I didn't have to worry about that when I took him to the hospital.

One participant discussed insurance coverage challenges they encountered prior to the legalization of gay marriage nation-wide. Participant #2 explained: "in 2015 with the Obergefell case, I could finally add her onto my insurance. And we've been together for 25 years at that point. So, in terms of being a caregiver. That's 1 of the wrinkles for a caregiver that used to be like for the generation my generation, that you're talking to the health care and not being able to cover your partner. That was something that we really dealt with."

Research Question 2

Research Question 2 was, "What is the perceived impact of the unmet needs of LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition?" which led to an in-depth exploration of the way the participants have built resilience and strength to compensate and overcome the struggles they have faced. Through RQ2, five structural descriptions and two superordinate themes emerged. There was one meaning unit regarding emotional experiences that I gathered from the individual participant analysis but split the responses into the two superordinate themes in the final stage. The significant statements in this structural description

category ranged from positive to negative, and the terms were present in many of the transcripts. Some of the significant statements included terms such as accept/ing, difficult/y, issues, respect/ful, and help/ing. When determining the best way to present this information, I decided that the positive experiences would fit into resiliency, and the negative experiences would represent challenges. The emotional experiences structural description was a fairly even split into the two superordinate themes.

Another structural description category that emerged when looking at the individual transcripts was the presence of various LGBTQ+ terms. The term discrimination was used by three participants, and that is included in the challenges superordinate theme. The more positive significant statements, such as *gay friendly* were presented in the resiliency superordinate theme. The term *out* was highly dependent on the context of the statement made by the participant and could therefore be placed in either superordinate theme.

As displayed in Table 3, four of the five participants discussed some degree of stress, anxiety, depression, or physical impairments as a result of their caregiving activities. Participant #2 did not disclose any of these issues as a side effect of caregiving, even when directly asked. All five of the recorded participants shared demonstrations of resiliency, often in ways that addressed previous adverse events.

Table 5

RQ2 Superordinate Themes

Superordinate Theme	Structural Descriptions
2.1 Challenges	• Stress • Anxiety, Depression, and Physical Impairments
2.2 Resiliency	• Respect & Acceptance • Friendships and Chosen Family • Strategies for Choosing Doctors

Superordinate Theme 2.1 Challenges. The participants shared a range of physical, emotional, and psychological issues that related to their caregiving experiences. This included not having their own caregiver when needed, but also not always being able to address their own needs.

Participant #2 described the challenges that she encounters as the spouse and caregiver of someone with dementia. This shared that this aspect of the caregiving journey has had a significant impact on her:

> When you're living with someone that has dementia, and you're taking care of that person. It's a frustration not to have your own space like. I know people that are taking care of their parents with dementia, and it's hard as hell on them. but they can go home to their partner and cry about it. and when you're taking care of your partner and my parents have died. I don't have someone I can go home, and cry to about it. This is home.
>
> But I ended up having 6 surgeries in a 2-year period between 2018 and 2020. And one of the hard things was that I didn't have a caregiver myself. So, one of the hard things was, I did have those 6 breast cancer surgeries, and I didn't have a caregiver. The church has been really a support to me. But one of the things about myself is, I don't like to ask.
>
> So, I definitely have dealt with depression, not as much anxiety, but depression.

Participant #6 shared information about situational depression he had in the past, and explained that even though his caregiving journey was overwhelming at times, there was too much he needed to accomplish to fall back into a depression again:

> So, (in the past) I tended to some depression, but he was wonderful. I was happy. He was happy. And then, when he came down with that, it was like a sudden crash. and I was beginning to feel an incredible amount of stress. And anxiety, and I didn't want to get

depression again. I'd never want to go back there again. but I was, you know. The good thing was, I was so busy with him that it kind of kept me so busy I didn't have time to be focused on me. And I understand that that's what happens with caregivers a lot that you know. So, I really got caught up in, you know, the things I needed to do. And so, I just kept going, you know, just keep moving. I thank God that I was able to get through that time without having a breakdown.

Participant #4 had described mostly positive experiences with medical professionals and others that she and her partner encountered. When asked about the ways that caregiving impacted her own health, she stated,

I find that I'm in much, not in as good a shape as I was, because I haven't had time to exercise. So, I'm an everyday walker, although I really haven't walked much in the last 2 and a half months. So, I'm trying to get back to that. But there, you know, there was always something to do like fix breakfast, or make the bed, or, you know, take the dog out whatever. Just exhaustion. Really, sometimes I'm really, really tired. Haven't been depressed about it or anything. You know. We talk. I think if she, you know, had Alzheimer's or something, dementia of some kind that would be difficult. But she doesn't. So, I'm lucky in that way.

Another challenge that was discussed was the reality of often having to navigate aspects of the caregiving journey on their own. One participant shared that as time goes on, “My circle shrinks right, and the people that I really need in it are the ones that are the diehards that know what's going on. And it's sad because there's old friends that are no longer kind of in the circle.” The experiences that were longer-term appeared to place more burden and frustration on the caregiver.

Superordinate Theme 2.2 Resiliency. A superordinate theme that emerged in the second interview, and continued through the remainder of the interviews, was resiliency. The participants demonstrated their own resilience by choosing environments and people who showed them respect and acceptance, developing lasting friendships and chosen families, and establishing strategies for choosing doctors. Many of the participants discussed being upfront about who they are, and at this point in their life, not caring if someone else did not like it. Participant #4 very clearly stated, "I didn't come out till I was 45. So, at that point I didn't care." When asked about discrimination or treatment by others, Participant #6 shared:

> I'm sure that there were some people that were uncomfortable. But again, the way we held ourselves, I think, like we did our whole lives. I think people. you know, respected us, and nobody ever said anything to our faces, but we could kind of tell sometime that you know we knew the tables that we might be welcome to sit at, and the tables that we might not be welcome to sit at. You know you, you kinda learn after a while. Well, we learned very quickly, you know what the signs were. And then, you know, you decide whether you want to deal with it or not. We're we were never, you know, the kind that would have to be showing. That oh, well, we can sit here. I don't care what you think. You know, not really that comfortable around us. But you know we dealt with it.

Most of the participants interviewed shared some discourse or reticence about accepting them on the part of their families, but also how this led to the establishment of their own chosen families. Participant # 2 detailed the challenges that a lack of familial ties can have on gay couples when one has chronic conditions. They shared:

> What happens sometimes with queer folks and caregiving, is sometimes people are estranged from their families of origin. And so, you don't necessarily have family of

> origin come in to help you. You know, older people who didn't have children right, who couldn't have had children. My child's not really old enough to help that much, but maybe there might be other families in which the caregiver might be supported by their children. Where, in a queer family, if there weren't the opportunities for reproductive freedom. And there may be queer folks who don't have kids that can help them. You know before my generation there might not be children that could help support that caregiver.

In response to this, most of the participants shared the friendships they have developed and the myriads of ways this chosen family assisted them through challenges. Regarding the drafting of advanced directives, three participants discussed friends who were attorneys working with them to ensure everything was in place to make medical decisions for their partners. Participant #5 shared that when their partner was in the hospital, they had many friends offering to help and several that came to their multiple times during the day to walk the dogs. This participant also stated, “When asked to talk about this story. I often tell people that, you know, I pray to God that I never forget the lessons that we learned during all of this trauma. And one of those lessons was that I learned just how much people love me. Love (my partner)”. Participant #2 described having a close friend living with them who is a great source of support, friendship, and assistance. Participant #6 described the chosen family they built with their partner:

> In other words, we had all that support, and with the 6 sons we had different places to stay so, and they would all come and see him. It was a beautiful thing. I'm so glad we and again I say, sons, loosely, because we never really adopted them. What happened was that they were, they came into our lives over the past like 30 years or so. And then all of a sudden, one of them said, well, you're like our dad. So, then we said, Yeah, well, that's good, you know, you're like, son. So, then we realized we had a little family, and then.

you know, when he died? Of course, all 6 of them participated…and all of them said individually to me, we're honored to be your son.

Another way the participants demonstrated resilience was the way many of them described screening doctors and caregivers. None of the participants reported issues with any of their current medical practitioners, but they described finding them through peer networks and through current doctors they already knew were gay-friendly.

Participant #2 was the first to discuss this dynamic and how they found doctors through their network of friends and medical professionals they know on a personal level:

> I have gone out of my way before to have a doctor added into her team. I make sure that they are going to be gay friendly, that they know me, that they know I'm her wife and her caregiver, and if they act any kind of weird, then we don't hire them. She has a great team. I do interview people. So, when I've been looking for a caregiver for her, for example. That's a place where it might not be comfortable. People that come into your house. Right? So, I do. I do like right up front before they ever meet her. I tell them. You know this is me. I'm looking for a caregiver for my wife in our home. And if I get any kind of a funky feeling, anything less than warmth, I just don't continue the interview.

This participant also noted that because they have the financial resources to choose different doctors, caregivers, and other medical professionals as needed, they have some degree of privilege that others may not:

> But I feel like in my case, I do have a certain amount of privilege by my financial resources to say: okay, well, we won't be needing to continue this interview. This is not going to be a real good fit. I get referrals for doctors from other people. And so, then I'll say to one of them, I need a neurologist who should we go to? I need an infectious

disease specialist. Who should we go to? And they are gay docs themselves. And so, they're going to send me to colleagues that will treat me right. So, there's a strategy to it.

When asked whether they would be comfortable disclosing their relationship status to a new doctor, Participant #3 stated,

> Yes, I would, definitely. Yeah, I would definitely make sure everything's good. And if I got like push back from the doctor, I'd find a different doctor. Amazingly, our doctor here in Atlanta, who we dearly loved, and it I think it was like 2 or 3 years after going to him before we found out that he was gay.
>
> And then he retired about 2 years, a year and a half ago. And the doctor that he turned us over to was someone that was practicing with him. It turns out that doctor is also gay, which I did not know. But (doctor's name) told us that because we were a little worried about okay, what's this doctor gonna be like? (Doctor's name) also told us that when he goes to the doctor I see (doctor's name) myself.

The spouse of Participant #5 had a very long recovery after an accident. When discussing his spouse's numerous hospital admissions and outpatient treatments, Participant #5 shared,

> They treated me as if I was his husband, his legal husband. Okay. Great respect. They went out of their way to make sure that I knew everything that was going on. If ever I would have felt that I needed to hide that from somebody, (I) would have found a different provider.

The spouse of Participant #6 also encountered several different hospitalizations. At one point, he was receiving treatment far from home, and they often stayed in a VA center, but described positive encounters:

> I identified myself as his husband all the time. You know. Thank God, I was able to do

that because I think it really helped in so many situations, you know, that we encountered. That because I was his spouse there was no question that I could make the determination as to what we would do. You know. When he was not able to respond, or whatever you know.

Participant #6 further explained that his husband's health issues began after they were legally married, and after Obergefell v. Hodges legalized gay marriage nationally:

> We had everything in place, before we even got married. So that we hopefully would not have any issues. Of course, when he got sick, by then we were already married. But then again, you know, you don't know how people are gonna react. Every single person that we met. I was amazed. And I think it's really the way (husband) and I carried ourselves through our entire relationship. We never hid it. Never hid from anybody that we were together. But once we got married, that kind of solidified it.

Evaluation of the Findings

This study addressed three main concepts related to the unmet needs of LGBTQ+ older adults providing care to a partner or spouse, through the use of two research questions. The three components that were addressed were: (a) lack of social support (Holcomb et al, 2021), (b) lack of advance directives and other necessary documents (de Vries & Gutman, 2016), and (c) fear of discrimination by medical and other professionals (Anderson & Flatt, 2018; Furlotte et al., 2016).

The first research question addressed lived experiences of the unmet needs of LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition. The interviewed participants shared details of each of their experiences while caring for their spouse or partner. Three superordinate themes emerged from these interviews, and each was broken into two or

more categories. The most common codes related to RQ1 were related to family relations, advance directive documents, and additional tasks caregivers took on, such as cooking and laundry.

It is noteworthy to add that all five participants also discussed their pets and dogs in particular. The current research underscored previous research, which showed that spouses/partners provide the bulk of caregiving duties to their partners (Kim et al., 2017), and four participants recounted how the demands on them increased over time (Gibson et al., 2019; Park, 2017). A main point that differed from previous research was that of advance directives documents. Previous research suggested that lack of advance directives documents would be an issue for older, LGBTQ+ individuals caring for a spouse or partner (de Vries & Gutman, 2016). While some of the individuals interviewed relayed prior struggles in regard to medical decision-making for their spouse or partner, all now had the proper documents in place in case the issue came up again. While previous research showed that older LGBTQ+ individuals feared discrimination by medical professionals, (Anderson & Flatt, 2018; Furlotte et al., 2016), the participants of this study all shared that they are currently comfortable sharing relationship information with their doctors.

The second research question examined the perceived impact of the unmet needs of LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition. This research question yielded two superordinate themes, each with two or more categories. The most prominent codes to emerge from this question centered around positive relationships, developing a chosen family that offers support and advocacy, and the resilience with which the participants have derived methods for finding doctors, professionals, and others who are accepting. These findings align with previous research which developed into the Iridescent Life Course

framework, which highlights that issues, events, and history that are unique to LGBTQ+ older adults are just as impactful as other aspects of the Life Course theory (Frederiksen-Goldsen et al., 2019a). The history that LGBTQ+ individuals over 50 years of age have experienced throughout their lifetime – such as health disparities, discrimination, and inequities – shaped their current relationships and how they navigate the healthcare and legal systems. The struggles that many from this community have overcome has led to resilience (Allen & Lavender-Stott, 2020; Bower et al, 2021; Chen et al., 2022) and the ability to take on new challenges on their own terms. This resilience is evident in the chosen families many participants have created, as well as their methods for finding doctors, professionals, and a support system who will accept and appreciate them as they are.

Summary

This chapter provided an overview of how the study was conducted and the results that it yielded. The purpose of this qualitative study with an interpretive phenomenological approach was to research the experiences of older LGBTQ+ individuals caring for a spouse or partner and uncover any unmet needs they may encounter. Six individuals were interviewed, applying the semi-structured interview guide developed for this study (see Appendix B). Due to technological difficulties, the interview with Participant #1 was conducted via phone call, while the rest were conducted and recorded over Zoom.

Applying an idiosyncratic approach, as described by Smith and Osborn (2015), I first examined each participant's responses in detail, before comparing their responses to the others. The responses were analyzed in-depth in relation to the research questions. Twenty-two meaning units, 12 structural descriptions, and five superordinate themes emerged. This information was stored in Excel and color-coded into each of the categories.

While some of the prior research aligned well with the results of this study, there were two areas where the results did not align. Prior research pointed towards older LGBTQ+ individuals being fearful of disclosing their LGBTQ+ or relationship status to medical professionals (Anderson & Flatt, 2018; Furlotte et al., 2016) – while this cannot be generalized based on the sample size used in the study, all participants shared that they are currently comfortable disclosing this information. All of the interviewees also stated that they currently (or at the time of their caregiving duties) had advance directives in place, which deviates from prior research (de Vries & Gutman, 2016). The study did confirm the prior findings related to caregiver duties and relationships (Gibson et al., 2019; Kim et al., 2017; Park, 2017) in addition to expounding on the resilience of the older LGBTQ+ population (Allen & Lavender-Stott, 2020; Bower et al, 2021; Chen et al., 2022).

Chapter 5: Implications, Recommendations, and Conclusions

Individuals caring for a spouse or partner living with a chronic medical condition in the LGBTQ+ community experience a unique set of challenges (Holcomb et al., 2021), which can in turn lead to a greater degree of unmet needs (Capistrant et al., 2020; Jones et al., 2018). Such challenges include higher prevalence of chronic medical conditions (Holcomb et al., 2021) and fear of discrimination by healthcare providers (Alba et al., 2020). This is especially significant for older LGBTQ+ individuals, as they experience a higher risk of chronic medical conditions than their heterosexual counterparts (Holcomb et al., 2021). There are currently 3 million adults over the age of 50 who identify as LGBTQ+ and this number is expected to grow to 20 million by 2060 (Fredriksen-Goldsen et al., 2019). Up to 45% of LGBTQ+ adults over the age of 50 are already caregivers to a partner or spouse compared to 23% of the overall population in that age group (Anderson & Flatt, 2018; Hawkley et al., 2020).

The problem addressed in this study was that older, LGBTQ+ individuals face a unique set of challenges and needs when caring for a spouse or partner with a chronic medical condition (Furlotte et al., 2016; Holcomb et al., 2020). The purpose of this qualitative interpretive phenomenological design study was to explore the perceptions and lived experiences of the unmet needs of older LGBTQ+ individuals caring for a spouse or partner with a chronic condition. Utilizing a qualitative methodology with an interpretive phenomenological design, this study captured the narratives of LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition. The interpretive phenomenological approach (Nizza et al., 2021) allowed for blending the researcher's preexisting notions and the information provided by the participant (Phillips-Pula et al., 2011). Semi-structured, one-on-one interviews were conducted to find an "improved understanding" (Aspers & Corte, 2019, p.145) of the significance of the lived

experiences of the participants (Husserl, 1977; Stahl & King, 2020; van Manen, 2014).

For this study, a purposive sampling method was used to recruit five participants based on their characteristics (Elhami & Khoshnevisan, 2022) utilizing a snowball effect through social media. The inclusion criteria were LGBTQ+ individuals 50 or older, caring for a spouse or partner with a chronic condition living in the US. Zoom interviews were scheduled with five participants between September 30, 2024, and November 7, 2024. Participants were between the ages of 57 and 77 when interviewed. All participants and their spouses or partners lived in their own homes during the time that they were caregivers. Due to technical problems during the interview with Participant #1, we had a phone call, which was not recorded and therefore not reflected in this study. After the completion of each of the five recorded interviews, the Zoom recordings were transcribed into Word documents, using the participant code number assigned to them. The transcripts were sent to the participants to verify content. The five recorded interviews yielded a total of 4.26 hours and 235 transcribed pages.

To analyze the data, I applied an idiosyncratic approach, as described by Smith and Osborn (2015), by first examining each participant's responses in detail, before comparing their responses to the others. IPA is rooted in three theoretical principles: phenomenology, hermeneutics, and idiography (Smith & Osborn, 2015). While phenomenology is the foundation for studying the lived experience of participants, the principle of hermeneutics gives the researcher space to interpret the information provided by the participant, rather than simply reporting it (Smith & Osborn, 2015). The principle of idiography allows the researcher to develop a deep understanding of each individual's experience before looking at the data in general terms as they apply to all participants (Smith & Osborn, 2015). The researcher performs

an in-depth analysis of each participant's personal responses and experiences before compiling the data.

This type of IPA analysis allows the researcher to consider convergence and divergence of meaning units. Each participant's significant statements were viewed independently and then compared to the other participants' significant statement to allow for a more detailed analysis. Next, significant statements were developed through the participant responses, and through the coding process meaning units and then structural descriptions emerged. Two new subjects of "chosen family" and strategies for choosing doctors were introduced in the second interview and thus became topics that were asked about in subsequent interviews. After pulling significant statements from the transcripts, I clustered the significant statements into meaning units. The meaning units were then combined into structural descriptions or general themes. A total of 22 meaning units and 12 structural descriptions emerged. By comparing and contrasting this information for each participant, I was able to identify five superordinate themes and apply three of the themes to RQ1 and two themes to RQ2.

There are several general limitations of IPA that was present in this research. The first general limitation is subjectivity (Brocki & Wearden, 2006). Each participant shares the details of their own personal experience, and their explanation, verbiage and tone may be distorted by their own interpretation of the events and how it affected them. The data is informed by not just the participants' experiences, but also how they communicate these experiences to the researcher (Tuffour, 2017). Adding to the subjectivity of the study, the researcher's experience, knowledge, and understanding of the subject may impact analysis. Another limitation of IPA research is the generally small sample size. Qualitative interviews are time-consuming; therefore, a smaller sample size is typically utilized (Anderson, 2010). The smaller sample size also limits the extent

to which the study results can be generalized across the chosen population being studied. IPA can describe the *what* of an experience, but not the *why*. The goal of IPA research is to uncover and understand the participant's experience from their point of view, but not to get to the root cause of why the experience happened or affected the participant in such a way (Tuffour, 2017).

Three general limitations of this qualitative phenomenological study were that I relied on the honesty and truthfulness of participants, there may be potential memory errors of the participants, and my own bias may impact data. To mitigate these limitations, I employed several techniques throughout the study. The participants were provided with the interview guide in advance of the interview to prepare themselves for the questions to be asked and give them time to focus on and remember details, to reduce the potential for memory errors. I also asked in-depth questions during the interview and probing questions to elicit more detailed responses, as needed. Participants were also provided transcripts of their interviews to verify accuracy.

Another methodological limitation was whether I would be able to bracket myself enough to keep personal biases and preconceived notions from impacting data collection and analysis (Stahl & King, 2020). As data were collected through qualitative interviews, it was subjective in nature. The data were analyzed using an interpretive phenomenological analysis approach (Alase, 2017) and had the potential to be impacted by researcher bias (Anderson, 2010), not necessarily present in a quantitative study. Bracketing for this study included noting assumptions about the phenomena being studied based on experience and/or prior knowledge, and setting them aside (Stahl & King, 2020; Tufford & Newman, 2012), and an attempt to uncover any conscious or subconscious biases present. Bracketing began during the literature review and proposal process, as well as journaling and writing down reflections throughout the data collection and analysis processes (Tufford & Newman, 2012). In this chapter I will present the

implications of the study findings, recommendations for how this information may be used in practice, recommendations for future research, and conclusions drawn from the study.

Implications

Two research questions were developed to explore the unmet needs of older LGBTQ+ individuals caring for a spouse or partner with a chronic condition. A total of 22 meaning units and 12 structural descriptions arose, as well as five superordinate themes. Three of the themes applied to RQ1 and two themes applied to RQ2. Research question 1 addressed the unique challenges faced by older LGBTQ+ caregivers by focusing on the distinctive family dynamics often experienced by LGBTQ+ individuals, additional duties caregivers take on, and legal issues that may be unique to LGBTQ+ individuals. Research question 2 addressed the problem statement by concentrating on challenges that are unique to LGBTQ+ older adults, as well as the remarkable ways they have developed resilience and created methods to minimize challenges. The interviews revealed that the participants did not currently experience significant discrimination from medical professionals, but this had not always been the case. The data also supported the significance of the need for, and ability to build resilience by LGBTQ+ older adults, as described by many previous researchers (Allen & Lavender-Stott, 2020; Bower et al, 2021; Chen et al., 2022).

The current study contributes to the body of work which supports the Iridescent Life Course framework developed by Frederiksen-Goldsen et al. (2019a). Frederiksen-Goldsen et al. developed this framework as a more in-depth approach to the Life Course framework, addressing the intersectionality of aspects of the LGBTQ+ experience, along with age, time, and place. The Iridescent Life Course framework addresses ways that inequities, trauma, and other disparities affect an LGBTQ+ individual in older adults. The current study shows how past negative

experiences with the medical community have built resilience and strategy-development among LGBTQ+ individuals as they age.

Building on this, the current study provides a critical example of the Iridescent Life Course framework in practice. While the framework addresses how past inequities and trauma impact LGBTQ+ older adults in many facets of their lives, the current research specifically shows how negative experiences with the medical community do not solely result in harm to older LGBTQ+ individuals. While some described prior negative experiences, they also shared positive stories of their current medical providers (Bower et al, 2021). The study reveals how these past negative experiences can foster resilience and the development of strategy-based behaviors among LGBTQ+ individuals as they age. This is demonstrated through the strategies the participants have employed to find LGBTQ+-friendly medical practitioners for their spouse or partner and themselves. This finding expands the framework by demonstrating that an individual's past is not simply a source of disparity but also a resource for growth and adaptation, highlighting the multi-layered nature of the LGBTQ+ Life Course, as well as the resilience displayed by older LGBTQ+ individuals.

RQ1. What are the lived experiences of the unmet needs of LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition?

The three superordinate themes that emerged from the data related to this RQ were relationship dynamics, additional duties, and legal issues. This section will explore the three superordinate themes that emerged from RQ1, including a deeper dive into the ways the current study compares to and adds to preexisting literature. This section will also explain how the study purpose and problem were addressed through RQ1.

Relationship dynamics. The theme of relationship dynamics addresses the research question by showing that the lived experiences of LGBTQ+ older adult caregivers are deeply shaped by how caregiving responsibilities may impact their partnerships with their spouse/partner, but also the impact felt by outside relationships. The chronic condition and caregiving that goes along with it, may affect intimacy and dynamic shifts within the home. The caregiver may feel a lack of support from friends, family members, and medical professionals who may not recognize the significance of the partnership created by the caregiver and care recipient. These dynamics highlight unmet needs for support, resources, and understanding that impact both the caregiving role and the unique relational context of LGBTQ+ older adults.

While relationship and family dynamics can have an impact on all caregivers, it is especially true in the LGBTQ+ community. Support systems are a necessary component for caregivers to have a positive experience and positive outcomes. Several previous studies show that having the necessary supports and resources can prevent declines to the caregiver's mental and physical health (Hawkley et al., 2020; Kim et al., 2021; Wardecker et al., 2021). Prior qualitative research has shown that older LGBTQ+ individuals have less of a support system than their heterosexual counterparts (Holcomb et al., 2021; Jones et al., 2018). Many LGBTQ+ individuals have fewer familial relations than their heterosexual counterparts (Holcomb et al., 2021) due to separation from family and being less likely to have children (Perone et al, 2019). LGBTQ+ individuals often find more support in their *chosen* families (Alba et al., 2020; Meyer, 2003), and all five participants in the current study discussed friends that they considered to be family. Two of the participants had biological children, while one described a parental relationship he and his spouse developed with six younger males that they consider sons.

Participants were asked about relationships with parents, siblings and friends. Each of the five participants described positive relationships with most family members, particularly parents and siblings. Two male participants detailed very loving relationships with their parents, and while it was generally known that they were gay, they never formally *came out* to their parents. The lifelong relationships these two participants had with their spouses were never acknowledged, discussed, or recognized by their parents. Three participants discussed their partner's siblings as being very involved in the caregiving journey, and mostly helpful when needed. One participant did suggest that they felt their spouse's siblings questioned some of the choices they made on behalf of their spouse and wondered if it was due to their same-sex relationship.

While all five participants described having close friends and chosen family members who were very supportive of their caregiving role, one participant shared that their circle of support has diminished as they have aged and her spouse's needs have grown deeper. As described by Holcomb, et al. (2021), many in the LGBTQ+ community start off with a smaller support system than their heterosexual counterparts, and this system continues to diminish as the couple ages, as explained in detail by one participant. This participant from the current study also shared that many older LGBTQ+ caregivers are already estranged from their families, do not have children to assist with caregiving, and must come to rely on their chosen families for support and assistance (Perone et al, 2019). Holcomb et al. conducted qualitative research into the social networks of older adults (ages 50–84) through semi-structured interviews with 37 gender minority adults. That research also included mostly White participants, as 30 of the 37 identified as White. Their study described how lack of familial ties could lead to the

development of families of choice, and a social support network consisting of these chosen individuals was a different structure than that of heterosexual older adults.

Perone et al (2019) studied social isolation among older LGBTQ+ adults through the lens of a community-based program that piloted a telephonic buddy program to try to prevent loneliness and isolation. That study used a mixed methods design, to conduct surveys and semi-structured interviews with 21 participants over a 5-12-month period and contained a much more culturally diverse group. That study did include participants as young as 45, as this was the threshold for the pilot program they were studying. That research highlighted that many individuals in the LGBTQ+ community have faced situations where, or worry that, their connections would decline as they age. The authors noted that the older adults in the study described various barriers to engaging and connecting with others, reinforcing the literature related to the lifelong impact issues such as discrimination may have on older LGBTQ+ adults. That study was conducted pre-COVID, and that may also have an impact on the findings, as the use of telephonic and telehealth "visits" became more commonplace for many older individuals out of necessity. As previous studies have shown that LGBTQ+ caregivers often face significant relationship challenges, it is possible that those who felt comfortable participating in the study are also the ones who feel supported in their caregiving role.

Additional Duties. The theme additional duties speaks directly to the lived experiences of these caregivers because it captures how caregiving often extends far beyond what they expected or were prepared for. Caregivers may need to take on more medical responsibilities that they are not equipped to handle and may not feel the necessary support from the medical community that the role warrants. Caregivers often absorb responsibilities like cooking, cleaning, finances, and transportation, sometimes while managing their own aging-related health challenges, as

described by the participants in Chapter 4. These added duties often compel caregivers to prioritize their partner's needs over their own, leading to burnout and neglect of self-care.

In general, caregivers take on additional tasks and roles when caring for a friend or family member. These tasks typically include assistance with activities of daily living, such as bathing, dressing, and grooming, as well as instrumental activities of daily living (IADLs). IADLs include tasks such as cooking, shopping, managing finances, scheduling appointments, and providing transportation (Amankwaa, 2017). Caring for a spouse or partner is an experience that is significantly different than caring for another friend of family member. The nature of caregiving may change the relationship dynamic between the couple, such as a new division of household tasks and chores, and a potential shift in the coupling (Gibson et al., 2019; Liew et al., 2019). For this study, participants were asked to explain any new household tasks they took on, and I provided cooking, cleaning, errands as suggestions, as well as asking about bathing, dressing, grooming, and assistance with ambulation and transfers.

Gallagher and Rickenbach (2020) studied the effect that caregiving can have on a spousal-type relationship and found that there can be drastic implications to the dyadic connection. That study was qualitative and used semi-structured interviews with 13 spousal caregivers ranging from 53 to 85 years old, which is the same age bracket used in the current study. That study did not focus on LGBTQ+ older adults, rather they focused on couples in general. Two other studies noted that taking on a caregiver role may impact the intimate connection the partners have, marital or household roles, as well as the previous balance in the relationship (Andréasson et al., 2021; Stockwell-Smith et al., 2018). Stockwell-Smith et al used a mixed methods approach to study the dyadic relationship between 88 caregiver and recipient couples, while Andréasson et al. used quantitative means to delve further into previous studies.

Their final sample consisted of 1,057 LGBTQ+ older participants, but they were not only caregivers to partners or spouses. Participants in the current study confirmed these changes, particularly regarding marital roles. Further research did find that it is possible for partners to retain their couplehood, as long as the care recipient *hands off* their responsibilities to their partner (Andréasson et al., 2021; Gallagher & Rickenbach, 2020; Stockwell-Smith et al., 2018),

Similar to what I found through the literature review, all five participants in the current study described taking on new tasks and household chores after their spouse or partner became ill, in particular, laundry and cooking. One participant detailed how he and his spouse had a fairly defined set of household chores that they each managed before the chronic condition. He also described how he had to very suddenly learn new tasks, such as cooking and doing laundry. Another participant described the sudden need to learn how to pay all their bills, as household finances were a task his spouse had been responsible for. Three participants described helping their partner with activities of daily living, including bathing, dressing, ambulation, and assistance with toileting. The closer the relationship dynamic between the caregiver and recipient, the greater amount of stress and implications felt by the caregiver (Amankwaa, 2017). One participant in the current study really highlighted the difference between caring for a spouse and caring for a parent or other relative. She acknowledged that caring for a parent is "hard as hell," but they get to go home and lean on their spouse in that situation. When caring for a partner, there is nowhere to get "away" from the situation and just cry or vent.

Legal Issues. The theme legal issues addresses unmet needs because LGBTQ+ older adult caregivers often encounter barriers in how their relationships and caregiving roles are recognized by law, policy, and institutions, which may create vulnerability in treatment, care, and medical decision-making. Caregivers may face challenges being acknowledged as the primary

decision-maker if not a legally recognized spouse, which is detailed in Chapter 4, when participants encountered this prior to the implementation of Obergefell. Even with documentation, healthcare providers may question or challenge LGBTQ+ caregivers' authority.

In a qualitative study published in 2016, de Vries and Gutman reported that LGBTQ+ individuals may lack advance directives documents that provide the legal basis for making medical decisions on behalf of their spouse or partner. They utilized focus groups and focused on end-of-life preparations for older LGBTQ+ individuals. Not having these documents can limit the decisions an individual can make on behalf of their partner, and this was particularly salient prior to the Supreme Court ruling of Obergefell v. Hodges in 2015. The Obergefell ruling guaranteed same-sex couples the right to marry on a national level. Prior to that ruling, not all states allowed same-sex marriage or would recognize a same-sex marriage from out-of-state. Three of the participants described issues they had in the past (before Obergefell), when medical providers did not allow them to make decisions on their partner's behalf. In these cases, other family members had to intervene to make medical decisions. Four of the participants are now married to their partners; one participant is not married to her partner.

The findings in the current study indicate that all five of the participants did have advanced directives at the time of their interviews. This may be due to better knowledge about the effectiveness of advanced directives or the Obergefell ruling itself. The Obergefell ruling may have empowered more LGBTQ+ couples to pursue necessary legal documents. The participants' prior experiences may also have contributed to their knowledge of the implications of not having these documents ready, if necessary. Three of the participants in the current study disclosed that the attorney who suggested getting documents in place were known to them socially. The research conducted by de Vries and Gutman (2016) indicated that LGBTQ+ with

terminal diseases were more likely to pursue legal documents, potentially due to the challenges they saw when the community faced the AIDS epidemic. The de Vries and Gutman publication is similar to my findings, in that some of my participants had negative past experiences around decision making for their partners and then moved forward with advance directives.

RQ2. What is the perceived impact of the unmet needs of LGBTQ+ older adults caring for a spouse or partner with a chronic medical condition?

Through RQ2, five structural descriptions emerged, which led to two superordinate themes. This section will explore the two superordinate themes that emerged from RQ2, including the ways the current study compares to and adds to preexisting literature, as well as explain how the study purpose and problem were addressed through RQ2. This section will conclude with a presentation of new findings around resiliency, which I have not encountered through literature reviews.

Challenges. The theme challenges addresses the research question by showing that unmet needs may render tangible difficulties, such as emotional distress, physical decline, strained relationships, and systemic barriers, felt by both the caregiver and the partner they are caring for. These challenges reveal the perceived impact of unmet needs as cumulative burdens that reduce caregivers' well-being, resilience, and ability to sustain the caregiver role on a long-term basis. Older LGBTQ+ individuals may experience a lack of inclusive services and/or providers, a higher degree of chronic conditions than their heterosexual counterparts and already strained family relations.

One of the challenges that prior qualitative research has focused on for older LGBTQ+ caregivers were higher rates of chronic conditions. As a whole, qualitative research has shown that LGBTQ+ individuals have higher rates of chronic conditions than their heterosexual

counterparts (Holcomb et al., 2021). This encompasses both physical debilities, and mental health diagnoses including depression, anxiety, and suicidal thoughts. This is similar to the findings in this study, as four of the five participants discussed conditions they experienced themselves, prior to becoming caregivers. Yet, LGBTQ+ individuals are also caregivers to spouses and partners at a higher rate than their heterosexual counterparts (Anderson & Flatt, 2018; Hawkley et al., 2020). This combination can lead to a great set of challenges and unmet needs. The research conducted by Anderson and Flatt was quantitative, drawing on survey data obtained by prior large studies. Hawkley et al also used quantitative methods to explore data obtained from a previous study. Their research included data from 588 marital couples, but not specifically those who are LGBTQ+. Prior qualitative and quantitative research has indicated that the history experienced by older LGBTQ+ individuals has played a role in this group having poorer health outcomes later in life (Fredriksen-Goldsen & Muraco, 2010; Fredriksen-Goldsen et al., 2013; Fredriksen-Goldsen et al., 2014).

Four of the participants in the current study described having new or worsening depression and/or anxiety as a result of their caregiving role. One participant discussed a severe condition that she endured, including several surgeries, but not having anyone to care for her during the illness and recuperation. During the time she was struggling with her own health, she still needed to be a caregiver to her spouse. This participant also suffered a back injury related to assisting her spouse with ADLs. Another participant described herself as having always been very active but not in as good of shape as she used to be. She explained that there are always tasks to accomplish and she no longer has the time for daily walks or other physical outlets she once enjoyed. The current research confirms the findings from the literature review, specifically that most participants started out with their own chronic conditions, these conditions worsened

during their caregiving journeys, and new conditions developed (Alba et al., 2020; Hoy-Ellis, 2023; Meyer, 1995; Meyer, 2003).

Resiliency. The theme resiliency captures how LGBTQ+ older adult caregivers adapt, cope, and persist despite unmet needs. It shows not only the strain, but also the strengths and strategies that shape the perceived impact of caregiving on LGBTQ+ older adults. The participants in this study demonstrated ways they have become creative problem-solvers in the face of adversity, challenges, and discrimination.

The last few decades have brought significant positive changes to the context of sexual orientation through legal affirmations such as the Obergefell Decision (Fredricksen-Goldsen et al., 2019a). One participant relayed that she came out later in life and therefore did not care what others thought of her. Another shared that he and his spouse "knew which tables" they were welcome at and would make the choice whether to deal with it. Rather, they shared ways that they built meaningful relationships and chosen families that provided support and assistance. One of the key findings of the quantitative research conducted by Frederiksen-Goldsen et al. (2019b), using data sourced from 2,450 individuals who participated in the Aging in Pride national, longitudinal study is that one individual's experiences may vary from another's, as it is dependent on their viewpoint and what has led to them experiencing this phenomenon. While some of the participants in my study shared negative experiences with family and/or professionals early on in their relationships, they all seemed to find a positive way forward. The data collected from the Aging in Pride study began in 2010, before Obergefell, which may be why there is a difference in their findings.

Several prior studies demonstrated that the need and ability to overcome challenges has led to resilience in the older LGBTQ+ population. One study performed a content analysis of

empirical literature encompassing the intersection of aging and the LGBTQ+ experience, spanning the years 2010–2019 (Allen & Lavender-Stott, 2020). The authors used a qualitative approach to study 36 articles that appeared in 25 journals. They found that most of the articles searched acknowledged that the older LGBTQ+ participants demonstrated strength and resilience despite marginalization. Bower et al. (2021) conducted qualitative research to address gaps in the literature and found the older LGBTQ+ population to demonstrate "hardiness, resilience, and generativity," (p. 231) even in the face of discrimination and stigma. The authors conducted face-to-face interviews with 18 participants with ages between 46–76 years old. All of the participants they interviewed were White. Chen et al focused their research review study on ethnic minority LGBTQ+, which included qualitative and quantitative articles. They found that the experiences of resiliency for ethnic minorities was similar to that of the White population of LGBTQ+ all adults.

Like all of these studies, I found that the LGBTQ+ older adults I interviewed displayed a great deal of courage, strength, and resiliency. The greatest evidence I saw of resiliency around medical and healthcare in this study, was that many of the participants described networking methods they have employed to find healthcare providers who are LGBTQ+ friendly. This was information I had not come across in my literature reviews. Participants described asking doctors they know socially to recommend specialists and even interviewing medical professionals before making a decision. When asked, all participants indicated that they would find new providers if their current provider was not gay-friendly. One participant described a situation where a physician did not seem open to their relationship, and they used their network to find a different specialist. One participant shared that when their doctor was retiring, they relied on him to recommend another gay-friendly doctor. As all of the participants described positive experiences

with their partner's current providers, part of this may come from the prior research, networking, and effort they expelled to find the right medical professional for them.

Recommendations for Practice

After researching this topic in previously published literature, interviewing participants, and analyzing the data obtained, medical professionals may use these findings to better position themselves to be open and supportive of LGBTQ+ patients and caregivers. As described by Fredriksen-Goldsen et al. (2018), key competencies such as attitude and/or bias towards LGBTQ+ older adults, understanding of the historical events and disparities that impact the health and wellbeing of LGBTQ+ older adults, knowledge of the differences within subgroups of LGBTQ+ older adults, relationship dynamics, and interviewing and assessment techniques created for this population, are necessary for providers to ensure they are aware of the needs of older LGBTQ+ patients and caregivers. Cultural competency training and resources can help ensure that medical providers are inclusive, supportive, and understanding of their LGBTQ+ patients.

The participants interviewed for this current study shared positive experiences with their current medical practitioners. They all indicated that they felt supported by their current practitioner, and the practitioners were aware of the relationship dynamic between the caregiver and their spouse/partner. This is supported by previous studies, which have shown that better support for the caregiver leads to better outcomes for the patient (Fredriksen-Goldsen et al. 2023a; Fredriksen-Goldsen et al. 2023b; Shiu et al., 2016). Shui et al. (2016) conducted quantitative research into the needs of older LGBTQ+ caregivers, utilizing survey data from the Aging in Pride survey. They reviewed data from 451 participants who were caregivers to a spouse or partner and found those who had adequate support were linked to lower perceived

stress, consistent with stress-process models that emphasize the benefits of support. Also utilizing data from the Aging in Pride survey, two other studies provided quantitative examinations of perceived stress among 754 LGBTQ+ individuals providing care to a partner, spouse, or friend. One study found that resources and engagement were associated with better quality of life for the caregiver (Fredriksen-Goldsen et al., 2023a) The other study they conducted (Fredriksen-Goldsen et al., 2023b) found that LGBTQ+ caregivers with higher levels of social support and engagement had lower stress levels and lessened strain. That study found that community resources and support served as a "protective factor" for caregivers (Fredriksen-Goldsen et al. 2023b, p. 657).

The participants in the current study felt comfortable disclosing their relationship status, in part due to the research they conduct through their social networks and current practitioners. Many of the participants shared that they find new or specialty LGBTQ+ friendly doctors through current doctors, or doctors that are part of their social support system. But previous studies have shown that fear of discrimination may prevent couples from disclosing their relationship status, even though this information is crucial to caregivers receiving the support and resources they need to prevent declines to their own physical and mental health (Hawkley et al., 2020; Kim et al., 2021; Wardecker et al., 2021).

Spousal/partner caregivers tend to provide care for a much longer time, and the demands will increase during this process (Gibson et al., 2019), which can lead to a greater degree of unmet needs (Capistrant et al., 2020; Jones et al., 2018). As a better support system contributes to better medical outcomes for the patient and caregiver (Hawkley et al., 2020), it is imperative that the medical professional is aware of the relationship dynamic between the two parties. Medical professionals can take small steps to ensure that patients and caregivers know that they

are LGBTQ+ friendly, such as adding pronouns to their organizational bios or including questions about gender, sexuality, and preferred names on intake forms. Medical organizations can offer cultural competency training (Fredriksen- Goldsen et al., 2018) to front office staff to ensure that patients and caregivers are comfortable from the time they walk into the office. A small indicator, such as an *ally* pin on their white coat, can go a long way to providing a safe, open space for patients and caregivers.

Recommendations for Future Research

Based on the limitations of this study, future research can expand upon the background and demographics of the participants, specifically, the impact of race, location, and socio-economic status. All five of the participants in this study were White, so there is a lot of room for different experiences and perspectives to be shared. Four of the participants resided in metro areas. The one participant who is in a smaller, semi-rural area reported that her partner sees doctors who are part of a large medical system based in a suburban/ more metro area. All five of the participants were of middle-to-upper-middle class status with private insurance, Medicare, or VA benefits. A different avenue to pursue may be older LGBTQ+ individuals who receive Medicaid benefits, as this often limits the providers they can see, and therefore limits their choice to find a different doctor.

A specific subgroup of individuals to focus on could be those who receive Home and Community Based Services (HCBS) through the Medicaid Waiver program (Centers for Medicare & Medicaid Services, n.d.) This waiver program is established in all 50 states and the District of Columbia to provide in-home care to disabled and older adults living in a community-based setting, rather than a nursing facility or similar institution. To participate, individuals must meet the financial eligibility requirements of their state, as well as meet a nursing home level of

care. Participants of this program are limited to providers who are enrolled in the Medicaid program and are approved to provide care in a specific service region; therefore, participants have fewer options when choosing a provider. Furthermore, professional caregivers staffed through these agencies are typically assigned to participants based on geography and availability. If a participant is unhappy or uncomfortable with a provider or caregiver, there may be a wait to receive services with a different provider.

Conclusions

It has been established that older LGBTQ+ caregivers may face a unique set of unmet needs (Furlotte et al., 2016; Holcomb et al., 2020) related to a history and fear of discrimination (Alba et al., 2020), increase in chronic conditions (Holcomb et al., 2021), and lack of support system (Holcomb et al., 2021; Jones et al., 2018). Previous research shows that caregiving can be a challenging experience (Amankwaa, 2017), and caregivers require support and resources in order to thrive in their role and provide better outcomes for themselves and the partner they are caring for (Amankwaa, 2017; Hawkley et al., 2020; Kim et al.; 2017, Silva de Sousa et al.; 2021). Yet, many older LGBTQ+ caregivers are reluctant to (Alba et al., 2020; Candrian & Cloyes, 2021; Wardecker et al., 2021).

One study showed that there are currently 3 million adults over the age of 50 who identify as LGBTQ+ and this number is expected to grow to 20 million by 2060 (Fredriksen-Goldsen et al., 2019). Up to 45% of LGBTQ+ adults over the age of 50 are already caregivers to a partner or spouse compared to 23% of the overall population in that age group (Anderson & Flatt, 2018; Hawkley et al., 2020). The ramifications of not addressing the unmet needs of this group of caregivers are the potential for poor outcomes for both the patient and the caregiver, while more knowledgeable practitioners who can provide a support system will provide better

outcomes (Hawkley et al., 2020) for both the caregiver and the care recipient. Culturally competent, open medical professionals can provide a significant difference in providing a space for LGBTQ+ caregivers to obtain the assistance and support they need when providing care for a spouse or partner with a chronic condition.

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Appendix A: Recruitment/ Social Media Flyer

My name is Jennifer Almond, and I am a doctoral student at National University. I am conducting a research study to uncover the unmet needs of LGBTQ+ individuals 50 or older, caring for a spouse or partner with a chronic condition living in the US.

I am recruiting individuals who meet all of these criteria:

1. LGBTQ+ individuals
2. Age 50 and older
3. Caring for a spouse with a chronic condition
4. Living in the United States

If you decide to participate in this study, you will be asked to do the following activities:

1. Contact researcher by email to convey interest and confirm eligibility.
2. Schedule a Zoom interview with researcher.
3. Participate in an interview consisting of semi-structured, open-ended questions.

During these activities, you will be asked questions about:

- Discrimination/fear of discrimination
- Advance directive documents
- Social support
- Caregiver stress/burnout
- Mental health
- Physical health & wellbeing
- Length of time in the caregiver role
- Perception of care/understanding received from the medical community

If you are interested in participating in this study, or have questions, please contact me at almond.jenniferc@gmail.com.

Thank you for considering participating in this voluntary research!

Jennifer Almond

Image description: Individual in front of a computer; text says, “Sign up now! Help uncover the unmet needs of older LGBTQ+ caregivers.”

Appendix B: Interview Guide

Interview Information

Date: _____ Time:_____ Participant #:_____

Interview Pre-Brief:

Thank you for taking the time to speak with me today over Zoom and participating in this research study. As a reminder, your participation is voluntary, and you can decline to answer any question or withdraw from the study at any time.

Prior to this Zoom meeting, you have completed an informed consent and received a copy of the information letter by email. What questions do you have before we begin?

As a reminder, the interview will be recorded and typed out by me afterward, with the help of transcribing software. What questions do you have about what I have covered so far?

Please be as detailed as possible when answering questions, and feel free to stop me at any time to ask me questions.

Are these directions clear and understandable? Before we begin, what questions do you have?

Interview Questions

As I mentioned previously, this study is about the perceptions and lived experiences of the unmet needs of older LGBTQ+ individuals caring for a spouse or partner with a chronic medical condition. In psychology, unmet needs refer to the needs that a person didn't get satisfied, which would have improved the situation for them. To start with, I'd like to hear what you think about what it's like for you in your current living situation. Please forgive me for not maintaining eye contact or responding while you talk; I'll be taking notes as you talk. So, how do you feel about your current situation?

1. How long have you been a caregiver to your spouse or partner? Tell me about your experience caring for your spouse or partner.

2. Tell me about additional household duties or tasks that you have taken on since assuming this role.
3. Tell me about your experiences with medical professionals. Can you describe any challenges you may have experienced with medical professionals in your role as a caregiver?
4. Tell me about your experiences sharing your relationship status with medical professionals.
5. Tell me about any difficulties you may have experienced in your caregiver role.
6. Tell me about any stressful or frustrating experiences you may have had as a caregiver.
7. Tell me about any physical health conditions you may have developed since caregiving or because of caregiving. Did you have any preexisting conditions that have worsened?
8. Tell me about any psychological health conditions you may have developed since caregiving or as a result of caregiving. Did you have any preexisting conditions that have worsened?
9. Tell me about the social supports you have.
10. Tell me about your experiences drawing up any advance directives documents. Tell me about your experiences with legal professionals.
11. What else is there about your role as a caregiver that you might share with me that would be helpful to others.

Probing Questions (as needed)

1. Can you tell me more about that experience?
2. How did you feel about this situation? How did it affect you?
3. What did you mean when you said…?

Appendix C: Consent Form

My name is Jennifer Almond, and I am a doctoral student at National University (NU).

I'm asking you to take part in a research study about the unmet needs of LGBTQ+ individuals 50 or older, caring for a spouse or partner with a chronic condition living in the US. The name of this research is "What's Love Got to Do with It? A Qualitative Study Addressing the Unmet Needs of Older LGBTQ+ Individuals Caring for a Spouse or Partner with a Chronic Medical Condition."

You may participate in this research if you meet all of the following criteria:

5. LGBTQ+ individuals
6. Age 50 and older
7. Caring for a spouse with a chronic condition
8. Living in the United States

I hope to include 12 people in this research.

Please read this form carefully and ask any questions you may have before agreeing to take part in the study.

What you will be asked to do: If you agree to be in this study, you will be asked to do the following activities:

4. Contact researcher by email to convey interest and confirm eligibility.
5. Schedule a Zoom interview with researcher.
6. Participate in an interview consisting of semi-structured, open-ended questions (45-60 minutes).

During these activities, you will be asked questions about:

- Discrimination/fear of discrimination
- Advance directive documents
- Social support
- Caregiver stress/burnout
- Mental health
- Physical health & wellbeing
- Length of time in the caregiver role
- Perception of care/understanding received from the medical community

Risks: There are minimal foreseeable risks or discomforts associated with this research. You can still skip any question you do not wish to answer, skip any activity, or stop participation at any time.

Benefits: If you participate, there are no direct benefits to you. This research may increase the body of knowledge in the subject area of this research.

Recording: I would like to audio/video record your responses and actions with Zoom. You can disable the video function of the online meeting platform at any time.

Confidentiality: I will keep the records of this study private and take reasonable measures to protect the security of all your personal information. In accordance with IRB and The Belmont Report (1979) procedures, names of participants will not be published, and pseudonyms will be used when necessary. Names of participants and any

identifying information will be stored separately from data collection in a locked drawer. The laptop and thumb drive used by the researcher will be password-protected. Although anonymity is not possible in this study due to the use of one-on-one Zoom interviews, confidentiality will be maintained. The researcher will request that the participants refrain from using their name or the name of their partner during the Zoom interview and will also turn off the Zoom feature that records participant names. All identifying information will be destroyed at the completion of the study/dissertation.

Taking part is voluntary: Participation in this study is completely voluntary. You may quit at any time.

If you have questions: Please ask any questions you have now. If you have questions later, you may contact me at XX.

If you have any questions or concerns regarding your rights as a subject in this study, you may contact the Institutional Review Board (IRB) via email at irb@nu.edu