UNDERSTANDING EXPERIENCES OF SOCIAL ISOLATION AMONG FORMAL CAREGIVERS OF ADULTS WITH DEVELOPMENTAL AND BEHAVIORAL DISABILITIES IN BALTIMORE COUNTY

by

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ABSTRACT

Background:

Social isolation among formal caregivers of adults with developmental and behavioral disabilities constitutes a significant public health concern, particularly in socioeconomically disadvantaged areas like Baltimore County, MD. Formal caregivers are paid professional staff such as certified nursing assistants, direct support professionals, medication technicians, etc., who often experience emotional distress, systemic neglect, and a lack of recognition. Such challenges adversely affect their mental health and, in turn, compromise the consistency and quality of care they can provide.

Methods:

This qualitative study explored the lived experiences of 14 formal caregivers through semi-structured qualitative interviews. Participants were purposively sampled from two community-based caregiving organizations to ensure diversity across key characteristics, including race, ethnicity, gender, age, and caregiving roles. Interviews were conducted in both virtual and in-person formats, transcribed verbatim, and analyzed using Braun and Clarke’s thematic analysis framework to identify recurring themes.

Results:

Seven overarching themes emerged through thematic analysis:

(1) Complex and demanding nature of caregiving work

(2) Dimensions of social isolation in caregiving

(3) Financial and structural challenges in formal caregiving

(4) Caregiver stigmatization and marginalization

(5) Psychological and identity impact

(6) Coping strategies and support systems

(7) Pathways to improvement in formal caregiving

Discussions:

These findings highlight the critical need for systemic and policy-level reforms to better support formal caregivers, with particular emphasis on enhancing access to mental health services, promoting social inclusion, and ensuring fair compensation. Reducing isolation among formal caregivers can play a vital role in strengthening the quality of care delivered and enhancing the overall wellbeing and resilience of this essential workforce (these formal caregivers). This study provides valuable insights into the lived experiences of formal caregivers and identifies actionable pathways for enhancing formal caregiving working environments.

Conclusion:

These findings reveal the urgent need for structural reforms to support formal caregivers, including equitable compensation, accessible mental health services, and broader societal recognition of their contributions. Practical interventions such as community-based support groups, flexible scheduling, virtual peer networks, and affordable respite care have shown meaningful impact in reducing caregiver burden and can guide future policy initiatives. Addressing these systemic barriers is essential not only to reducing caregiver isolation but also to enhancing the quality of care delivered to vulnerable populations.

Keywords: formal caregivers, public and population health, developmental and behavioral disabilities, social isolation, mental health, coping strategies

DEDICATION

To the Eternal Author of all wisdom ……GOD ……

the One who wrote every step of this journey before I ever took the first.

Your grace has been my compass, Your strength my shelter,

and Your light my guide through every moment of stillness, doubt, and discovery.

This work, this labor of both heart and mind, is not mine alone ……

it is Yours before it is anyone's.

To my beloved FAMILY,

whose love knows no pause, whose support knows no condition.

You are the soil in which my roots have grown deep, very strong, very steady, very unshakable.

Your sacrifices echo in these pages; your hopes live within every word.

To my MENTORS and minds who shaped this pursuit ……

thank you for challenging me, guiding me, believing in what I could not yet see.

This journey has been as much yours as it has been mine.

And to the silent ones……

those whose names are not spoken here but whose impact is carved in spirit ……

I honor you too. Your quiet influence resonates through this work in invisible, eternal ways.

LIST OF ABBREVIATIONS AND SYMBOLS

DDA	Developmental Disabilities Administration
IDD	Intellectual and Developmental Disabilities
DSP	Direct Support Professional
CMT	Certified Medication Technician
CNA	Certified Nursing Assistant
RBT	Registered Behavior Technician
MD	Maryland
GNA	Geriatric Nursing Assistant
HHA	Home Health Aides
IRB	Institutional Review Board
P1- P14	Participant 1 – Participant 14
%	Percent or Percentage
IHSS	In-Home Supportive Services
CDC	Centers for Disease Control and Prevention
MDH	Maryland Department of Health

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CHAPTER 1 – INTRODUCTION

Study Background

Social isolation among marginalized caregivers of adults with developmental and behavioral disabilities remains a significant public health concern, especially in areas like Baltimore County where socioeconomic disparities are prevalent [1]. According to one study conducted in 2021 by Victor et al., 20–40% of caregivers experience social isolation, with prevalence varying based on caregiving obligations, demographics, and access to support systems [2].

Baltimore County, Maryland, has a population of roughly 850,000, and is one of Maryland's largest jurisdictions [3]. Approximately 60% of Baltimore County residents identify as White, 27% as African American, 6% as Asian, and 7% as Hispanic or Latino [3]. The population is fairly evenly distributed by gender, with females making up 52% and males 48% [3, 4]. In terms of age, around 21% of the population are children under 18, 61% are working-age adults between 18 and 64, and 18% are 65 or older, showing a significant number of older adults who are likely to need caregiving support [4].

Problem Statement

Formal caregivers for adults with developmental and behavioral disabilities provide vital, hands-on support to the individuals and families that rely on them every day. Despite the importance of their work, these caregivers, particularly in Baltimore County, frequently report feeling devalued emotionally stressed and working in under resourced workplaces [1, 4]. Their experiences reflect their personal challenges as well as broader systemic issues (e.g., low wages, lack of paid leave, inadequate health benefits, limited professional development opportunities) [1, 2]. Caregivers work long hours, often without appropriate compensation or recognition. They face financial difficulties, staffing and workforce shortages, and limited access to workplace support [4, 5]. Many formal caregivers also face language barriers, racial discrimination, and a lack of culturally responsive resources [4, 5]. Focusing on marginalized caregivers is important because they often experience these challenges more acutely due to intersecting social and economic disadvantages. This lens allows for a deeper understanding of how structural inequities uniquely impact their caregiving experiences.

These intersecting pressures or issues can contribute to a deep sense of social isolation that affects their emotional well-being, professional identity, and social connection to others [1]. Few studies have explored the experiences of isolation among caregivers. Even fewer have done so among caregivers from culturally marginalized groups, who may face additional challenges [4, 5]. Without increasing our understanding, it is impossible to design meaningful policies and support systems. This study addresses that gap in the literature by investigating the lived experiences of formal caregivers in Baltimore County. It seeks to understand how social isolation affects formal caregivers, what factors contribute to it, and how caregivers are affected individually and professionally. Through their voices, the study lays the groundwork for effective, informed change.

Thesis Statement

This study seeks to examine the perceptions of formal caregivers of adults with developmental and behavioral disabilities on social isolation, systemic inequities, and structural challenges in Baltimore County.11.4 percent of residents in Baltimore County live below the poverty line, exceeding Maryland's 9.2 percent state average. The long term aim of this study is to inform transformative policy, institutional reform, and equitable caregiver support strategies.

Research Objectives

1. To explore the lived experiences of formal caregivers of adults with developmental and behavioral disabilities in Baltimore County in relation to social isolation.
2. To identify caregivers' perspectives of the structural, systemic, and interpersonal factors that contribute to caregiver social isolation.
3. To identify the coping strategies and support systems employed by formal caregivers to navigate and manage experiences of isolation.
4. To develop evidence-based recommendations that can inform policy reforms and practice-focused interventions aimed at reducing social isolation among formal caregivers and improving their overall well-being within the caregiving sector.

Study Significance

This is a significant study because it sheds light on the day-in-day-out realities of formal caregivers working with adults with developmental and behavioral disabilities. These caregivers are often isolated, overworked, and undervalued but rarely get a chance to share their stories [3, 5]. With this study, we have a better idea of how things such as low pay, long shifts, and limited support impact their mental well-being and how they care for other people. The objective is to inform strategies for reform.

CHAPTER 2 – LITERATURE REVIEW

Caregiving in Baltimore County

Economic challenges are a key concern in Baltimore County, as about 11.4% of residents live below the poverty line [3, 4, 5]. These financial challenges severely affect specific racial and ethnic groups and create barriers to access healthcare and social services [4, 5]. Caregiving is another critical issue in the region, with an estimated 30,000 individuals involved in caregiver roles [5]. These include both unpaid family caregivers and professionals providing support to individuals with disabilities and chronic illnesses. The county is also home to over 150 caregiving facilities, including nursing homes, assisted living centers, and adult day programs, which strive to meet the needs of this population [5].

Formal caregivers of individuals with dementia, report higher rates of loneliness and isolation compared to their counterparts. Contributing factors include caregiving stress and limited opportunities for social interaction [5, 6]. These challenges are made worse by systemic issues like occupational and social stigma, and limited access to respite care, which unfairly impact caregivers from underserved communities [6]. Stigmatization of caregiving refers to negative societal perceptions that undervalues caregiving as low-skilled or invisible labor and often portrays caregivers as secondary to those they support. This contributes to a lack of recognition and social support, reinforcing feelings of marginalization [5, 6].

For the purpose of this study, “formal caregivers” refers to individuals who are employed as full-time professional caregivers [6]. These caregivers work in paid roles through caregiving agencies, healthcare institutions, or support organizations. Unlike informal caregivers, who are typically family members or friends providing unpaid assistance, formal caregivers are responsible for delivering structured care under the guidelines and regulations set by their employing agencies [5, 6, 7]. We have chosen to focus on formal caregivers in this study because their experiences are often overlooked in research, despite facing distinct challenges related to professional expectations, emotional labor, and systemic constraints.

According to Aryeetey et al. (2017), marginalized formal caregivers are individuals who are socially or economically disadvantaged [7]. Based on the literature, "socially disadvantaged" in this context refers to individuals with limited financial resources, restricted access to healthcare or community services, and those belonging to minority or underserved populations who face systemic inequities [7, 8]. Formal caregivers in these roles often face certain challenges that can contribute to isolation, including limited access to support networks, increasing the demanding nature of their caregiving responsibilities [7, 8]. Consequently, social isolation in this context can impact the caregivers' mental health and the well-being of those they support, as restricted or limited access to resources can prevent caregiving effectiveness [9, 10].

According to the literature, several factors contribute to social isolation among caregivers, including financial stress, stigma, and limited access to healthcare [10]. Caregiver stigma refers to the negative societal perceptions that caregiving is low-status, emotionally draining, or unskilled work, which can lead to social exclusion, reduced recognition, and internalized feelings of shame among caregivers [10].

Moreover, research suggests that communities often fail to recognize the specific needs of caregivers, which further isolates them [10]. Negative stereotypes and biases toward caregiving roles can make caregivers feel overlooked within their communities, creating barriers to emotional and social support [10, 11]. For instance, caregivers are often seen solely as extensions of the individuals they care for, rather than as people with their own needs, which can lead to their struggles being dismissed or undervalued. One study showed that caregivers who reported feeling unsupported by their communities were significantly more likely to experience loneliness and emotional exhaustion, necessitating the importance of community recognition and support systems in reducing isolation [12]. Without addressing these challenges, formal caregivers remain vulnerable to the long-term impacts of neglect and stigmatization, further perpetuating or contributing to the cycle of social isolation.

Financial Challenges Facing Formal Caregivers

Formal caregivers, such as professional healthcare workers, home health aides (HHA), and staff in caregiving facilities such as Registered Behavior Technician (RBT), Certified Medication Technician (CMT), Certified Nursing Assistant (CNA), Geriatric Nursing Assistant (GNA), often face significant financial challenges [12, 13]. Many formal caregivers are employed in low-wage positions that fail to provide adequate or sufficient compensation for the physical, psychologically and emotionally demanding nature of their work [13]. Additionally, formal caregivers frequently incur out-of-pocket expenses for professional certifications, continuing education, and travel to caregiving facilities, which puts additional pressure on their financial security [13, 14]. Financial challenges are also common in underfunded formal caregiving institutions, where limited resources restrict or prevent pay raises (pay increases), employee benefits, job security and opportunities for professional development [12, 13, 15]. Low-income wages and a lack of financial stability also contribute to workforce retention issues, leading to high turnover rates, which place more labor demands on the remaining staff, and this can negatively affect the quality of care provided to clients [14, 15].

Barriers to Healthcare Access and Well-being

Formal caregivers often experience barriers to healthcare access, which can directly contribute to their social isolation [13, 14, 15]. Long shifts, emotionally taxing responsibilities, and physically demanding tasks frequently lead caregivers to neglect their own health [14, 15]. Moreover, many formal caregivers do not receive sufficient health insurance benefits from their employers, creating significant barriers to accessing preventative care, mental health services, and treatment for occupational injuries [14, 15]. For example, formal caregivers exposed to occupational hazards, such as musculoskeletal injuries from lifting clients, may avoid seeking treatment due to cost concerns or inadequate workplace support systems [15, 16]. The lack of access to healthcare services affects caregivers' physical and mental well-being, as well as their ability to consistently provide high-quality care to clients [14, 15, 16]. Addressing these issues requires policies that prioritize caregiver health, including affordable healthcare benefits and employee wellness programs.

Stigma and Lack of Professional Recognition

Stigma is also a major issue for formal caregivers, undermining their professional recognition and well-being [14, 15, 16]. Despite the critical services they provide, caregiving is often undervalued and perceived as low-skilled work, diminishing the societal respect and acknowledgment caregivers deserve [14, 16]. This lack of recognition can lead to feelings of isolation and demotivation among formal caregivers [15, 16]. Male caregivers, for example, often encounter stigma in predominantly female caregiving environments, which can contribute to increased workplace stress and reduced job satisfaction [17]. Additionally, formal caregivers supporting marginalized populations, such as individuals with disabilities or chronic illnesses, frequently face bias and judgment toward their clients, further increasing the psychological burden of their roles [17].

Additionally, social misunderstandings and biases toward developmental and behavioral disabilities often stigmatize formal caregiving for adults with these conditions, leading to negative perceptions of both the formal caregivers and those they support (their clients) [17, 18]. As a result of this stigma, formal caregivers may feel judged or excluded by others, which increases their sense of social isolation. Public education campaigns and workplace initiatives aimed at reducing stigma are essential to improving the professional image of formal caregivers and fostering or prioritizing a more supportive environment [17, 18].

Interventions to Address Caregiver Isolation and Specific Needs

Current intervention strategies, including community-based programs and technology-assisted solutions, have demonstrated some positive outcomes in reducing isolation for formal caregivers [18]. For example, in their 2019 study, Wang et al. found that the Inlife program, an online social-support intervention, significantly improved formal caregivers perceived social support through virtual interaction. Specifically, formal caregivers had the opportunity to participate in guided discussions, share personal experiences, and receive emotional encouragement from peers in similar caregiving roles, all facilitated through a secure digital platform [19]. Similarly, in their 2018 study, Kovaleva et al. found that community-based workshops reduced isolation by fostering peer connections and providing tailored training for caregivers. These workshops focused on skill-building in stress management, effective communication, and self-care practices, while also providing a safe space for participants to reflect on their caregiving experiences and also engage in mutual support [20]. Hoang et al. found in a 2022 systematic review that telehealth interventions helped formal caregivers reduce loneliness and improve mental health by connecting them with specialists and peers via video [21]. These initiatives provide opportunities for formal caregivers to share experiences, access resources, and build coping strategies [21]. Programs that combine technology and social interaction are particularly effective for reducing stress and isolation. Evidence from these studies suggests that such approaches improve caregivers' well-being and resilience [19, 20, 21]. Such interventions are essential for addressing the widespread isolation many formal caregivers experience.

However, these approaches often fail to address the specific needs of formal caregivers for adults with developmental and behavioral disabilities, particularly those who are marginalized and face additional financial and technological challenges [22]. Research suggests that these unmet needs include access to affordable respite care, culturally appropriate support services, specialized training for managing complex behaviors, and peer support groups tailored to their experiences [22, 23]. Therefore, it is crucial to better understand community-specific challenges and develop tailored interventions that account for both individual circumstances and broader systemic barriers to accessing essential support services and resources [22, 23].

This study aims to address gaps in existing literature by exploring the lived experiences of social isolation among formal caregivers of adults with developmental and behavioral disabilities in Baltimore County. Specifically, it seeks to understand how these formal caregivers describe their experiences of social isolation, including its impact on emotional well-being and mental health. The research question guiding this study is: What are the experiences and contributing factors of social isolation among formal caregivers of adults with developmental and behavioral disabilities in Baltimore County? Baltimore County provides an important setting for this study because of its demographic diversity and the unique challenges faced by its residents.

By providing an in-depth understanding of the intersectional factors underlying formal caregiver isolation, this study seeks to inform intervention strategies and promote the development of policy recommendations and specialized and inclusive support systems [22]. The findings from this study have the potential to support the development of resources that enhance formal caregiver resilience, improve access to supportive networks, and promote overall well-being for both formal caregivers and the individuals (clients) in their care [22, 23].

CHAPTER 3 – METHODOLOGY

Study Design

I adopted a qualitative research design, employing semi-structured interviews to explore the lived experiences of formal caregivers in Baltimore County. This methodological approach enabled an in-depth investigation of how social isolation influences caregivers' mental health, quality of life, and caregiving effectiveness. The semi-structured format allowed participants the flexibility to articulate their experiences in their own terms, facilitating the emergence of detailed, contextually grounded narratives. This design was particularly appropriate given the study's aim of identifying the complex and overlapping factors contributing to social isolation among formal caregivers in marginalized communities, thereby generating insights with potential relevance for targeted interventions and structural support strategies [24].

Participants and Recruitment

In this study, I focused on paid (formal) caregiving professionals who serve as primary caregivers for adults with developmental and behavioral disabilities in Baltimore County. These individuals face distinct challenges associated with the structural and emotional demands of caregiving, particularly when navigating their roles with limited access to support resources. The literature suggests that social isolation is a significant aspect of the caregiving experience, inherent to the solitary and often undervalued nature of their work. By concentrating specifically on formal, paid caregivers, I aimed to develop an understanding of the social and systemic dynamics that contribute to caregiver isolation within institutional and community-based care environments and therefore contribute to the literature on strategies for intervention for this specific subgroup of caregivers.

Participants were selected through purposive convenience sampling to ensure that each had substantial, first-hand experience with formal caregiving-related social isolation. Participants were purposively sampled to reflect variation in gender, age, race/ethnicity, and training background. I collaborated with two community-based caregiving organizations serving individuals with developmental and intellectual disabilities (DDA/IDD) to facilitate the identification and referral of eligible participants. The first organization, located on Reisterstown Road in Pikesville, Maryland, provides in-home healthcare services and employs professional caregivers who assist clients with chronic illnesses and disabilities in activities of daily living and medical care. The second organization, located on Dolfield Boulevard in Owings Mills, Maryland, offers residential and day programs for adults with developmental, intellectual, and behavioral disabilities, delivering structured support to both clients and their caregivers. Both organizations are located within Baltimore County and represent critical components of the region's caregiving infrastructure. In recruiting participants, I aimed to capture a range of perspectives that reflect the diversity and complexity of the formal caregiving profession. To meet the inclusion criteria, participants were required to have a minimum of three years of experience in paid caregiving roles and to work at least 40 hours per week. Recruitment concluded when thematic saturation was achieved, consistent with established qualitative research standards, resulting in a final sample of 14 participants.

Inclusion Criteria for this Study

Eligible participants had to meet the following criteria:

1. Age: Participants were 18 years of age or older.

2. Professional Role: Participants were full-time, paid formal caregivers who served as the primary caregiver for an adult (aged 22 or older) with developmental or behavioral disabilities.
3. Residency: Participants resided within Baltimore County.
4. Demographic Background: Participants self-identified as belonging to an underserved group. This included individuals from marginalized socioeconomic backgrounds, racial or ethnic minority groups, or those with limited access to institutional support.
5. Participation Capacity: Participants were willing and able to engage in a semi-structured interview conducted in English.

Exclusion Criteria for this Study

Participants were excluded if they met any of the following criteria:

1. Care Recipient Age: Formal caregivers whose primary care responsibilities involve individuals under the age of 22.
2. Residency: Formal caregivers who reside outside of Baltimore County.
3. Consent and Language Proficiency: Formal caregivers who were unwilling or unable to provide informed consent, or who could not participate in an English-language interview.

Data Collection

I collected data using a two-part process that included a brief quantitative survey followed by in-depth, semi-structured interviews with each participant. The initial survey captured key demographic information such as birth year, gender, marital status, race or ethnicity, years of caregiving experience, and indicators of socioeconomic status, including household composition. This demographic data provided essential context for interpreting the qualitative findings and enabled a more comprehensive understanding of the participants' diverse backgrounds.

The primary qualitative data were obtained through semi-structured interviews, each lasting approximately 45 to 60 minutes. I developed an interview guide to ensure consistency while allowing for flexibility in participants' responses. The guide focused on caregivers' experiences of social isolation, perceived contributing factors, and the psychological, social, and occupational impacts of that isolation on their well-being and caregiving roles. Sample questions included: "Can you share how caregiving has affected your ability to maintain social connections or relationships?", "What do you think contributes most to your feelings of isolation as a caregiver?", "How has caregiving impacted your mental and emotional well-being?", "What types of support do you wish were available to help you feel more connected?", and "Tell me about a time when you felt especially isolated or supported in your role as a caregiver." (See Appendix III for the full interview guide.)

I conducted a total of 14 interviews, accommodating participant preferences to maximize accessibility and comfort. Ten interviews were conducted virtually using platforms such as Zoom, WhatsApp, and FaceTime, while four were conducted in person. All interviews were audio-recorded with participants' informed consent and transcribed verbatim to ensure accuracy in the subsequent analysis. This combined approach facilitated a comprehensive understanding of both demographic characteristics and lived experiences, supporting a deeper exploration of social isolation among formal caregiving professionals [25].

Data Analysis

I analyzed the interview transcripts using thematic analysis, following Braun and Clarke's six-phase framework: familiarization with the data, generation of initial codes, identification of themes, review of themes, definition and naming of themes, and production of the final report [26]. This systematic process enabled the identification of both overarching themes and more detailed subthemes that captured the complexity of participants' experiences with social isolation and formal caregiving. To assist with data organization and coding, I used NVivo software, which provided a structured platform for managing and tracking patterns across the dataset. Coding began concurrently with data collection, allowing for ongoing reflection and refinement of thematic categories. I worked closely with my thesis chair, Dr. Morales-Alemán, to construct and refine the codebook, and through continuous discussion and analytical review, we established shared interpretive understanding of the emerging themes and subthemes.

The thematic analysis was guided by both inductive and deductive reasoning. While core themes were rooted in participant narratives, the identification of subthemes offered a more differentiated interpretation of context-specific experiences, such as emotional exhaustion, institutional invisibility, and informal coping strategies. This multi-layered approach broadened the analysis and supported the study's objective of capturing the varied dimensions of social isolation among formal caregivers. Finally, I contextualized the findings within the broader academic literature, emphasizing the extent to which caregivers lived experiences reflect persistent structural inequities in caregiving systems. The analysis also aimed to generate practical insights that could inform equitable policies and responsive support structures for marginalized caregivers in Baltimore County [26, 27].

Consenting Process

To ensure ethical engagement with participants, I implemented a comprehensive consenting process that prioritized participant autonomy, privacy, and informed understanding (detailed below). Participation in this study was entirely voluntary, and I obtained informed consent from each participant prior to any data collection.

1. Initial Outreach and Study Introduction

I identified and contacted potential participants through two community-based caregiving organizations. Initial communication took place via telephone, email, or secure messaging platforms. During this outreach, I introduced myself, explained the purpose of the study, and asked whether they would be interested in learning more.

If a potential participant expressed interest, I provided them with an Informed Consent Form, which included:

1. A summary of the study's purpose and objectives.
2. A description of what participation involved (a demographic survey and a 45–60-minute interview).
3. An explanation of participants' rights, including the right to decline any question or withdraw at any point.
4. Information on data confidentiality and storage procedures.
5. A statement of any foreseeable risks (there was none) and potential benefits.
6. Contact details for myself, my faculty advisor, and the University of Alabama Institutional Review Board (IRB).

Participants were given the option to review the consent form electronically or in printed form, based on their communication preferences.

2. Obtaining Informed Consent

Before beginning the interview, I reviewed the consent form with each participant to confirm their understanding of the study and its voluntary nature. I encouraged questions and addressed any concerns. I obtained written consent from participants prior to data collection. For virtual interviews, I accepted electronic consent in the form of e-signature or a documented confirmation via email or secure text. I also recorded verbal consent at the start of each audio-recorded interview using a standardized script.

Separate consent was requested for audio recording. I emphasized that participation in the interview was not contingent on agreeing to be recorded.

3. Privacy and Confidentiality

All consent forms were stored securely, either in a password-protected digital folder or a locked physical cabinet accessible only to me. Audio recordings were transcribed and de-identified; once transcription accuracy was confirmed, the recordings were permanently deleted. Identifying details such as participant names, workplace affiliations, and any potentially traceable information were omitted from transcripts and were not included in any reporting or dissemination of the findings. The identities of the participating organizations were also kept confidential throughout the research process.

4. Withdrawal Rights and Support

Participants were reminded that their involvement in the study was entirely voluntary. They were informed that they could choose not to answer specific questions or withdraw from the study at any time without consequence. If a participant experienced emotional discomfort during an interview, I paused or discontinued the session and offered access to a list of local mental health and caregiver support services.

To acknowledge their time and contributions, I provided each participant with a $25 gift card upon completion of the interview.

Positionality Statement

I was born and raised in a small village in Sierra Leone, West Africa, where my parents worked as farmers. Growing up in a context with limited access to quality healthcare and public health system, I became acutely aware of the challenges faced by individuals with both infectious and chronic illnesses, including developmental and behavioral disabilities, as well as the immense burden placed on both familial and professional caregivers. These early experiences ignited my passion for healthcare and advocacy, motivating my lifelong commitment to supporting underserved and marginalized populations.

Due to financial constraints and the lack of educational opportunities in my village, my parents made the difficult decision to send me to live with my maternal aunt in Freetown, the capital city, at the age of five so I could access better schooling. I dedicated myself fully to my studies and achieved one of the highest scores on the National Primary School Examination (NPSE). This academic success enabled me to attend Sierra Leone Grammar School, a prestigious institution with a 180-year legacy and one of the oldest boys' schools in West Africa. I recognized education as a vehicle for creating change and committed myself to making a meaningful difference in my community.

In 2015, during my secondary school years, I volunteered during the Ebola outbreak with the encouragement of my mother. This was my first experience with a public health crisis, and witnessing its devastating impact firsthand profoundly shaped my perspective. The experience deepened my awareness of systemic healthcare disparities and reinforced my determination to advocate for vulnerable communities. I came to understand how public health emergencies not only expose but also contribute to existing social and health inequities, further marginalizing already underserved populations.

While I was pursuing my education, my father relocated to Freetown to continue his studies in electrical and mechanical engineering, and my mother joined him to attend nursing school. She later worked in government hospitals, often assisting individuals who could not afford medical care and delivering children in our home. As my parents advanced professionally and became more financially stable, they were able to reunite our family, bringing together my siblings and me, who had previously lived with relatives. Their commitment to education, professional development, and community service shaped my own aspirations and instilled in me a deep commitment to equity in healthcare and public health.

After excelling in the West Africa Senior School Certificate Examination (WASSCE), my parents supported my dream of pursuing higher education in the United States. I arrived in Baltimore County in early 2017 and quickly recognized familiar patterns of disparity and social isolation among underserved communities. These cross-cultural parallels broadened my perspective and reinforced my understanding that the challenges caregivers face transcend geographic boundaries. My journey from Sierra Leone to the United States has fundamentally shaped my worldview and deepened my commitment to addressing systemic barriers impacting vulnerable and marginalized population.

Initially, I lived with a family friend who discouraged my educational ambitions. During this challenging period, I struggled with anxiety and depression and eventually made the difficult decision to leave and live independently. Determined to continue my education, I earned my Certified Nursing Assistant (CNA) and Geriatric Nursing Assistant (GNA) certifications, which allowed me to work while supporting myself. My experience in direct patient care solidified my interest in public health and social support, as I witnessed the physical, emotional, and social demands placed on caregivers.

I began my academic journey in nursing but soon realized that my passion lay in public health. I returned to community college to complete an associate degree in public health before transferring to complete my bachelor’s and, ultimately, my master’s degree in the same field. Each stage of this journey has deepened my commitment to addressing the structural determinants of health, particularly those affecting marginalized population. My academic and professional experiences have strengthened my resolve to advocate for solutions to issues such as caregiver isolation, burnout, and limited access to resources.

Over the past six years, I have worked in various public health and healthcare roles including Disease preventionist, nursing assistant, direct support professional, medication technician, and community living assistant etc. These roles have offered me firsthand insight into the lived realities of caregivers supporting adults with developmental and behavioral disabilities. I have developed a deep respect for their resilience and a clear understanding of the structural and emotional challenges they endure. These experiences have further informed my commitment to exploring the causes and consequences of social isolation within caregiving professions.

Guided by values of empathy, equity, and social justice, I approach this research with intentional reflexivity and self-awareness. I acknowledge that my personal and professional background informs my perspective, and I strive to ensure that this positionality enhances, rather than biases, my understanding of the participants lived experiences. My goal is to conduct research that authentically promote formal caregivers' voices and shed light on the social and systemic conditions that contribute to their isolation. Through this work, I aim to advocate for meaningful change by informing policy and practice that center the well-being of formal caregivers and those they support. Ultimately, I hope to contribute to a more just and supportive infrastructure for marginalized formal caregiving professionals in Baltimore County and beyond.

CHAPTER 4 – RESULTS

In this section, I present the major findings from interviews conducted with 14 formal caregivers of adults with developmental and behavioral disabilities in Baltimore County. In conducting the thematic analysis of the data, I coded, grouped, and finally structured the results in seven prevalent themes and corresponding sub-themes that reflected the lived experiences of participants (formal caregivers). I obtained written consent from participants prior to data collection. Participants were labeled with sequential numbers (i.e., P1, P2, … P14) throughout this document to maintain confidentiality.

Demographic Characteristics

The demographic information table (APPENDIX IV) provides detailed information for each individual participant. Below is a summary table presenting the overall demographic distribution based on my analysis.

Table 1: Summary of Demographic Characteristics of Participants

Characteristics	**Frequency (%)**
Gender Male Female	7 (50%) 7 (50%)
Age Range (based on birth year)	1959-1996 (Approximate age range: 29 to 66 years)
Race/Ethnicity	African: 6 African American: 4 Hispanic / Latino/a: 2 Asian: 2
Marital Status	Single: 6 Married: 6 Divorced: 2
Household Composition	Lives Alone: 4 Lives with Family/Roommate: 10

Years in Baltimore County	Range: 7 to 42 years Median: approx. 17 years
Years as Caregiver	Range: 4 to 14 years Median: approx. 7 years
Primary Roles	All participants are paid formal caregivers (DSPs, Med Techs, etc.)
Hours Worked per Week	Stated Range: 40-64 hours Min= 40 hours/week Max= 64 hours/week Most work 50+ hours or are on-call

The table provides an overview of demographic participant profiles. Their ages ranged between 29 and 66 years (birth years between 1959 and 1996). With regard to gender, the sample was evenly distributed between males (n=7) 7 females (n=7). There was cultural/ethnic and racial diversity in the sample, with 6 Africans, 4 African Americans, 2 Asians, and 2 Latino/Hispanics. This distribution is consistent with broader trends in Maryland and nationwide, where caregivers from racial and ethnic minority backgrounds are frequently overrepresented in direct care roles. Participants were long-term residents of Baltimore County averaging about 20 years of residency. Their experience in caregiving varied between 4 and 14 years. With regard to marital status, 6 participants identified as single, 6 as married, and 2 as divorced. As to who they lived with, 4 participants lived by themselves, 9 lived with family members, and 1 lived with a roommate. Lastly, all participants were full-time employed professional caregivers, with working titles of Certified Medication Technicians, Direct Support Professionals, Behavioral Technicians, and House Managers. The participants worked with diverse populations of individuals with behavioral disabilities, autism spectrum disorder, developmental disabilities, and intellectual disabilities. Participants worked between 40 and 64 hours and averaged around 49 hours of work, often supplemented with additional on-call duties.

Thematic Analysis

Table 2: Identified themes and subthemes from formal caregivers' interviews

Theme	Subthemes
1. Complex and Demanding Nature of Caregiving Work	Time-related strain from intensive daily caregiving responsibilities
	Professional invisibility with limited recognition
	Emotional burdens associated with identity conflict
2. Dimensions of Social Isolation in Caregiving	Emotional isolation despite physical presence
	Loss of meaningful relationships through social withdrawal
3. Financial and Structural Challenges in Formal Caregiving	Low income and financial stress limiting social participation
	Limited access to resources like transportation, support programs, and services
4. Caregiver Stigmatization and Marginalization	Occupational stigma and the invisibility of caregiving work
	Intersectional marginalization in formal caregiving
5. Psychological and Identity Impact	Mental and emotional exhaustion in formal caregiving
	Loss of self and cultural disconnection
	Reinforcing cycle of burnout and withdrawal
6. Coping Strategies and Support Systems	Personal coping mechanisms and barriers to self-care
	Workplace and informal support in reducing caregiver isolation
7. Pathways to Improvement in Formal Caregiving	Expanding economic relief, respite care, and flexible support services
	Structural and workplace policy changes to support formal caregivers
	Professional training, mentorship, and life skills for caregiver growth
	Empowerment through storytelling and advocacy for change

The results above are organized based on the sections of the interview guide, for ease of interpretation. These sections were caregiving challenges, emotional impact of formal caregiving, experiences of isolation, factors contributing to isolation, impacts of well-being and mental health, coping mechanisms, and lastly, suggestions and recommendations. Themes and subthemes were identified within each of these inquiry categories. Specifically, each section generated one major theme, with a total of 7 themes and 18 subthemes across all categories. For instance, under *caregiving challenges*, one overarching theme titled *complex and demanding nature of caregiving work* emerged, supported by three subthemes. Similarly, the section on *factors contributing to Isolation* produced the theme *financial and structural challenges in formal caregiving*, which included two key subthemes. A full summary of all themes and their corresponding subthemes is provided in Table 2 above to guide understanding of the structure and focus of the findings.

Theme 1: Complex and demanding nature of caregiving work

The complex and demanding nature of caregiving in Baltimore County was the primary theme that emerged following analysis. Formal caregivers disclosed the complex and demanding nature of caregiving, especially when attending to individuals with developmental and behavioral disabilities. Three key subthemes of their roles emerged in the interviews*: (1) time-related strain from intensive daily caregiving responsibilities, (2) professional invisibility with limited recognition in the caregiving environment, and (3) emotional burdens associated with identity conflict.* These subthemes are discussed in detail below to highlight the layered experiences of formal caregivers and the various pressures they navigate in their work.

Subtheme 1: Time-related strain from intensive daily caregiving responsibilities

The first emergent subtheme was *"time-related strain from intensive daily caregiving responsibilities."* This subtheme captures the challenges formal caregivers face in managing time while balancing caregiving responsibilities. Participants consistently described navigating demanding daily routines marked by limited personal time and ongoing, overlapping responsibilities. Their narratives revealed three prevailing patterns: the need to multitask and coordinate care, the experience of time scarcity and disrupted work-life balance, and the emotional burden of missing meaningful life events. Many described caregiving as an all-consuming responsibility that made it nearly impossible to separate work from personal life.

One female participant even stated, *"I get up around 5 in the morning and don't get home until about 8 at night. My partner [husband] helps with the kids, but by the time I'm home, they're already tired, and so am I. Some nights I just sit in the car for a bit before I walk inside, just to breathe and take a minute. That's really the only quiet time I get all day."* (P2)

Another participant with more than 5 years' experience talked about how their schedule kept them from being involved in their children's lives. *"I miss a lot of their school stuff [activities], games, events, the kind of things that matter to them. It's not that I do not care. It's just that I'm always working or something comes up. They stopped asking me to come, which honestly makes me feel worse."* (P1)

A third female participant explained that it is hard to switch between roles, *"When I get off work, I go straight into cooking, cleaning, helping with homework. There's no break. I don't even have time to think about what I want to do. There's no space to rest or hang out with anyone. After a while, you kind of forget who you were before all of this."* (P10)

Together, these responses show how formal caregivers are caught in routines that leave little room for rest, reflection, or connection with others. Over time, this constant cycle of formal caregiving can wear them down and leave them feeling alone and overwhelmed.

Subtheme 2: Professional invisibility with limited recognition in the caregiving environment

The second emergent subtheme was *"professional invisibility with limited recognition in the caregiving environment."* This subtheme focused on the professional caregiving environment, where participants highlighted experiences of working in isolation, dealing with workplace challenges, and feeling that their work was undervalued or dismissed. Many participants expressed that despite working in care teams or around others, they often felt emotionally and professionally alone.

One participant in his early 30s shared, *"I'll be honest, the feeling of isolation feels a lot stronger here in Baltimore County. I'm always around people, clients, coworkers, even my supervisors [house manager], but it still feels like no one really sees the work I'm doing. It's like we're invisible, even while we're doing everything."* (P6)

Another African American participant explained how the job was often dismissed by others, including those outside the caregiving profession. "*People hear 'caregiver' and assume I just sit around or babysit adults all day. They don't see the behavior support, medication management, crisis de-escalation. It's a real profession, but no one treats it like one. That kind of disrespect makes you stop talking about your job altogether."* (P11)

These quotations suggest that formal caregivers are faced by the practical demands of their roles and experience emotional distance and social dismissal in their professional environments. The lack of recognition contributes to feelings of invisibility and deepens their sense of disconnection from others.

Subtheme 3: Emotional burdens associated with identity conflict

The third emergent subtheme was *“emotional burdens associated with identity conflict.”* This subtheme captures how caregiving responsibilities shaped participants’ personal lives and disrupted their sense of identity. Most participants described carrying a persistent emotional weight, including feelings of worry, mental fatigue, stress, and emotional disconnection, because of their caregiving roles. Many reflected on the sacrifices they made in their personal relationships and expressed a quiet loss of self while trying to meet the constant demands of others.

One male formal caregiver (participant) explained, *“Caregivers find themselves, as I do, balancing extended working hours and personal duties, and it ends in exhaustion and, at times, loneliness. You’re always trying to be everything for everyone, and in the end, you feel like you have nothing left for yourself.”* (P8)

Another participant reflected on how the demands of the caregiving role gradually diminished her sense of personal identity. *“After a while, I stopped doing things that made me feel like me. I used to draw, go out with friends, even just take walks. Now I don’t even think about those things. It’s just work, home, sleep, repeat. I feel like I’ve disappeared into my role.”* (P3)

A third Asian male participant even shared a similar experience. *“It’s like you’re always in care mode. Even when I’m home, I’m thinking about what happened at work or what I need to do tomorrow. It’s hard to just be present with my own family. Sometimes I wonder if I’m losing parts of myself without even realizing it.”* (P6)

These narratives were repeated by most participants, indicating that the personal and professional burdens described across the subthemes were not isolated experiences but rather common and deeply embedded realities among formal caregivers. Collectively, the themes of time-related strain, professional invisibility, and emotional burden reveal how multifaceted and taxing the caregiving role is. Despite these challenges, several participants expressed intentional efforts to maintain a sense of purpose and personal meaning in their work, even as their own emotional needs were frequently overlooked or unmet.

Theme 2: Dimensions of social isolation in caregiving

This second theme emerged from the *"Experiences of Social Isolation"* section of the interview guide, which explored how caregiving may impact individuals' emotional wellbeing and social connections. Participants were asked to reflect on the effects of their roles on their relationships, social networks, and sense of connection to others. The second overarching theme that emerged was the "*dimensions of social isolation in caregiving"* experienced by formal caregivers of individuals with developmental and behavioral disabilities. Two subthemes emerged on how caregivers experienced disconnecting from others: *(1) emotional isolation despite physical presence, (2) loss of meaningful relationships through social withdrawal.* These subthemes captured both the internal and external experiences of isolation, highlighting how caregivers may be surrounded by people yet feel emotionally alone, and how their personal relationships often weaken over time due to the demands of caregiving.

Subtheme 1: Emotional isolation despite physical presence

The first emergent subtheme was *"emotional isolation despite physical presence."* Participants frequently spoke of a dissonance between their physical proximity to others and their internal sense of emotional solitude. Although they were consistently surrounded by clients, colleagues, and family members, many described a persistent feeling of disconnection. The caregiving environment, while socially active, did not always provide opportunities for genuine emotional exchange. As a result, participants often felt unseen or unsupported, despite being constantly engaged with others.

One single parent participant even reflected, *"I am around people every day and every evening. I have clients, staff, even my daughter, and to be frank, I still feel most of the time I am by myself. It's not the same as being with someone who really gets what you're carrying. You can be in a room full of people and still feel like no one hears you."* (P7)

Another married participant shared a similar sentiment, *"At work, I'm surrounded by clients and team members, and at home, I have my family, but I still feel like I'm going through all this alone. No one really understands the mental load. It's not about being alone physically, it's about the kind of loneliness that comes when you don't feel seen."* (P12)

These narratives reflect a shared pattern across participant experiences, where isolation was shaped not by physical absence, but by a lack of emotional connection. For participants, this perceived distance intensified the emotional burden of their responsibilities and reinforced the sense that their roles were unseen and undervalued. While this subtheme captures the internal dimension of disconnection, the following subtheme explores how caregiving also contributes to the external loss of meaningful relationships and increased social withdrawal.

Subtheme 2: ***Loss of meaningful relationships through social withdrawal***

The second emergent subtheme was *"loss of meaningful relationships through social withdrawal."* Unlike the internal disconnection described above, this subtheme captures a more outward and observable shift: the steady decline of participants' engagement with personal relationships and social networks. Rather than emotional invisibility, participants described a tangible reduction in their ability to maintain meaningful contact with others. This was attributed to long working hours, chronic fatigue, and an overall lack of time and energy to sustain previous forms of social life.

One male participant in his mid-30s explained, *"My homies [friends] stopped inviting me out because I was always either working or too tired to go. At first, they would check in and try to include me, but eventually, they just stopped asking. I can't really blame them, it's hard to plan anything when you don't know your schedule. But still, it makes you feel like you're no longer part of their lives."* (P11)

The other participant shared how exhaustion interfered with efforts to remain socially engaged, *"By the time I arrive home, it's late, and I'm just too tired. I try to spend some time with my family, help my kids with homework, and be there in the little ways. But to be honest, I'm so tired I end up falling asleep while they're still talking to me. I know I'm missing out, but I just don't have anything left to give."* (P1)

A third female participant described how structural issues at work, like staffing shortages, prevented her from being able to take time off or even try planning ahead, *"We [the company] just don't have enough staff. We're short-staffed all the time, and it means we're constantly filling in or staying longer than expected. Even if I wanted to see people or do something social, I usually can't. There's no room for it."* (P7)

These quotations revealed a pattern of unintentional social withdrawal caused by the combined pressures of emotional fatigue and institutional limitations. As participants became less able to engage with their social networks, the resulting isolation was experienced primarily as personal loss and as an unavoidable consequence of the conditions under which they worked.

Having explored the emotional and relational dimensions of isolation, the following theme turns to the financial and structural barriers that influence the daily realities of caregiving.

Theme 3: Financial and structural challenges in formal caregiving

The third major theme identified in the analysis was the range of *financial and structural challenges* that contributed to participants' experiences of social disconnection. These challenges extended beyond emotional or relational factors, instead highlighting systemic and material conditions that limited opportunities for rest, participation, and access to supportive services. Two subthemes emerged: *(1) low income and financial stress limiting social participation, (2) limited access to resources like transportation, support programs, and services.* These subthemes collectively demonstrate economic hardship and structural constraints that limit participants' ability to maintain social bonds and access vital forms of support.

Subtheme 1: Low income and financial stress limiting social participation

The first emergent subtheme was *"low income and financial stress limiting social participation."* Participants described how the economic demands of their roles often left them with insufficient time, energy, or financial capacity to engage in activities beyond work. In many cases, this extended beyond budgeting difficulties and reflected a deeper sense of exclusion from everyday social experiences.

One African American male participant explained, *"The pay [shakes head], it's not good. I mean, I'm working 50 hours, at times even 60 hours every week, and I'm still just managing to survive. After rent, food, and bills, there's nothing left. It's hard to think about going out [bar] or doing something with friends when I am constantly worried about money."* (P1)

Another single female participant also discussed how financial demands limited not only social options but also her perceived ability to belong, *"I work two jobs just to keep up. Between* *groceries, gas, and my daughter's school supplies, there's barely room to breathe. I turn down invitations all the time, not because I don't want to go, but because of my kid and I can't afford Uber or the meal. It makes me feel like I am not part of anything anymore."* (P7)

A further female participant described how economic pressure gradually disrupted her social ties, *"Even when I have a few hours off, I don't go anywhere. I'm constantly thinking about what I owe or what I need to cover next. Friends will ask me to hang out, but I always say no. After a while, they stop asking. They just kinda disappeared!"* (P10)

These quotations revealed that financial challenges impact far more than household budgets. It limits participation, interrupts routines of connection, and gradually distances individuals from their social environments.

Subtheme 2: Limited access to resources like transportation, support programs, and services

The second emergent subtheme was *"limited access to resources like transportation, support programs, and services."* Participants described various structural barriers that constrained their ability to reach supportive environments or take advantage of available resources. These included unreliable transportation, inflexible scheduling, and the high cost of services. Even when formal support mechanisms were in place, they were often inaccessible in practice.

One male participant shared how service access was blocked by strict eligibility and long delays, *"I've tried to get help a few times, like respite or counselling, but it's always either a long waitlist or they tell me I don't qualify. It's discouraging. You hear about these services, but when you try to use them, it feels like they're not meant for you."* (P8)

Another female participant explained how unreliable transport became a constant logistical barrier, *"My car breaks down constantly, and repairs cost money I don't have. I've had to take three buses just to get to work. There are times I just give up on going to events or appointments because getting there is too much of a burden. It's like the system wasn't designed for people who live like this."* (P2)

A third Asian female participant with 14 years' experience explained how program schedules clashed with her work hours, *"There's a local support group I really wanted to attend, but it meets during my shifts. Everything seems to run on a fixed schedule, and if you can't make it, that's just it. There's no flexibility, no alternatives. It's like they assume we all work nine to five."* (P5)

These quotations demonstrate that even attempts to seek support or maintain social engagement can be undermined by infrastructure that is poorly aligned with the realities of participants' lives. The result is not only logistical inconvenience but also a greater sense of exclusion from systems intended to support them. In addition to these structural challenges, participants also reported facing social and cultural attitudes that contributed to their isolation. The following theme explores how stigma and marginalization further shaped participants' experiences as formal caregivers.

Theme 4: Caregiver stigmatization and marginalization

The fourth major theme that emerged from participant interviews and the analysis was the experience of stigma and marginalization, which played a significant role in the social isolation reported by formal caregivers. This theme captured how societal and systemic biases contributed to caregivers feeling unseen, misunderstood, or devalued. Two main subthemes were identified*: (1) occupational stigma and the invisibility of caregiving work and (2) intersectional* *marginalization in formal caregiving.* These subthemes reflect the ways caregivers were impacted by both how their work was perceived and how their intersecting identities, including race, gender, and immigration status, influenced their sense of belonging and connection.

Subtheme 1: Occupational stigma and the invisibility of caregiving work

The first emergent subtheme was *"occupational stigma and the invisibility of caregiving work."* Participants consistently reported that their roles as formal caregivers for adults with developmental and behavioral disabilities were poorly understood and underappreciated, both within the healthcare system and in wider society. Many participants described a lack of public recognition, minimal respect, and a perception that their work was simplistic or secondary to other health professions. Unlike registered nurses or clinical professionals, formal caregivers were often excluded from decision-making, regarded as unskilled, or treated as supplementary staff despite bearing substantial responsibilities. This sense of invisibility contributed to feelings of being emotionally unsupported in their professional lives.

One Hispanic male participant described how this lack of recognition was reinforced within workplace hierarchies: *"We are doing essential work, but no one sees us that way. Nurses get the credit, the pay, the respect. But we are the ones with the clients all day, taking care of everything: physical, emotional, everything. And still, people think we are just assistants."* (P9)

Another Asian male participant with 4 years of experience reflected on how this perception shaped his sense of value, *"Sometimes I feel like our work is deliberately kept in the background. Even in meetings or team discussions, our input is barely asked for. It is like they want the work done but do not want to acknowledge who is doing it."* (P6)

These quotations illustrate how caregiving was frequently positioned as invisible labor within institutional and social frameworks. Rather than being recognized as integral to client care, participants were routinely marginalized within team structures and public narratives. This contributed not only to frustration but also to a diminished sense of professional identity and belonging.

Subtheme 2: Intersectional marginalization in formal caregiving

The second emergent subtheme was *"intersectional marginalization in formal caregiving."* Several participants reported feeling marginalized not only because of their caregiving roles but also due to their racial, ethnic, and linguistic identities. These intersecting forms of prejudice and discrimination contributed to a deeper sense of isolation and created barriers to trust and support within their caregiving environments. Participants described experiences of mistrust, scrutiny, and discriminatory behavior from clients, families, or colleagues who did not share their background.

One female participant noted how her identity shaped perceptions of competence, *"Also, I am Nigerian and sometimes the clients' families don't trust me. They ask, 'Where are you from?' as if that is supposed to decide whether I am good at my job. It's not about curiosity; it's more like they're deciding if they can trust me or not. That kind of question makes me feel like I feel like I have to prove myself before I even start."* (P2)

Another Hispanic female participant with over 10 years of experience described being undermined because of her accent, *"People think just because I have an accent, I don't know what I'm doing. A parent once questioned my ability to care for their adult child just because I mispronounced something. It's humiliating. You work hard, you study, get certified, and still you're treated like you're not good enough."* (P4)

A third Asian female participant with 14 years' experiences also reflected on how race and gender shaped their daily interactions. *"As an Asian woman in this field, sometimes I feel* *like I have to prove myself over and over. I notice how certain families look at me differently or ask more questions than they do my coworkers. It's exhausting having to constantly show that you're capable just because of how you look or speak."* (P5)

These experiences demonstrate how identity-based marginalization extended beyond interpersonal dynamics and into participants' professional self-perception. The combined effects of racial, linguistic, and gender bias made it more difficult to build trust with clients and teams, and further intensified feelings of exclusion in the caregiving workplace.

Theme 5: Psychological and identity impact

This fifth theme explores the mental health and identity-related consequences of formal caregiving for adults with developmental and behavioral disabilities. While earlier themes examined structural and social isolation, this theme focuses on the *internal and psychological toll* of sustained caregiving responsibilities. Participants shared how caregiving shaped their emotional well-being, disrupted their sense of self, and initiated patterns of withdrawal. Three core subthemes were identified*: (1) mental and emotional exhaustion in formal caregiving, (2) loss of self and cultural disconnection, and (3) the reinforcing cycle of burnout and withdrawal*. Collectively, these experiences reflect the personal cost of caregiving when support are limited, and recovery time is unavailable.

Subtheme 1: Mental and emotional exhaustion in formal caregiving

The first emergent subtheme was *"mental and emotional exhaustion in formal caregiving."* Many participants described symptoms of chronic stress, including cognitive fatigue, persistent worry, emotional dysregulation, and disrupted sleep. This exhaustion often extended into their personal lives, affecting relationships and daily functioning. Participants also reported feelings of guilt over being emotionally unavailable to loved ones, which further contributes to their mental strain.

One participant, a mother of three who had worked in caregiving for over a decade, explained, *"By the time I finish my shift, I'm physically and emotionally drained. My kids want to talk or want to play, but I can barely keep my eyes open. I feel like I'm failing them, even though I'm doing everything I can for others all day."* (P5)

A second participant, a 45-year-old caregiver supporting both her clients and her own elderly parents, shared, *"I worry about my residents, I worry about my parent, I worry about my kids, I worry about money, all I do is worried. I just do not feel there is ever any time to catch a break and take it easy. Even when I'm home, my mind is racing, thinking about everything I didn't do or what might go wrong tomorrow."* (P4)

A third participant, an African male caregiver with seven years of experience, explained how caregiving was wearing him down mentally and emotionally, *"These days, I just feel worn out. I forget where I put things, or I walk into a room and can't remember why I went there. I don't sleep properly, and I get irritated so easily, even with the people I love. My mind feels 90 years old when I'm not, ha-ha. It's like I'm always thinking about something, and I can't shut it off."* (P13)

These quotations illustrate how caregiving can lead to a level of emotional and cognitive fatigue that surpasses ordinary tiredness, affecting both mental clarity and personal relationships

Subtheme 2: Loss of self and cultural disconnection

The second emergent subtheme was *"loss of self and cultural disconnection."* Participants reported that prolonged caregiving blurred the boundaries between their professional identity and personal sense of self. Many participants felt they had become defined entirely by their caregiving duties, leaving little space for individual interests, identity expression, or connection to cultural traditions. This theme was especially evident among immigrant caregivers, who reported feeling disconnected not only from themselves but also from their cultural roots.

One participant, a female caregiver originally from Ethiopia, explained, *"It feels like my whole life is just about work now, and there is nothing left for me at the end of the day. I used to enjoy reading and dancing. Now, I don't even remember the last time I did something just for myself. It's like the old me disappeared and no one noticed."* (P14)

Another participant, a Mexican man living in the U.S. for over 40 years, described cultural displacement, *"Back home in Mexico, I was surrounded by community, by people who understood me and shared my background. Here, I'm always adjusting, always explaining myself. Between work and trying to fit in an elderly Hispanic man, I've lost touch with who I was. It's like I'm absent in two worlds."* (P9)

These narratives show how caregiving can weaken personal identity and cultural belonging, particularly for those who are already navigating life in unfamiliar or marginalized contexts.

Subtheme 3: Reinforcing cycle of burnout and withdrawal

The third emergent subtheme was *"reinforcing cycle of burnout and withdrawal."* Participants described a cyclical pattern where emotional fatigue led to social withdrawal, which then intensified their feelings of isolation and self-doubt. As mental health declined, motivation to seek connection or engage socially also diminished, reinforcing the experience of being emotionally and physically alone.

One participant, a 33-year-old caregiver of Filipino descent, described this withdrawal process, *"I feel isolated, and that just makes me feel worse; and the worse I feel, the more I pull* *away from everyone. I stop answering messages, I don't call people back. Then I start thinking maybe they don't care about me, even if they do. It becomes easier to stay quiet than to explain how bad I'm feeling."* (P6)

Another participant, a single mother in her late 20s, described how the emotional weight of an imbalanced relationship and caregiving responsibilities led to ongoing social withdrawal, *"I was engaged to my baby daddy, but he was lazy. He didn't work, just stayed home playing video games all day while I worked long hours. I felt like everything was on me, the bills, the baby, the stress. Eventually, I ended it because it felt one-sided. Since then, I've just been tired. I don't talk to many people anymore. It's easier to be alone than explain everything."* (P7)

A third participant, a married African male caregiver with seven years of experience, reflected on how emotional exhaustion had shifted his social behavior and priorities, *"I've stopped going out or meeting up with people, even when I have the chance. These days, I mostly just stay home and keep to myself. My wife tells me I've gone quiet, that I don't talk the way I used to. She's right, I just feel drained. Now I just want to be with my immediate family, which is my wife and my two children. I'd rather spend quality time with them than go out and make small talk when I have nothing to give."* (P13)

These narratives demonstrate how emotional withdrawal, professional strain, and isolation can reinforce one another in a cyclical pattern that is difficult to disrupt without targeted intervention, ultimately contributing to long-term psychological distress among formal caregivers.

The next section of the interview explored the coping strategies and support systems participants relied on to manage the emotional demands of caregiving. For instance, they were asked questions such as, "How do you manage stress or difficult days at work?" and "Who or what do you turn to for support when you feel overwhelmed?” These questions aimed to understand the personal and relational resources caregivers use to alleviate social isolation and maintain their emotional well-being.

Theme 6: Coping strategies and support systems

Coping mechanisms and support networks were prominent in the findings, as participants described a range of ways, they managed the emotional difficulties associated with social isolation. These strategies reflected both individual efforts and the role of external support in alleviating caregiver stress. Two subthemes were identified: *(1) personal coping mechanisms and barriers to self-care, and (2) workplace and informal support in reducing caregiver isolation.* Together, these findings highlight how caregivers drew on both internal resilience and external relationships to manage their well-being, while also facing limitations in time, resources, and recognition.

Subtheme 1: Personal coping mechanisms and barriers to self-care

The first emergent subtheme was *“personal coping mechanisms and barriers to self-care.”* Participants described how engaging in small, individualized routines helped manage the emotional demands of caregiving. Self-care activities ranged from walking and listening to music, to expressive practices such as journaling. These strategies, while often brief, created valuable moments of personal restoration.

One participant, a caregiver in his early 40s, explained, *“I do try to fit in a walk where I can, even just around the block where I live. It’s not much, but for those ten or fifteen minutes, I feel like I can breathe. It’s my way of clearing my head and not thinking about work or stress.”* (P1)

Another participant a single African male described using emotional release to cope with stress, *"I tried to do one of those journals. I wrote two pages about how much I despise this job and then burned them. To be real, I felt good for about, like, five minutes. Then the stress came back, but at least I let it out somehow."* (P3)

Other participants engaged with media as a means of both emotional regulation and maintaining a sense of connection to the outside world, A 33 year old Asian Male reported, *"Sometimes I'll listen to stuff like music or a podcast when there are quieter periods in my shift. It helps drown out the noise in my head and makes me feel a little more connected to the rest of the world, like I'm not totally cut off."* (P6)

Nevertheless, many participants acknowledged that although they recognized the importance of self-care, they often lacked the time, energy, or capacity to engage in it consistently. As one participant explained, *"I have things I want to do for myself, I read, I meditate, and I even cook something nice, but by the time I finish work and get through the rest of my day, I'm just too tired. I crashed. Self-care becomes another thing I don't have time for. But still, I do it when I have the chance."* (P13)

These quotations reveal both the resilience, and the constraints participants encounter in attempting to create space for themselves, often managing brief but meaningful coping strategies while struggling to sustain them over time.

Subtheme 2: Workplace and informal support in reducing caregiver isolation

The second emergent subtheme was *"workplace and informal support in reducing caregiver isolation."* Most participants emphasized that emotional support from coworkers and family members played a key role in reducing feelings of isolation. Interactions at work, such as brief walks or casual conversations with colleagues, offered short-term relief. However, support from family, particularly from mothers, was described as more meaningful and sustained, and contributed significantly to participants' overall well-being.

A divorced male participant reflected on the emotional reliability of her mother: *"My mom is everything to me. She listens without judging, even when I'm venting about things she doesn't fully understand. Sometimes I'll call her after a long shift, and just hearing her voice makes me feel like I'm not completely alone in this."* (P1)

Another participant, a single mother in her late 20s, described the practical and emotional relief provided by her mother's support, *"I wouldn't have made it through some of the hardest moments without my mom. She checks in on me all the time, baby sit my kid while I am at work, makes sure I've eaten, reminds me to rest. It's the small things she says or does that bring me back when I feel very overwhelmed."* (P7)

A third participant emphasized the importance of being emotionally seen and supported, *"Honestly, my mom has been my anchor. When I feel like I'm stretched too thin or ready to break down, she's the one who reminds me that I matter too. She knows when I need a pep talk or just silence. She's been my biggest support system through everything."* (P10)

These narratives illustrate how informal support, especially from mothers, can play a vital role in helping formal caregivers navigate the emotional demands of their roles. Such familial connections provided consistency, emotional reassurance, and a rare sense of reciprocal care.

Theme 7: Pathways to improvement in formal caregiving

Finally, participants discussed future directions and offered insights into how the caregiving experience could be improved. The data revealed a recurring theme centered on potential pathways to improve caregiver well-being and reduce social isolation. Participants offered practical and reflective suggestions aimed at addressing the challenges they faced in both institutional and community-based caregiving roles. These recommendations highlighted areas for systemic change, resource expansion, and personal empowerment. Four actionable strategic subthemes were identified: *(1) expanding economic relief, respite care, and flexible support services, (2) structural and workplace policy changes to support formal caregivers, (3) professional training, mentorship, and life skills for caregiver growth, and (4) empowerment through storytelling and advocacy for change.* Together, these subthemes reflect the participants' desire for meaningful, structural reforms that recognize the realities of caregiving and promote long-term solutions.

Subtheme 1: Expanding economic relief, respite care, and flexible support services

The first emergent subtheme was *"expanding economic relief, respite care, and flexible support services."* Most participants emphasized the urgent need for practical, economic, and emotional support structures that are specifically designed to reflect the realities of formal caregiving. Many of them expressed that improving compensation and providing consistent financial incentives would directly improve both their quality of life and ability to remain in the caregiving field.

One participant, a 36-year-old male formal caregiver with five years of experience, was direct in his recommendation, *"Start with money. Pay us like the professionals we are. No more minimum wage for maximum trauma. We're not just assistants or helpers; we're managing medications, behavior plans, emergencies. If you want us to stay and do the job well, we need to be paid like it matters."* (P3)

The importance of affordable and accessible respite care was raised across multiple interviews. One participant, a divorced father working full-time, reflected, *"I think one of the biggest things that would really help is having respite care that's affordable and easy to access.*

Right now, even when it exists, it's either too expensive or doesn't fit into my schedule. That makes it feel like it's not even a real option for me." (P1)

Other participants suggested that technology-based emotional support could reduce isolation. One formal caregiver, an Asian man in his early 30s who often worked overnight shifts, noted, *"Like, maybe virtual groups that I could join from home after work. That would really help. Sometimes I just need someone to talk to who gets it, even if it's late at night."* (P6)

Another participant, an African-born formal caregiver and mother of three, described the limits of in-person services, *"After work, I'm too exhausted to go to an in-person support group. But if I had access to an online space, something supportive and flexible, I'd actually use it. It would make a difference just knowing there's a place to connect."* (P10)

A final participant, an immigrant woman in her mid-30s living alone, lamented the importance of flexible access to emotional support, *"Having access to a 24/7 online group or hotline would be a game-changer. Sometimes I feel isolated at the worst possible times, like two in the morning. Just knowing someone's there could ease that weight."* (P14)

These responses emphasized that meaningful support must go beyond surface-level recognition, requiring flexible, accessible systems that address caregivers' needs both emotionally and practically. Yet for many participants, meeting these needs also depended on how their roles were recognized, structured, and supported within the workplace, a concern that led directly to the second emergent subtheme.

Subtheme 2: Structural and workplace policy changes to support formal caregivers

The second emergent subtheme was *"structural and workplace policy changes to support formal caregivers."* Most participants expressed a strong need for workplace and structural reforms that would better support the realities of formal caregiving. Many participants emphasized that without systemic changes to policies such as time off, staffing, and benefits, isolation and burnout would remain inevitable consequences of the profession.

One participant, a single African American mother working long shifts, pointed to the combined effects of understaffing and emotional fatigue, *"We need paid time off, mental health days, and consistent staffing. We cover someone else's shift in addition to our own, and it's just too much. You can't give quality care if you're barely holding it together yourself."* (P7)

Another participant, a married African male formal caregiver with 7 years of experience, highlighted the consequences of inflexible leave policies, *"We just need real benefits. Affordable health care that will not make us bankrupt, and paid leave so I can travel to Africa and lay to rest my paternal uncle in good conscience. I shouldn't have to choose between honoring my family and keeping my job."* (P13)

A third participant, a woman in her mid-30s working in residential care, discussed how limited scheduling autonomy undermined work-life balance, *"One big change would be giving caregivers more flexible scheduling. Not every facility can do that, but if we had more room to switch shifts or trade hours without being penalized, it would really help us balance caregiving and personal life better. Right now, it feels like the job takes over everything."* (P14)

These quotations emphasized formal caregivers' calls for comprehensive policy reforms that acknowledge both the structural and personal challenges of their caregiving roles. Participants proposed reforms such as hazard pay, restrictions on back-to-back shifts, and access to mental health resources on site. Additionally, several participants advocated for broader societal interventions, including public awareness campaigns to reduce stigma, employer-sponsored wellness programs, and inclusive community events involving caregivers' families. Many participants also emphasized the importance of transportation assistance and culturally competent training, particularly for multilingual and immigrant caregivers. As these findings suggest, structural improvements must be paired with long-term investments in caregiver development. This subtheme leads directly to the next area of focus: professional training, mentorship, and life skills for caregiver growth.

Subtheme 3: Professional training, mentorship, and life skills for caregiver growth

The third emergent subtheme was *"professional training, mentorship, and life skills for caregiver growth."* Participants identified a strong need for structured training and mentorship programs to support their growth, development and confidence as formal caregivers. Many participants described how unprepared they felt when entering the field, particularly when facing emotional or behavioral challenges in high-pressure environments. Participants emphasized the importance of skill-based professional training not only in caregiving techniques, but also in stress management, de-escalation strategies, trauma-informed practice, and crisis response protocols.

One participant, a woman in her late 30s working in community-based residential and daycare program, reflected on the absence of early guidance*, "When I started, I felt lost. If I had someone to guide me or just explain what to expect, it would have made a huge difference. Even now, I see new people come in and burn out quickly because no one is helping them adjust. Mentorship would help keep more people in this work and make it feel less overwhelming."* (P12)

Another participant, a Hispanic formal caregiver in her mid-40s, shared how broader life skills were just as essential to sustaining her role: *"I think we need real-world stuff too. Like how to manage money on a tight paycheck, how to cook healthy meals when you're exhausted, or* *even just how to calm your mind when you can't sleep. That's the kind of training that leaves a lasting impact and proves genuinely useful in everyday caregiving practice."* (P4)

These quotations suggested that training programs must extend beyond technical caregiving skills. By including emotional, financial, and practical life skills, such initiatives can offer holistic support that strengthens caregivers both on and off the job. For many participants, this sense of empowerment also extended to having a voice, a desire to share their experiences and advocating for change, which led to the fourth emergent subtheme.

Subtheme 4: Empowerment through storytelling and advocacy for change

The fourth emergent subtheme was *"empowerment through storytelling and advocacy for change."* The analysis revealed that despite the intensity of their caregiving responsibilities; many participants found a renewed sense of strength through the act of sharing their stories. Speaking openly about their lived experiences provided emotional release, encouraged personal reflection, and inspired hope for systemic reform. For several participants, simply having a space to speak openly about their experiences was a transformative act. Other participants emphasized how storytelling brought a sense of validation and purpose that extended beyond their individual struggles.

One participant, a formal caregiver in his early 40s with over 5 years of experience, expressed his desire for the study to drive real change, *"I just hope it helps make a difference. That what we're saying doesn't just sit in a file somewhere. We want to be heard, and we want it to matter. Even if nothing changes for me, maybe it'll help the next person doing this work."* (P1)

Another participant, a 50-year-old female West African formal caregiver, voiced that same hope, *"You don't always get the chance to speak about this job in a real way. I'm glad I* *did. I kept thinking, if someone reads this and does something with it, maybe all the stress, all the isolation, maybe it wasn't for nothing."* (P2)

A third participant, a young woman in her mid-40s living away from most family [close relatives], reflected on how unexpected emotional clarity surfaced during the interview, *"It made me realize just how much I've been holding in. I never talk about how I really feel because no one asks. But talking here, being honest, it brought out things I didn't even know I needed to say. It felt like lifting a weight I didn't know I was carrying."* (P4)

Another male participant in his mid-30s, who had recently returned to work after a personal loss, made a direct appeal, *"Please don't let this information you gathered just gather dust. I opened myself and told you what I am truly going through. I just hope that sharing my experience leads to something that helps individuals like me. We talk because we want things to change."* (P11)

These quotations show that storytelling was not only a form of emotional healing, but also a tool for collective advocacy. Through these narratives, participants contributed to a larger dialogue about visibility, justice, and reform in caregiving systems. The significance and interconnection of all seven themes are visually summarized in the following thematic map, which illustrates the overarching structure of the study's key findings.

Thematic Map

The thematic map below illustrates the main themes and subthemes derived from the analyzed data. It presents seven major themes:

(1) Complex and demanding nature of caregiving work (with subthemes: time-related strain from intensive daily caregiving responsibilities, professional invisibility with limited recognition, and emotional burdens associated with identity conflict),

(2) Dimensions of social isolation in caregiving (comprising emotional isolation despite physical presence, and loss of meaningful relationships through social withdrawal),

(3) Financial and structural challenges in formal caregiving (highlighting low income and financial stress limiting social participation, and limited access to resources like transportation, support programs, and services),

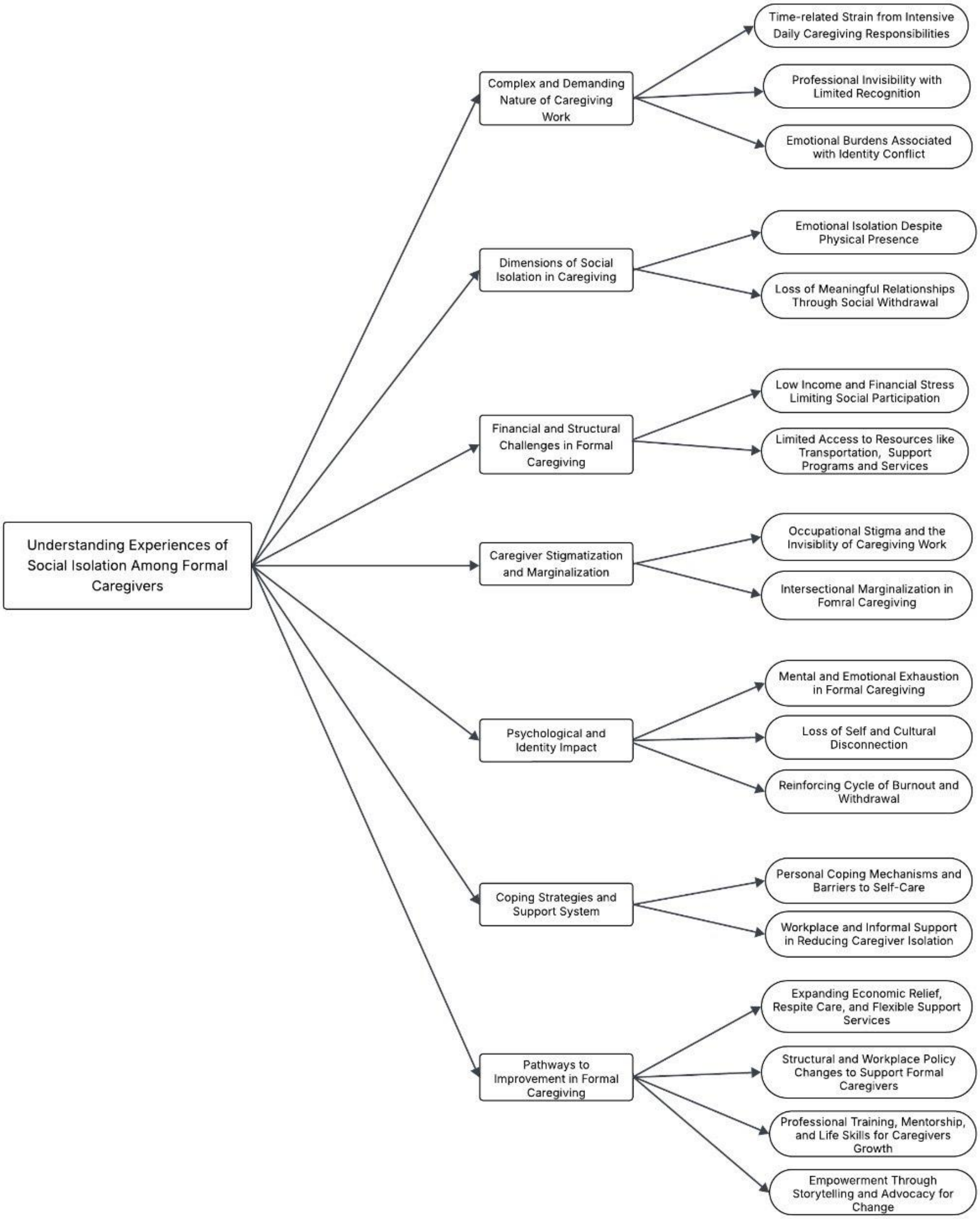
(4) Caregiver stigmatization and marginalization (including occupational stigma and the invisibility of caregiving work, and intersectional marginalization in formal caregiving),

(5) Psychological and identity impact (covering mental and emotional exhaustion in formal caregiving, loss of self and cultural disconnection, and the reinforcing cycle of burnout and withdrawal),

(6) Coping strategies and support systems (emphasizing personal coping mechanisms and barriers to self-care, as well as workplace and informal support in reducing caregiver isolation), and finally

(7) Pathways to improvement in formal caregiving (consisting of expanding economic relief, respite care, and flexible support services; structural and workplace policy changes to support formal caregivers; professional training, mentorship, and life skills for caregiver growth; and empowerment through storytelling and advocacy for change).

Figure 1: Thematic Map



CHAPTER 5 – DISCUSSION

This study explored the lived experiences of social isolation among formal caregivers of adults with developmental and behavioral disabilities in Baltimore County. Through qualitative thematic analysis of narratives from fourteen formal caregivers, this research revealed a multifaceted interaction of emotional, structural, and cultural factors influencing formal caregiving. While these findings add to and broaden existing literature about formal caregiver challenges, they also significantly highlight a unique subtheme of occupational and identity-based marginalization previously overlooked in the existing literature.

The following discussion interprets the key findings, highlights the study's novel contributions to existing knowledge on formal caregiving, and discusses the significance of advancing public and population health practice and informing policy development. Finally, I contextualized the findings within the broader academic literature, emphasizing the extent to which formal caregivers lived experiences reflect persistent structural inequities in caregiving systems. The analysis also aimed to generate practical insights that could inform equitable policies and responsive support structures for marginalized caregivers in Baltimore County [25, 26, 27].

One of the most salient findings from this study is the recognition of formal caregiving as a role defined not merely by its intensity of labor but by profound psychosocial disintegration. Although previous research acknowledged formal caregivers' emotional burdens and chronic stress [10, 12, 30], this study introduces a critical understanding like formal caregivers frequently experience a progressive dissolution of self, caused by the constant combined of personal and professional identities. Unlike general descriptions of burnout, participants expressed how formal caregiving reduced their capacity to engage with previously meaningful personal identities, hobbies, or cultural practices. This disruption of self-perception represents a deeper level of impact, suggesting that the consequences of social isolation in formal caregiving extend beyond burnout, stress leading to existential disorientation. This study's contribution advances the literature by demonstrating that formal caregiver identity loss is not only a byproduct of long hours but of systemic neglect and structural invisibility.

Another critical insight pertains to emotional isolation despite physical proximity to others. For instance, several participants also reported feeling ignored or misunderstood by their own partner or family members. Several participants received comments that caused them to question the level of respect their efforts deserved. Participants also described experiencing deep emotional detachment even when surrounded by clients, colleagues, or family members. While this study aligns with prior findings on emotional and social isolation among formal caregivers [29, 31, 32,], this study emphasizes the structural and systemic causes of that social isolation. Participants did not describe social isolation as a passive outcome of workload, but as an active result of being unseen, unrecognized (lack of recognition), and extremely undervalued (not valuing their profession). This study perspective transforms the narrative from considering social withdrawal as an individual experience to seeing it as a socially constructed condition influenced by job hierarchies, societal stigma, and cultural devaluation. Formal caregiver isolation, on the other hand, is reframed as an institutionalized consequence of neglect rather than an individual failure. Although prior research has documented high rates of social isolation among caregivers, much of the literature attributes these experiences to personal stress or lack of time [12, 28, 29].

Few studies have explicitly examined how occupational roles and structural devaluation contribute to emotional isolation in formal caregiving contexts [30, 33]. By focusing on this structural lens, this study offers a novel contribution to the literature, illustrating how social isolation can be both consequence and a result of systemic neglect within caregiving systems.

This study further contributes to existing knowledge or literature by introducing an intersectional lens of occupational stigma. Although prior research has noted the invisibility of formal caregiving labor [34, 40], participants in this study explicitly described how factors like race, accent, gender, and immigrant status influenced perceptions of their professional competence. Such detailed insights extend beyond general under recognition. For instance, caregivers from African or Asian backgrounds reported instances of racialized scrutiny, such as families questioning their capabilities based solely on accents or cultural origins, a topic rarely explored in-depth in the social, public and population health literature [33, 34, 35]. However, this study identifies intersectional marginalization as a crucial subtheme (or mechanism) that causes additional formal caregiver isolation, strengthening the analysis beyond occupational identity alone.

Structural barriers or challenges have also been identified as a recurring cause of social isolation among formal caregivers. While existing literature traditionally cites low wages and overwork as major barriers to formal caregiver well-being [36, 37, 43, 47], participants in this study emphasized how these economic constraints specifically prevented their social inclusion. Financial instability and unreliable transportation frequently prevented formal caregivers in Baltimore County from participating in social activities, community events, or family gatherings. Beyond the practical challenges these formal caregiver faced, participants described how these exclusions caused their social identity, leaving them feeling simultaneously overcommitted and abandoned. This study highlights an underexplored intersection of economic vulnerability and cultural disconnection, especially among immigrant formal caregivers [participants] who described losing ties to their cultural traditions and languages as a result of demanding work schedules. However, additional research is needed to better understand how caregiving schedules affect cultural participation and identity maintenance over time, especially among immigrant caregiver populations. This study also contributes to existing knowledge by demonstrating how systemic economic vulnerabilities undermine overall caregiving well-being, as well as the preservation of cultural identity and continuity.

Despite these challenges, participants made remarkable efforts in managing emotional distress. While diverse or different coping strategies such as journaling, spirituality, religion and nature-based activities were widely acknowledged for their therapeutic value [10, 42, 44], participants in this study also described self-care as conditional and episodic, rather than sustainable practice. Participants also reported that while activities like walking or listening to music provided temporary relaxation, they rarely resulted in long-term emotional recovery despite the continuous demands of formal caregiving. This study suggests that, while theoretically valued, self-care is nevertheless generally inaccessible (i.e., not all formal caregivers make time for self-care), which is consistent with previous research demonstrating that formal caregivers frequently deprioritize their own well-being due to time constraints, emotional exhaustion, and systemic workplace demands [14, 25, 38, 42, 44].

Informal networks, including family members (immediate family and non-immediate family) emerged as essential emotional support systems. Family members, especially mothers, were described as key providers of emotional stability, providing both moral support and practical assistance with childcare [care for their grandchildren] and household responsibilities.

This study findings aligns with results regarding the “buffering effects of social support” [38]. However, this study adds an important point, such as, while these support systems reduced distress, they were rarely supplemented by institutional support. The majority of participants believed that their emotional survival was dependent on personal resilience rather than systemic or structural support. The distinction between privatized coping and public neglect is crucial in this context. It emphasizes a gap in public health infrastructure where the burden of emotional endurance is significantly transferred to formal caregivers themselves, without sufficient policy-based support systems.

Participants also expressed a strong desire for systemic and structural change, advocating for improvements beyond compensation, including staffing policies, adequate transportation, scheduling flexibility, and mental health support services. While previous studies discussed caregiver retention and satisfaction [34, 38, 45], participants in this study specifically defined their advocacy in terms of dignity, equity, and professional recognition. This change from entirely economic demands to moral appeals highlighting the psychological consequences of policy neglect and redirects caregiver advocacy as a justice and systemic reform issues.

These findings also contribute to the growing and ongoing discussion about technological interventions in formal caregiving. Participants expressed interest in virtual support networks, especially those accessible during non-traditional hours. While previous studies have shown that digital communities can reduce feelings of isolation [31, 46, 49], this current study suggests that asynchronous, culturally responsive online platforms may be especially effective and beneficial for formal caregivers working night shifts or irregular schedules. This study also recommends an opportunity for innovation in formal caregivers’ outreach in Baltimore County, one that meets formal caregivers where they are, both in time and emotional need. It supports a comprehensive appeal for hybrid support models that integrate technology with human interaction in order to build more sustainable and adaptive care networks.

This study also prioritizes the urgency of multi-tiered policy interventions. At the institutional level, employers must re-evaluate workplace structures that contribute to emotional and social fatigue. Interventions such as paid mental health leave, on-site counseling, and protected rest periods should be viewed not as luxuries, but as essential components of formal caregiver well-being in Baltimore County. At the community level, culturally tailored respite programs and peer-led support circles or groups can play a vital role in restoring and strengthening formal caregiver networks. Policy-level strategies must prioritize increased or more funding, wage protection, and expanded access to employment benefits. These comprehensive interventions are both ethically necessary and economically useful, considering the well-documented effects of caregiver burnout on workforce or staff retention and the quality of care provided [31, 34, 45 50].

Based on participant responses, this study suggests the need for multidisciplinary discussions in population health, public health, social science, and care work studies. While many previous investigations have examined caregiver burden through clinical or economic lenses [35, 39, 40], this study contextualizes formal caregiving within a relational and structural ecosystem. This study focuses on the daily experiences of formal caregivers, revealing how their roles are influenced not just by their responsibilities but also by the overall social, economic, and political system they encountered. By bringing these lived experiences to the forefront, this study provides a critical perspective on the realities of formal caregiving. A perspective that is sometimes lacking or missing in policy conversations, which tend to focus solely on logistics or outcomes rather than the individuals (formal caregivers) doing the labor.

This study also brings new attention to the perceived boundaries that shape how formal caregiving roles and responsibilities are defined and experienced. Although administrative distinctions based on pay or credentials exist, participants' stories revealed deep emotional involvement, personal sacrifice, and blurred relational lines that are also similar to the experiences of unpaid family caregivers. These similarities suggest that caregiving roles exist along a continuum rather than in separate categories. Rethinking these boundaries may pave the way for more inclusive and responsive support systems that will acknowledge and address the shared emotional, systemic and structural burdens across diverse caregiving contexts [41, 46, 50].

This study also demonstrates the importance of narrative or storytelling methods in community and population health research. Although quantitative metrics proficiently monitor overarching trends and prevalence in caregiver well-being, they frequently neglect the detailed reality of everyday caregiving situations or experiences. By conducting in-depth narrative interviews, the participants in this study provided detailed perspectives of minor emotional changes, interpersonal dynamics, and types of resilience that survey methods generally miss. The qualitative approach used here involved a shift, highlighting formal caregivers lived experiences as critical expertise for developing more inclusive and responsive health policies.

Finally, this study’s findings bring to light the profound emotional burden that emerges when formal caregiving labor is persistently undervalued and structurally unsupported. While the narratives collected convey hardship, poverty, lack of resources, participants also revealed acts of resilience that can’t be erased. Participants did not simply recount isolation; they offered insight into how they continue to show up for others despite the absence of sustained recognition or care for themselves. These participants’ responses are not merely research findings; they represent lived evidence that highlights ethical responsibility. Their lived experiences invite a reevaluation of how formal caregiving is socially constructed, institutionally managed, and ethically addressed.

Implications of the Study

This study has significant implications for public health systems and policies, social equity, and the well-being of formal caregivers. Through centering the lived experiences of formal caregivers in Baltimore County, the research demonstrates how emotional distress, systemic neglect, and limited societal recognition shape their everyday realities. The findings reveal that when formal caregiver isolation is left unaddressed, it not only adversely affects their personal and psychological well-being but also compromises the quality of care delivered to individuals with developmental and behavioral disabilities.

Public Health Perspective

From a public health standpoint, the isolation experienced by formal caregivers must be explicitly acknowledged by healthcare systems, policymakers, and public health agencies as a critical threat to system performance and community well-being. Formal caregivers subjected to chronic stress, limited opportunities for respite, and inadequate mental health support face increased risks of physical illness, psychological exhaustion, and eventual disengagement from the workforce. These outcomes compromise both formal caregiver health and the reliability and effectiveness of care services for individuals with complex needs.

Institutions such as the Centers for Disease Control and Prevention (CDC) and various state health departments like Maryland Health Department (MDH), and Baltimore County Health Department now recognize formal caregiver well-being as foundational to the resilience and sustainability of healthcare systems [48, 50, 55]. Without strategic investment in trauma-informed care, specified formal caregiver education, and structural safeguards, the public health infrastructure stands to lose a crucial segment of its workforce, and this can further contribute to existing inequities in care access and quality. Addressing formal caregiver isolation is essential to prevent burnout, ensuring the continuity and quality of long-term care, and promoting the overall health and equity of communities.

Population Health Perspective

From a population health standpoint, formal caregiver isolation functions as a social determinant of health that influences outcomes. This is for both the formal caregivers and the individuals they serve. When formal caregivers faced limited support, social isolation, or financial challenges, the downstream effects often manifest as increased in healthcare utilization, interruptions in care continuity, and reduced compliance to treatment plans. These outcomes more severely impact vulnerable populations, including individuals with developmental and behavioral disabilities. Studies have shown that interventions aimed at supporting formal caregivers, such as community-based respite programs and caregiver stipends, can lead to improved long-term outcomes at the population level. These include reduced hospitalization rates and improved behavioral health metrics [54, 55]. A population health approach to supporting formal caregivers calls for policy design that is guided by data and responsive to the realities of formal caregiver burden. This includes integrating formal caregiver-related factors into risk stratification models, reimbursement mechanisms, and equity-focused evaluations. Through such an approach, health systems can better identify and address systemic gaps, ultimately enhancing health outcomes across diverse and underserved communities.

Social Justice Perspective

From a social justice perspective, the structural invisibility and economic marginalization of formal caregivers must be understood as a pressing issue of labor equity. The invisibility and devaluation of formal caregivers reflect broader structural inequities shaped by race, gender, and class. Formal caregiving roles, especially those held by low-income women and formal caregivers of color, are frequently excluded from labor protections and dismissed as unskilled. Participants described experiences of exclusion from policy decisions, a lack of upward mobility, and chronic underpayment. Promoting justice in caregiving means redefining it as skilled, essential labor and ensuring fair compensation, institutional visibility, and access to workplace rights. Equitable systems must acknowledge formal caregivers' expertise and ensure their representation in shaping the policies and environments that govern their work.

Policy Recommendations

The findings of this study support several actionable policy directions. These include raising compensation standards, improving workplace flexibility, and expanding access to culturally responsive mental health resources and respite care. Organizational priorities should include initiatives to improve retention while also fostering workplace environments that uphold formal caregiver's dignity, promote their wellness, and acknowledge the complexity and value of caregiving labor (their caregiving contributions).

Several policy-level interventions in the United States have shown positive outcomes in addressing the needs of formal caregivers. For instance, California's In-Home Supportive Services (IHSS) program has helped improve job stability, reduced caregiver burnout, and provided consistent compensation, proving the beneficial effects of wage protections and structured benefits on workforce retention [51]. In Maryland, the "Time to Care Act of 2022" established a paid (providing up to 12 weeks) family and medical leave insurance program that enables eligible caregivers to provide critical care while maintaining income and job security [51]. At the federal or national level, the 2022 National Strategy to Support Family Caregivers established a multi-agency framework to improve both family and formal caregiver professional training programs, well-being and mental health support, and access to financial relief, expanding access to respite care and inclusive workplace policies [52]. This is a federally coordinated initiative to organize or link healthcare, labor, and social systems around caregiver needs.

Furthermore, recent research on dementia caregiving revealed the increasing reliance on paid (formal) and unpaid (informal) caregiving and the importance of funding flexible models that support both family members and professional formal caregivers over time [53, 55]. Together, these interventions demonstrated the need for integrated, multi-level policy frameworks that address the immediate financial challenges and support long-term formal caregiver well-being, professional or formal development, and equitable access to services across diverse populations.

To strengthen these existing initiative efforts, multi-level strategies for scaling up should be considered. These include:

1. Public investment in the welfare of formal caregivers through allocated financing for trauma-informed mental health services and 24/7 (i.e., 24 hours and 7 days weekly) digital support services
2. Policy innovation, including the adjustment of caregiver compensation (wages, bonuses etc.) in accordance with inflation and the cost of living, especially in high-demand areas
3. Flexible care models include hybrid work options, changeable or adjustable shift patterns, and employer-sponsored wellness initiatives.

4. Collaborations between government agencies (state and federal) and community organizations to implement culturally tailored support systems for caregivers from marginalized backgrounds.
5. Increased, improved and expanded professional pathways, including continuing education stipends, credential recognition, and formal mentorship programs designed to promote caregiving as a career rather than temporary employment (stopgap job).

Future Research Directions

Future research should expand the scope of inquiry surrounding formal caregiver experiences to ensure findings are both representative and actionable across diverse populations. This entails prioritizing marginalized regions, including rural and under-resourced communities, where access to mental health care, respite services, and formal support networks may be significantly more limited. Additionally, research focusing specifically on immigrant, multilingual, and nonbinary caregivers may provide critical insights into the often-neglected intersections between identity and caregiving labor.

Longitudinal research is particularly important for assessing the long-term effects of policy reforms, wage adjustments, and workplace innovations on caregiver well-being, employment stability, and the quality of care provided. In addition, mixed-method research offers valuable potential to capture the complex social, cultural, and emotional dimensions that shape the experiences of formal caregivers. By combining quantitative analysis with insights drawn from caregivers lived experiences, future research can contribute to the design of more inclusive, responsive, and evidence-informed interventions. Elevating the perspectives of formal caregivers within academic research represents an essential step toward the creation of equitable care systems that authentically reflect the realities faced by those directly engaged in caregiving work.

CHAPTER 6 – LIMITATIONS OF THE STUDY

This study offers useful insight into care experience among formal caregivers in Baltimore County, but there are several limitations that must be addressed. The emphasis on a particular geographical location limits the scope of other areas with varied public health systems, health care systems or social support systems. The study also has limited generalizability with a participant sample of only 14. Moreover, because participation was voluntary, self-selection bias is also introduced; those who participate might differ significantly from those who do not. The cross-sectional design collects experiences at a particular point in time and does not account for changes that occur in isolation over longer periods.

Although participants' educational background was not a central focus of the thematic analysis, some participants voluntarily shared educational details during the demographic survey or through their interviews. For instance, one participant disclosed that they were currently completing an online Doctorate in Social Work (DSW). However, this study did not systematically examine the relationship between educational attainment and social isolation. This omission may limit the interpretive scope of the findings, as variations in education level could influence access to coping strategies, interpretation of support systems, or navigation of structural barriers. Future research may consider exploring how caregivers' educational backgrounds shape their experiences of social isolation and resilience.

Furthermore, data were self-reported through interviews, which could be influenced by recall errors or social desirability bias. The study focused solely on formal caregivers, without comparing their experiences to informal caregivers, an angle that could have offered broader contextual understanding. It also relied exclusively on qualitative methods, without incorporating standardized measures that could provide quantitative insight into levels of social isolation. Finally, while the study highlights support requirements, it does not evaluate specific solutions, which limits its usefulness for program or policy development.

CHAPTER 7 – CONCLUSION

This study explored the lived experiences of formal caregivers of adults with developmental and behavioral disabilities in Baltimore County, providing an in-depth and deep human perspective on how social isolation develops, continues, and is managed within formal caregiving environments. Using a qualitative approach, the study revealed the structural, emotional, and cultural factors that influence formal caregiver isolation. The insights gathered from participants showed that social isolation was not a secondary effect of formal caregiving but rather the result of systemic and structural neglect, workforce undervaluation, and limited recognition of formal caregivers' humanity and knowledge (job expertise).

A central theme in these findings was the emotional impact of caregiving and the gradual loss of personal identity over time. Participants described how formal caregiving responsibilities slowly replaced their own needs, roles, and relationships. This study contributes to existing literature by presenting formal caregiving as both work and a way of life, where formal caregivers must manage logistical demands with ongoing emotional strain. Although earlier studies have highlighted caregiver stress and burnout, this research provides a deeper look into how feelings of invisibility and cultural disconnection add to that strain. By centering the voices of caregivers, the study shows that truly understanding their experiences is key to building effective and compassionate support systems.

Another important insight from the study's findings was the resilience formal caregivers demonstrated despite having limited resources. Many participants relied on personal coping strategies such as journaling, prayer, and leaning on informal support networks to manage their emotional well-being. However, these approaches were often practiced in isolation and lacked consistent external support, revealing a disconnect between the personal efforts of formal caregivers and the support offered by institutions. This gap highlights the urgent need for public health systems to play a more active role in addressing formal caregiver isolation and fostering long-term well-being. To be effective, interventions must be flexible, easily accessible, and culturally responsive, ensuring that formal caregivers from diverse settings and backgrounds receive the support they need.

The study also revealed that the experiences of formal caregivers are deeply influenced by intersecting social identities, such as race, gender, and immigration status. These combined factors increased their sense of isolation and further limited their access to recognition, essential resources, and opportunities for professional growth. This research adds to broader discussions about equity in the workplace by demonstrating that caregiving is not only emotionally demanding but also closely tied to systemic patterns of inequality. Formal caregivers often take on roles that demand significant emotional effort, yet they are met with minimal recognition, low wages, and limited opportunities for advancement. Recognizing this imbalance is a critical first step for leaders in healthcare, policy, and community planning to address caregiving as a matter of equity and collective responsibility.

Ultimately, this thesis calls for a fundamental rethinking of how caregiving is understood and valued across institutions and society. Rather than being seen as supplemental or informal, caregiving should be acknowledged as essential, skilled, and deeply relational work that deserves recognition and investment. Formal caregivers must play an active role in shaping the policies and services that impact their lives. Their first-hand insights are vital for creating care systems that are not only effective but also equitable and responsive to real-world needs. Moving forward will require coordinated efforts across sectors that elevate caregiver voices and prioritize meaningful change. By doing so, we can shape a public health landscape built on respect, inclusion, and a shared commitment to the collective well-being.

REFERENCES

1. Greenwood, N., Mezey, G., & Smith, R. (2018). Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness. Maturitas, 112, 39–45.

2. Victor, C. R., Rippon, I., Quinn, C., Nelis, S. M., Martyr, A., Hart, N., Lamont, R., & Clare, L. (2021). The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme. Aging & mental health, 25(7), 1232–1238. https://doi.org/10.1080/13607863.2020.1753014

3. U.S. Census Bureau. (2020). QuickFacts: Baltimore County, Maryland. Retrieved from https://www.census.gov/quickfacts/fact/table/baltimorecountymaryland

4. Granbom, M., Nkimbeng, M., Roberts, L. C., Gitlin, L. N., Taylor, J. L., & Szanton, S. L. (2021). "So I am Stuck, but it´s OK": Residential Reasoning and Housing Decision-Making of Low-Income Older Adults with Disabilities in Baltimore, Maryland. Housing and society, 48(1), 43–59. https://doi.org/10.1080/08882746.2020.1816782

5. Fabius, C. D., Wolff, J. L., & Kasper, J. D. (2020). Race Differences in Characteristics and Experiences of Black and White Caregivers of Older Americans. The Gerontologist, 60(7), 1244–1253. https://doi.org/10.1093/geront/gnaa042

6. Musich, S., Wang, S. S., Kraemer, S., Hawkins, K., & Wicker, E. (2017). Caregivers for older adults: Prevalence, characteristics, and health care utilization and expenditures. Geriatric nursing (New York, N.Y.), 38(1), 9–16. https://doi.org/10.1016/j.gerinurse.2016.06.017

7. Nortey, S. T., Aryeetey, G. C., Aikins, M., Amendah, D., & Nonvignon, J. (2017). Economic burden of family caregiving for elderly population in southern Ghana: the case of a peri-urban district. International journal for equity in health, 16(1), 16. https://doi.org/10.1186/s12939-016-0511-9

8. Hajek, A., Kretzler, B., & König, H. H. (2021). Informal Caregiving, Loneliness and Social Isolation: A Systematic Review. International journal of environmental research and public health, 18(22), 12101. https://doi.org/10.3390/ijerph182212101

9. Jansen-van Vuuren, J., & Aldersey, H. M. (2020). Stigma, Acceptance and Belonging for People with IDD Across Cultures. Current developmental disorders reports, 7(3), 163–172. https://doi.org/10.1007/s40474-020-00206-w

10. Donovan, N. J., & Blazer, D. (2020). Social Isolation and Loneliness in Older Adults: Review and Commentary of a National Academies Report. The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry, 28(12), 1233–1244. https://doi.org/10.1016/j.jagp.2020.08.005

11. Macdonald, S. J., Deacon, L., Nixon, J., Akintola, A., Gillingham, A., Kent, J., … Highmore, L. (2018). 'The invisible enemy': disability, loneliness and isolation. Disability & Society, 33(7), 1138–1159. https://doi.org/10.1080/09687599.2018.1476224

12. Hussain, R., Wark, S., & Ryan, P. (2018). Caregiving, Employment and Social Isolation: Challenges for Rural Carers in Australia. International journal of environmental research and public health, 15(10), 2267. https://doi.org/10.3390/ijerph15102267

13. Puga, F., Wang, D., Bibriescas, N., Poe, A., Alvarez, L., Jablonski, R., & Vance, D. (2023). ROLE CAPTIVITY, DAILY SOCIAL ISOLATION, AND THE MENTAL HEALTH OF DEMENTIA CAREGIVERS. Innovation in Aging, 7(Suppl 1), 457–458. https://doi.org/10.1093/geroni/igad104.1505

14. Lopez-Anuarbe, M., & Kohli, P. (2019). Understanding Male Caregivers' Emotional, Financial, and Physical Burden in the United States. Healthcare (Basel, Switzerland), 7(2), 72. https://doi.org/10.3390/healthcare7020072

15. Selick, A., Durbin, J., Casson, I., Lee, J., & Lunsky, Y. (2018). Barriers and facilitators to improving health care for adults with intellectual and developmental disabilities: what do staff tell us?. Éléments qui favorisent ou freinent l'amélioration des soins de santé destinés aux adultes souffrant d'une déficience intellectuelle ou développementale : qu'en dit le personnel?. Health promotion and chronic disease prevention in Canada : research, policy and practice, 38(10), 349–357. https://doi.org/10.24095/hpcdp.38.10.01

16. Grant, J. S., & Graven, L. J. (2018). Problems experienced by informal caregivers of individuals with heart failure: An integrative review. International journal of nursing studies, 80, 41–66. https://doi.org/10.1016/j.ijnurstu.2017.12.016

17. Fong, V. C., McLaughlin, J., & Schneider, M. (2023). "We are exhausted, worn out, and broken": Understanding the impact of service satisfaction on caregiver well-being. Autism Research, 16(11), 2198-2207.

18. Mao, W., Qi, X., Chi, I., Wichinsky, L., & Wu, B. (2023). Technology-Based Interventions to Address Social Isolation and Loneliness Among Informal Dementia Caregivers: A Scoping Review. Journal of the American Medical Directors Association, 24(11), 1700–1707. https://doi.org/10.1016/j.jamda.2023.08.005

19. Newman, K., Wang, A. H., Wang, A. Z. Y., & Hanna, D. (2019). The role of internet-based digital tools in reducing social isolation and addressing support needs among informal caregivers: a scoping review. BMC public health, 19(1), 1495. https://doi.org/10.1186/s12889-019-7837-3

20. Kovaleva, M., Spangler, S., Clevenger, C., & Hepburn, K. (2018). Chronic Stress, Social Isolation, and Perceived Loneliness in Dementia Caregivers. Journal of psychosocial nursing and mental health services, 56(10), 36–43. https://doi.org/10.3928/02793695-20180329-04

21. Hoang, P., King, J. A., Moore, S., Moore, K., Reich, K., Sidhu, H., Tan, C. V., Whaley, C., & McMillan, J. (2022). Interventions Associated With Reduced Loneliness and Social Isolation in Older Adults: A Systematic Review and Meta-analysis. JAMA network open, 5(10), e2236676. https://doi.org/10.1001/jamanetworkopen.2022.36676

22. Labrum, T., & Newhill, C. E. (2021). Perceived Isolation among Family Caregivers of People with Mental Illness. Social work, 66(3), 245–253. https://doi.org/10.1093/sw/swab019

23. Savela, R. M., Schwab, U., & Välimäki, T. (2022). An integrative review of the social determinants of mental health among older caregivers. Nursing open, 9(1), 94–107. https://doi.org/10.1002/nop2.1094

24. Marshall, C., & Rossman, G. B. (2014). Designing qualitative research. Sage publications.

25. Creswell, J. W., & Creswell, J. D. (2017). Research design: Qualitative, quantitative, and mixed methods approaches. Sage publications.

26. Braun, V., & Clarke, V. (2021). Thematic analysis: a practical guide.

27. Faronbi, J. O., Faronbi, G. O., Ayamolowo, S. J., & Olaogun, A. A. (2019). Caring for the seniors with chronic illness: The lived experience of caregivers of older adults. Archives of gerontology and geriatrics, 82, 8–14. https://doi.org/10.1016/j.archger.2019.01.013

28. Vaismoradi, M., & Snelgrove, S. (2019). Theme in qualitative content analysis and thematic analysis.

29. Sun X. (2020). Behavior skills training for family caregivers of people with intellectual or developmental disabilities: a systematic review of literature. International journal of developmental disabilities, 68(3), 247–273. https://doi.org/10.1080/20473869.2020.1793650

30. Perkins, E. A., & Hewitt, A. (2016). Coping with caregiver stress. Health care for people with intellectual and developmental disabilities across the lifespan, 2165-2183.

31. Chen, C. C., Lan, Y. L., Chiou, S. L., & Lin, Y. C. (2022, December). The effect of emotional labor on the physical and mental health of health professionals: Emotional exhaustion has a mediating effect. In Healthcare (Vol. 11, No. 1, p. 104). MDPI.

32. Vasileiou, K., Barnett, J., Barreto, M., Vines, J., Atkinson, M., Lawson, S., & Wilson, M. (2017). Experiences of Loneliness Associated with Being an Informal Caregiver: A Qualitative Investigation. Frontiers in psychology, 8, 585. https://doi.org/10.3389/fpsyg.2017.00585

33. Brandt, L., Liu, S., Heim, C., & Heinz, A. (2022). The effects of social isolation stress and discrimination on mental health. Translational psychiatry, 12(1), 398. https://doi.org/10.1038/s41398-022-02178-4

34. Leland, N. E., Prusynski, R. A., Shore, A. D., Cary, M. P., Jr, Falvey, J., Mroz, T., & Saliba, D. (2024). Skilled nursing facility staffing shortages: Sources, strategies, and impacts on staff who stayed. Health services research, 59(6), e14355. https://doi.org/10.1111/1475-6773.14355

35. Hoffman, G. J., & Wallace, S. P. (2018). The Cost of Caring: Economic Vulnerability, Serious Emotional Distress, and Poor Health Behaviors Among Paid and Unpaid Family and Friend Caregivers. Research on aging, 40(8), 791–809. https://doi.org/10.1177/0164027517742430

36. Bouldin, E. D., Shaull, L., Andresen, E. M., Edwards, V. J., & McGuire, L. C. (2018). Financial and Health Barriers and Caregiving-Related Difficulties Among Rural and Urban Caregivers. The Journal of rural health : official journal of the American Rural Health Association and the National Rural Health Care Association, 34(3), 263–274. https://doi.org/10.1111/jrh.12273

37. Koumoutzis, A., Vivoda, J. M., & Cao, J. (2022). With a Little Help From My Friends and Family: Transportation and Caregiving Hours. Journal of applied gerontology : the official journal of the Southern Gerontological Society, 41(8), 1914–1923. https://doi.org/10.1177/07334648221089624

38. Del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., Ruzafa-Martínez, M., & Ramos-Morcillo, A. J. (2018). Social support and subjective burden in caregivers of adults and older adults: A meta-analysis. PloS one, 13(1), e0189874. https://doi.org/10.1371/journal.pone.0189874

39. Musich, S., Wang, S. S., Kraemer, S., Hawkins, K., & Wicker, E. (2017). Caregivers for older adults: Prevalence, characteristics, and health care utilization and expenditures. Geriatric Nursing, 38(1), 9-16.

40. Dako-Gyeke M. (2018). Courtesy stigma: A concealed consternation among caregivers of people affected by leprosy. Social science & medicine (1982), 196, 190–196. https://doi.org/10.1016/j.socscimed.2017.11.030

41. Diniz, M. A. A., Melo, B. R. D. S., Neri, K. H., Casemiro, F. G., Figueiredo, L. C., Gaioli, C. C. L. D. O., & Gratão, A. C. M. (2018). Comparative study between formal and informal caregivers of older adults. Ciencia & saude coletiva, 23, 3789-3798.

42. Johansson, G., Juuso, P., & Engström, Å. (2022). Nature-based interventions to promote health for people with stress-related illness: An integrative review. Scandinavian journal of caring sciences, 36(4), 910–925. https://doi.org/10.1111/scs.13089

43. Howard, A. H., Roberts, M., Mitchell, T., & Wilke, N. G. (2023). The Relationship Between Spirituality and Resilience and Well-being: a Study of 529 Care Leavers from 11 Nations. Adversity and resilience science, 4(2), 177–190. https://doi.org/10.1007/s42844-023-00088-y

44. Kim-Godwin, Y. S., Kim, S. S., & Gil, M. (2020). Journaling for self-care and coping in mothers of troubled children in the community. Archives of Psychiatric Nursing, 34(2), 50-57.

45. Svec, J., Nemmers, N., & Lee, J. E. (2024). Support for Family Caregivers: Implications of Work Strain and Its Intersections With Formal and Informal Help. The journals of gerontology. Series B, Psychological sciences and social sciences, 79(8), gbae087. https://doi.org/10.1093/geronb/gbae087

46. Wang, J., Liu, W., Li, X., Ma, Y., Zhao, Q., Lü, Y., & Xiao, M. (2024). Examining the social networks types and their effects on caregiving experience of family caregivers for individuals with dementia: a mixed-methods study. Innovation in aging, 8(6), igae040.

47. Åkerman, S., Nyqvist, F., & Nygård, M. (2023). A Cross-Sectional Study on the Associations between Economic, Social, and Political Resources and Subjective Caregiver Burden among Older Spousal Caregivers in Two Nordic Regions. Nursing reports (Pavia, Italy), 13(1), 365–377. https://doi.org/10.3390/nursrep13010034

48. Wylie, M. J., Kim, K., Liu, Y., & Zarit, S. H. (2021). Taking a Break: Daily Respite Effects of Adult Day Services as Objective and Subjective Time Away From Caregiving. The Gerontologist, 61(8), 1231–1240. https://doi.org/10.1093/geront/gnaa178

49. Hoel, V., Wolf-Ostermann, K., & Ambugo, E. A. (2022). Social isolation and the use of technology in caregiving dyads living with dementia during COVID-19 restrictions. Frontiers in public health, 10, 697496.

50. Goodman, J. M., & Schneider, D. (2021). The association of paid medical and caregiving leave with the economic security and wellbeing of service sector workers. BMC public health, 21(1), 1969. https://doi.org/10.1186/s12889-021-11999-9

51. Feinberg L. F. (2019). Paid Family Leave: An Emerging Benefit for Employed Family Caregivers of Older Adults. Journal of the American Geriatrics Society, 67(7), 1336–1341. https://doi.org/10.1111/jgs.15869

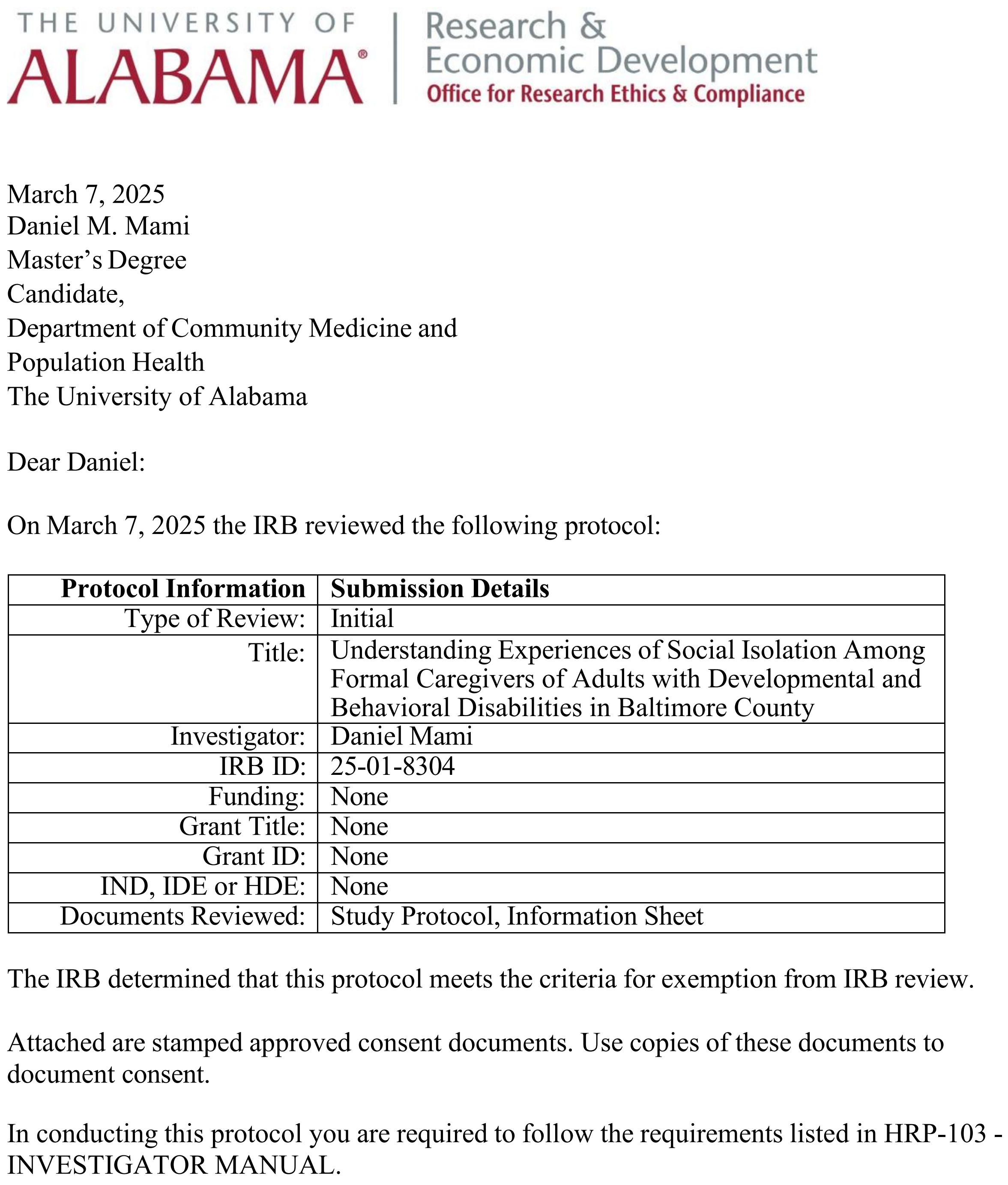
52. Administration for Community Living. (2022). 2022 National Strategy to Support Family Caregivers. U.S. Department of Health and Human Services. https://acl.gov/CaregiverStrategy

53. Reckrey, J. M., Watman, D., Perez, S., Franzosa, E., Ornstein, K. A., & Tsui, E. (2024). Paid Caregiving in Dementia Care Over Time: Paid Caregiver, Family Caregiver, and Geriatrician Perspectives. The Gerontologist, 64(7), gnae055. https://doi.org/10.1093/geront/gnae055

54. Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: a reappraisal from population-based studies. The Gerontologist, 55(2), 309–319. https://doi.org/10.1093/geront/gnu177

55. Centers for Disease Control and Prevention. (2019). Caregiving for family and friends—a public health issue. Centers for Disease Control and Prevention, 7.

APPENDIX I: IRB APPROVAL



THE UNIVERSITY OF ALABAMA
Research & Economic Development
Office for Research Ethics & Compliance

March 7, 2025
Daniel M. Mami
Master's Degree
Candidate,
Department of Community Medicine and
Population Health
The University of Alabama

Dear Daniel:

On March 7, 2025 the IRB reviewed the following protocol:

Protocol Information	Submission Details
Type of Review:	Initial
Title:	Understanding Experiences of Social Isolation Among Formal Caregivers of Adults with Developmental and Behavioral Disabilities in Baltimore County
Investigator:	Daniel Mami
IRB ID:	25-01-8304
Funding:	None
Grant Title:	None
Grant ID:	None
IND, IDE or HDE:	None
Documents Reviewed:	Study Protocol, Information Sheet

The IRB determined that this protocol meets the criteria for exemption from IRB review.

Attached are stamped approved consent documents. Use copies of these documents to document consent.

In conducting this protocol you are required to follow the requirements listed in HRP-103 - INVESTIGATOR MANUAL.

Ongoing IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities impact the exempt determination, please submit a new request to the IRB for a determination.

If you have and questions or require further information, please contact the UA HRPP via email at rscompliance@ua.edu.

APPENDIX II: CONSENT FORM

RESEARCH INFORMED CONSENT FORM FOR MASTER'S THESIS

By Daniel Mami

TITLE OF RESEARCH STUDY:

Understanding Experiences of Social Isolation Among Formal Caregivers of Adults with Developmental and Behavioral Disabilities in Baltimore County

(Master's Thesis)

Principal (Student) Investigator:

Name: Daniel Maada Mami

Role: Master's Degree Candidate,

Department of Community Medicine and Population Health

The University of Alabama

Contact Information: dmmami@crimson.ua.edu

Faculty Advisor (Supervisor)

Name: Dr. Morales-Aleman

Contact: mmmoralesaleman@ua.edu

Department of Community Medicine and Population Health

The University of Alabama

KEY INFORMATION

Why am I being invited to take part in a research study?

We invite you to take part in a research study because you are a formal caregiver of an adult with developmental and behavioral disabilities in Baltimore County. Your experiences can help us better understand social isolation among caregivers.

What should I know about a research study?

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

Why is this research being done?

My name is Daniel Maada Mami, a master's degree candidate at The University of Alabama. I am conducting this thesis research to explore and understand the lived experiences of social isolation among formal caregivers of adults with developmental and behavioral disabilities in Baltimore County. By gathering insights into your personal experiences, I hope to identify ways to develop strategies and policies that better support caregivers' overall health and well-being. While there may be no direct benefits to you personally, your participation could inform future interventions and programs to help other formal caregivers facing social isolation.

How long will the research take and what will I need to do?

We expect that you will be in this research study for one 45–60-minute interview. If you agree to participate, you will:

- *Participate in a single interview in a location of your choice or electronically (virtually) via Zoom, WhatsApp, or FaceTime, depending on your preferences and availability.*
- *Answer questions regarding your experiences as a caregiver, the challenges you face, the support systems available to you, and how social isolation affects your caregiving role and personal life.*

Is there any way being this study that could be bad for me?

This study is not expected to pose any significant risks to you as a participant. However, during the interview, you may discuss personal or emotional topics related to caregiving. If you feel uncomfortable at any time, you may pause or stop the interview. You are not obligated to answer any question that makes you uneasy.

Will being in this study help me in any way?

We cannot promise any benefits to you or others from your taking part in this research. However, your input will provide important insights into the experiences of formal caregivers facing social isolation. These insights may help shape future support programs, interventions, and policies to better serve caregivers in similar situations.

What happens if I do not want to be in this research?

Participation in this thesis research is completely voluntary. You can decide to participate, not participate, or discontinue at any time without penalty or loss of benefits to which you are otherwise entitled. Your alternative to participating is simply not to participate.

DETAILED INFORMATION

Who can I talk to?

If you have questions, concerns, or complaints, or think the research has hurt you, you can contact:

- *Daniel Maada Mami at dmmami@crimson.ua.edu.*
- *Faculty Advisor (Supervisor), Dr. Morales-Aleman, at mmmoralesaleman@ua.edu.*

This research has been reviewed and approved by an Institutional Review Board (“IRB”). You may talk to them at (205) 348-8641 or rscompliance@ua.edu if:

- *Your questions, concerns, or complaints are not being answered by the research team.*
- *You cannot reach the research team.*
- *You want to talk to someone besides the research team.*
- *You have questions about your rights as a research subject.*

- *You want to get information or provide input about this research.*

How many people will be in this study?

A total of 14 people participated in this research study, all recruited from Baltimore County.

What happens if I say yes, I want to be in this research?

If you say yes:

- *I will interview you for about 45–60 minutes at a place you prefer or via video/phone.*
- *During the interview, you will answer questions about your caregiving experiences and how social isolation affects your life.*
- *With your permission, the interview will be audio-recorded so I can ensure accuracy of the data collected. If you prefer not to be audio-recorded, I will take written notes instead.*
- *Your identity will be kept confidential; no personal identifiers will be used in my thesis, presentations, or any reports.*

What happens if I say yes, but I change my mind later?

You may withdraw from this study at any time without any penalty. If you choose to withdraw, any data you have provided will be destroyed and excluded from the study analysis. Your decision will not be held against you or affect any services or benefits you are otherwise entitled to.

Is there any way being in this study could be bad for me?

- *Possible psychological or emotional risks: You may feel discomfort if discussing personal or sensitive information. You may stop the interview at any time or skip any question you do not want to answer.*
- *Privacy risks: While every effort will be made to keep your information confidential, there is always a minimal risk of unintended disclosure.*

There is no known physical, legal, or economic risks to your participation. If you experience distress, you may pause the interview or withdraw entirely.

What happens to the information collected for this research?

Your privacy and confidentiality are extremely important. All collected information will be kept confidential, and your name or any other identifying information will not be linked to the data. Audio recordings will be securely stored and erased once the study is complete. The findings may be published or presented, but your identity will remain anonymous.

Will my data or samples be used for future research?

Audio recordings and transcripts will be used solely for this thesis research. They will not be stored for future studies unless you separately agree to that in writing.

What else do I need to know?

- *Compensation: As a token of appreciation for your time, you will receive a $25 gift card once the interview is completed.*
- *This study is being conducted by Daniel Maada Mami in partial fulfillment of the requirements for a master's degree at The University of Alabama. It is not externally sponsored.*

Signature Block for Capable Adult

Your signature documents your permission to take part in this research.

Signature of subject Date

Printed name of subject Date

Signature of person obtaining consent Date

Printed name of person obtaining consent

APPENDIX III: INTERVIEW QUESTION GUIDELINE

Here is my interview questionnaire guideline.

Understanding the Experiences of Social Isolation Among Formal Caregivers of Adults with Developmental and Behavioral Disabilities in Baltimore County

Student Researcher: ***Daniel Maada. Mami***
Institution: ***The University of Alabama***
Participant Identification (PID): ____________ Date: ____________ Time: ____________
Interviewer sign: ____________

INTRODUCTION

As we discussed during the informed consent process, I will be audio recording this conversation with your permission. May I turn on the recorded at this time? [Turn on recorder and record the date, time, interviewer name, and PID.]

My name is Daniel Maada Mami, and I am conducting this study (thesis) as part of my Master of Science in Population Health Sciences at The University of Alabama. The purpose of this research is to investigate and understand the experiences of formal caregivers of adults with developmental and behavioral disabilities in Baltimore County including those of social isolation.

This study interview aims to understand the challenges, support systems, and coping strategies that influence your caregiving role. Your participation is entirely voluntary, and your responses will remain confidential. The interview will take approximately 45–60 minutes. You are free to skip any questions or withdraw at any time.

If you have any questions, feel free to ask me before we start. If you're comfortable, we can begin the interview now.

Section A: Demographic Background Information

QUESTION	**RESPONSE**
In what year were you born?	
What is your gender?	
What is your race or ethnicity?	
How long have you lived in Baltimore County?	
What is your marital status?	
How many adults and children live in your household?	Adults: _______ Children: _______
How long have you been working as a caregiver?	
What is your primary caregiving role (e.g., paid professional caregiver)?	
How many hours a week do you work as a caregiver?	

Section B: Caregiving in Baltimore County

1. Can you tell me what a typical day is like for you as a caregiver?
2. In your experience, what is it like being a caregiver in Baltimore County?
3. How has being a caregiver impacted your relationships with family, friends, or colleagues?

Section C: Experiences of Social Isolation

1. How would you describe your experiences with social isolation as a caregiver?
2. Can you recall specific moments or situations that made you feel particularly isolated? *For example, times when you couldn't attend social events or felt unsupported by those around you.*
3. Do you feel that your caregiving responsibilities make it difficult to maintain social connections? *If yes, can you share examples, like missing important gatherings or feeling left out?*

Section D: Contributing Factors to Isolation

1. What personal challenges make you feel isolated as a caregiver? For example, do you ever feel that stress, fatigue, or limited free time contributes to your sense of isolation?
2. Sometimes caregivers talk about financial constraints or limited resources, like not having enough money, transportation, or respite care, which can make them feel cut off from others. Have you experienced anything like that?
3. Sometimes caregivers experience stigma. Stigma means negative attitudes, misunderstandings, or judgments from others because of their caregiving role. Have you ever encountered this kind of stigma, and if so, what was that experience like for you?

Section E: Impact on Mental Health and Caregiving

1. Many caregivers feel increased stress or anxiety because of isolation. How has social isolation affected your mental or emotional well-being? For instance, do you notice feeling overwhelmed or more worried due to isolation?

2. Can you tell me about a time when you felt especially isolated as a caregiver, what that situation was like for you, and how did it affect the way you went about your caregiving tasks at that time?
3. Can you describe an example where isolation influenced your caregiving work or personal life, what was that situation like for you, and how did it affect the way you handled your responsibilities?

Section F: Coping Strategies and Support Systems

1. What personal strategies have you used to manage feelings of isolation? *For example, do you take breaks, practice self-care, or talk to someone you trust?*

2. Who do you rely on for emotional or practical support, and how effective is that support? In *other words, do you have friends, family, or groups that help you manage stress?*

3. Have you accessed any formal services or resources to help reduce isolation? *For instance, have you used respite care, support groups, or counseling services?*

4. What challenges have you encountered when trying to access support services or resources? *For example, do you face barriers like transportation issues, long waiting lists, or high costs?*

Section G: Recommendations and Suggestions

FOCUS	**QUESTION**	**RESPONSE**
Additional Resources or Services	What additional resources or services would you recommend to support caregivers facing isolation? For example, would more support groups, better training, or financial assistance help?	
Support Groups	Would having access to a caregiver support group make a difference? If so, how would you like these groups to be structured (e.g., in-person, virtual)?	
Training Opportunities	What kind of training or resources would help you feel more prepared and supported in your caregiving role? For example, training on managing stress or handling behavioral challenges.	
Policy Changes	Are there specific changes to workplace or community policies that you think could reduce caregiver isolation? For instance, what could employers or community organizations do to make your caregiving role easier?	
Message to Policymakers or Leaders	If you could share one message with policymakers or healthcare leaders about caregiver needs, what would it be? What do you think is the most urgent issue for caregivers that needs attention?	

Section H: Final Reflections and Closing

1. **Opportunity for Additional Insights**
    1. Is there anything else about your experiences as a caregiver that you feel is important to share but haven't been covered in this interview?
2. **Reflections on the Conversation**
    1. How did you find this interview process?
    2. Was there a particular question or topic that stood out to you or felt especially relevant to your experiences?

APPENDIX IV: DEMOGRAPHIC INFORMATION

ID	Birth Year	Gender	Race/ Ethnicity	Years in Baltimore County	Years as a Caregiver	Marital Status	Household	Primary Role	Hours/ Week
001	1982	Male	African American	15	9	Divorced	1 adult (self), 2 children (ages 10 and 14)	Full-time caregiver at a residential facility for adults with severe autism.	50-60
002	1975	Female	African	10	8	Married	2 adults (self & spouse), 3 children (6,8,13)	Full-time caregiver at a day program and sometimes Residential for adults with intellectual disabilities.	45-55
003	1989	Male	African	7	5	Single	1 Adult (Self-Lives alone) No Child	Behavioral technician for adults with behavioral	40-50

								Disabilities	
004	1980	Female	Hispanic/Latino	20	12	Married	4 adults (self, spouse & maternal parents), 2 children (ages 12 and 15)	Full-time caregiver at a residential facility for adults with multiple disabilities.	50-60
005	1979	Female	Asian	18	14	Married	2 adults (self & spouse), 4 children (7, 10,15, 20)	Full Time Direct support professional for Residential adults with developmental disabilities	55-60
006	1992	Male	Asian	33	4	Single	1 Adult (Self-Lives alone) No Child	Full-time DSP caregiver for adults with developmental and intellectual disabilities	40
007	1996	Female	African American	29	6	Single	1 Adult (self) 1 Child (13)	Full Time Certified Medication Technicia	64

								n /Direct support professional for Residential adults with developmental disabilities	
008	1993	Male	African	15	8	Single	1 Adult (Self-Lives alone) No Child	Full Time Certified Medication Technician /Direct support professional for Residential adults with developmental and Intellectual disabilities	40
009	1959	Male	Hispanic/Latino	42	5	Married	2 adults (self & spouse), 2 adult children (22, 25)	Full-time Certified Medication Technician / DSP House Manager for residential adults with developmental & behavioral	40 (but on Call)

								disabilities.	
010	1985	Female	African	12	6	Divorced	1 adult (self), 3 children (5, 8, 11)	Full-time DSP working night shifts in a group home for adults with developmental disabilities.	40- 50
011	1990	Male	African American	35	4	Single	2 adults (self & roommate - live with roommate), no child	Fulltime DSP and weekend caregiver for group home adults with intellectual disabilities.	40
012	1987	Female	African American	25	10	Married	2 adults (self & spouse), 1 child (17)	Full time Lead residential caregiver and trainer at a day program for adults with autism and behavioral disorders.	60

013	1983	Male	African	14	7	Married	2 adults (self & spouse), 2 children (9, 12)	Full-time DSP for adults with severe physical and intellectual disabilities.	50-60
014	1991	Female	African	8	4	Single	1 adult (self - lives alone), no child	Full time residential DSP working rotating shifts for group homes.	40-48

APPENDIX V: EMAIL SCRIPT FOR PARTICIPANT RECRUITMENT

EMAIL SCRIPT

Subject: Invitation to Participate in Research on Caregiver Experiences

Dear Participant,

I hope this email finds you well. My name is Daniel Maada Mami, and I am a graduate student at The University of Alabama, College of Community Health Sciences. I am conducting a research study on the experiences of formal caregivers of adults with developmental and behavioral disabilities in Baltimore County, with a focus on understanding social isolation and the challenges formal caregivers face.
I am reaching out to invite you to participate in this study because of your valuable experience in caregiving. Your insights will contribute to a deeper understanding of the systemic and social factors affecting caregivers, and I would greatly appreciate your time.

What Participation Involves:

- *A single, one-on-one interview lasting 45–60 minutes, conducted in person or via Zoom at your convenience.*
- *The interview discussion will focus on your formal caregiving experiences, challenges, support systems, and the impact of social isolation.*
- *Compensation: As a token of appreciation for your time, you will receive a $25 gift card once the interview is completed.*

Confidentiality & Your Rights:

- *Participation is completely voluntary, and you may decline to answer any question or withdraw at any time.*
- *Responses will be confidential, de-identified, and securely stored. Only the research team will have access to the data.*
- *With your permission, the interview will be audio-recorded for accuracy.*

After the Interview:

- *You will receive a brief debriefing, and if needed, a list of caregiver support resources in Baltimore County.*

If you are interested or have any questions, please reply to this email or contact me at dmmami@crimson.ua.edu

Thank you for considering this opportunity and I truly appreciate your time and insights.

Respectfully Always,
Daniel Mami
Master of Science Candidate in Population Health Sciences
The University of Alabama
Email: dmmami@crimson.ua.edu

APPENDIX VI: THEMATIC MAP COLORED

The figure below is a thematic map with color code.