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Caring for the Caregiver: A Study on the Quality of Life of Informal Caregivers of Aging and Elderly Adults with Down Syndrome

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CARING FOR THE CAREGIVER: A STUDY ON THE QUALITY OF LIFE OF INFORMAL CAREGIVERS OF AGING AND ELDERLY ADULTS WITH DOWN SYNDROME

by

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Abstract

This research studied the quality of life of informal caregivers of aging and elderly adults with Down syndrome. Prior research indicates some degree of deteriorating Quality of Life (QoL) for caregivers, however, there is no empirical research isolating the aspect QoL affected. This study seeks to research the following two questions: 1) What are the trends in the four domains that influence Quality of Life, both positively and negatively, of informal caregivers of aging and elderly adults with Down syndrome? and 2)What supports do caregivers of aging and elderly adults with Down syndrome want to improve their own Quality of Life? The methodology is a Qualtrics questionnaire administering the WHOQOL-BREF to caregivers of the aging (30-39 years old) and elderly (40+ years old) individuals with Down syndrome. The results showed that informal caregivers caring for elderly adults with Down syndrome lowest Quality of Life domain was social and highest Quality of Life domain was physical. Informal caregivers caring for aging adults with Down syndrome lowest Quality of Life domain was physical and highest Quality of Life domain was environmental.

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Chapter One: Introduction

On October 25, 2017, Frank Stephens delivered a speech to Congress which touched the hearts and minds of many and resulted in thousands of dollars poured into Down syndrome (DS) research. Stephens passionate affirmation reverberated across his audience when he states, “Just so there is no confusion, let me say that I am not a research scientist. However, no one knows about life with Down syndrome more than I do. Whatever you learn today, please remember this, I am a man with Down syndrome and my life is worth living” (Massachusetts Down Syndrome Congress 2017). While Frank Stephens and I may have different personality traits and characteristics, we have something in common - the belief that research on Down syndrome is of paramount importance to advance the lifestyle of both people with Down syndrome and their caregivers who are often overlooked.

Each year, one in every 1,000 babies are born with Down syndrome (DS) (Grimm et al., 2021 as cited by Chen et.al 2022), an Intellectual Disability that affects one’s adaptive and intellectual ability (Hamburg et.al 2019). Additionally, people with DS age at an earlier onset than the typical population (Devenny & Krinsky-Mchale 1998, Ilacqua et.al 2020). Researchers Devenny and Krinsky-Mchale (1998) stated that the aging of people with DS “was detectable approximately two decades earlier” (p. 6). Within the last century there has been a 30% increase in the prevalence of DS (CDC, 2023), and people with DS's life expectancy has nearly increased by sixfold in the last century. In the 1960s, life expectancy for people with DS was about 10 years old, in the 1980s their life expectancy was 25 years old, and in 2020, their life expectancy reached 60 years old (CDC, 2023; Tsouc et.al., 2020 as cited by Chen etl.al 2022). Researchers accredit this increase in life span to an "elevated consciousness, modified treatment protocols and advanced social supportive medical care" (p. 2) (Verstegen et.al 2020 as cited by Chen et.al 2022). For example, during these years in the United States, laws were enacted to improve QoL for people with DS. It is also pertinent to know that the Individuals with Disabilities Education Act signed into law in 1975 guarantees children with special needs a free and appropriate education. The Americans with Disability Act (ADA), which protects the rights of all individuals with a disability was enacted in 1990. People with DS were finally included in the classrooms, allowed to have jobs, were provided with needed therapies, among other benefits.

All people have an innate value to their life and are worth understanding, however beyond the moral reasons to understand DS, the prevalence of having DS makes it a priority for researchers to discuss. In 2008, over 250,000 people with DS lived in the United States (CDC 2023). These individuals and their families are partially supported by federal funds expanding this matter to one that impacts all people who live in the United States. Trillions of federal tax dollars go into providing services for individuals with disabilities, including DS (Policy Basics: Where do our federal tax dollars go? n.d). Hence, research is necessary to maximize use of these federal dollars to improve the quality of life of individuals with DS.

Due to their lifespan increasing drastically over the past century, recent protections by laws, and the increased prevalence of DS, a cohort of aging and elderly adults with DS who are being cared for by informal caregivers has risen and are facing the challenges of aging unprepared. An informal caregiver is one who is not professionally trained and is providing care for the individual with a disability, for example: parents and siblings (National Alliance for Caregiving and AARP Public Policy Institute 2015 as cited by Sacco et.al 2022). It is important to emphasize that at the time of birth of the current aging adults with DS, their parents were advised to institutionalize them and informed that their lifespan would be less than half of the expected norm of this era. The parents, who opted not to institutionalize their children but instead raise them, are now facing unforeseen expectancy with their child outliving them. Likely, too, their child could be diagnosed with Dementia/Alzheimer's, which is a common comorbidity for aging adults with DS (Ilacqua et.al's 2020); thus, facing the heart-wrenching decision of transferring guardianship of their child to siblings or group homes.

The present cohort of aging adults with DS needs support right now because of the unforeseen challenges they face. Not only is additional support needed for the individual with Down syndrome, but also for their caregivers. Through current research, there is a trend of a suffering quality of life for these informal caregivers. In Lemoine and Schneider's (2023) article on the relationship between sibling caregivers of adults with DS, beyond the scope of the research, "many respondents annotated the questionnaire with comments expressing their gratitude for being offered an all-too-rare opportunity to express their feelings, including their difficulties and suffering…" (p. 16). The quality of life of informal caregivers of the aging population with DS is multifactorial and under-researched. Glimpses show a hurting quality of life, yet little empirical research exists about what to do to help. The World Health Organization (WHO, 1998) definition of Quality of Life (QoL) states, "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (p.1)." The WHO developed an instrument to measure quality of life, the WHOQOL and WHO BREF, which “yield a multi-dimensional profile score across domain and sub-domains (facets) of quality of life) (World Health Organization, 1998, p. 8). The four domains of WHOQOL are: Physical, Psychological, Social, and Environmental.

There is limited research on the caregiver QoL of aging and elderly adults with DS. From the research on the aging population of people with DS and their caregivers, consensus exists that more adult services are needed (Bertolie et.al 2011; Ilacqua et.al 2020; Liao 2023). Due to the limited research in this niche to establish background knowledge on this topic, the inclusion criteria for the literature review encompass caregiving for the elderly and caregiving across the lifespan of people with DS. By including these two categories, a theme establishing a need to support caregiver mental health emerges, as well as the desire for caregivers to be supported formally, informally, and equipped by resources (Ilacqua 2020; Sacco et.al 2022; Vos et.al 2021; Xie 2016). Since the inclusion criteria is large, these findings cannot be transferred over to describe the QoL of caregivers of aging and elderly adults with DS; however, they can provide a framework and guidance for this study. The goal of this study is to identify QoL characteristics for caregivers of aging and elderly adults with DS. In this study, aging adults with DS are between the ages of 30 to 39 years and elderly adults with DS are 40 years and above due to the different health concerns each cohort has (Cabrera et.al, 2022). The two research questions are:

1) What are the trends in the four domains found to influence Quality of Life, both positively and negatively, of informal caregivers of aging and elderly adults with Down syndrome?

2) What supports do caregivers of aging and elderly adults with Down syndrome want to improve their own Quality of Life?

Before beginning to collect data, a framework of empirical research was needed to understand the exact QoL needs. This study had a quantitative and qualitative approach to reveal the empirical trends in QoL of informal caregivers of aging and elderly adults with DS. To begin, a target population of informal caregivers needed to be identified. Then, informal caregivers filled out a questionnaire that contains demographic information, the WHO BREF, and an option to schedule an interview with the researcher. With the WHO BREF, a tested QoL survey, and an optional interview, a holistic perspective on caregiver QoL can be determined. Additionally, the demographic questionnaire will reveal if any trends arise across different demographics. After analyzing the data submitted, research recommendations can be made to caregivers, professionals, and support organizations to implement programs with an empirical foundation that target the QoL of these informal caregivers.

Chapter Two: Literature Review

To grasp a comprehensive understanding on the needed support of the aging and elderly population of adults with Down syndrome and their caregivers, this literature review inclusion criteria are studies that focus on aging and elderly adults with DS and their caregivers, studies that focus on caregiving for the elderly in general, and studies on caregiving for people with DS across their lifespan. The rationale for choosing to examine caregiver QoL over the aging and elderly adults with DS QoL stands behind the notion that very little research has been conducted on the caregivers. For the most part, studies are more focused of caregivers answering questionnaires on behalf of their care-recipient. Additionally, caregivers have a tremendous influence on the care-recipients QoL, which indicate a high need to ensure caregivers' welfare are in optimal condition to avoid further additional hurt on both caregivers and care-recipients. Lastly, it is difficult for this age range of adults with DS to answer questionnaires, typically it is care-recipient who answer QoL questions on their behalf.

The process of creating this literature review utilized the Education Database (ProQuest) (1988+) and examining peer reviewed articles with the key words: Quality of Life, Elderly Adults with Down Syndrome, and Caregivers. Upon reviewing the articles Abstracts, if deemed relevant to this study they were read in their entirety. A total of 27 articles were analyzed, 18 were chosen to be used in this literature review with an additional two reputable websites (CDC and WHO) to provide contextual information, due to the inclusion criteria of relating to elderly adults with Down syndrome, adult services, and caregiver QoL.

A need for DS Adult and Caregiver Services

Many articles on the adult population with DS emphasize the need for more adult services for individuals with DS and for their caregivers. Bertolie et.al (2011) who did a study in

Rome about what needs and challenges people with DS face stated that there was a need for help across the lifespan. This was confirmed by people with DS and their caregivers in researcher Brown's (1994) study which was a review of another longitudinal study comparing the QoL of people with DS with and without a personalized intervention. Brown (1994) stated that during those six years the group with personalized intervention "became more aware of their needs and were more critical of their environment" (p. 1). Caregivers also agree with this need for more adult services. In Ilacqua et.al's (2020) study on the impact of caring for family members with DS who have Alzheimer's, a typical comorbidity for this aging population, DS programs were mainly focused on younger children. This was second by Liao (2023), whose study was on culturally and linguistically diverse families with individuals with Intellectual Disabilities, who mentioned that parent training was also for younger children with DS and not for older adults with DS.

The need for services to support this aging population is not only spoken of but also visible. The literature review of Sacco and colleagues' (2022) study on the QoL of informal caregivers caring for the elderly states that effects of QoL were both positive and negative but more profoundly negative. The positive effects are in self-esteem, but the profound negative effects were in mental health (Jacobi et.al 2013 as cited by Sacco et.al 2022). There was "psychological distress, lower wellbeing and poorer QoL" (Del- Pino-Casado et.al as cited by Sacco et.al 2022 p. 2). Similarly, in the research of Ilacqua and colleagues (2020) found the greatest impact to caregiver health was emotional stress and least impact was on caregivers' sense of fulfillment and purpose. In China, Xie, and colleagues (2016) found that for caregivers of the elderly, the physical health was better, but mental health was lower.

Caregivers' Desire for Support

Caregivers of people with DS and the elderly desire to feel supported formally and informally (Vos.et al's 2021). In a caregiver-authored article in the *National Down Syndrome Newsletter*, Miller (2020), sister and caregiver of Robin, an elderly adult DS, said "caregiving is not a journey that can be taken alone" (p. 6). Vos et.al (2021) echoed Ms. Miller by stating that caregivers long for a "sympathetic ear' to share situations, questions, and concerns" (p 8). Sunelaitis et.al (2007), as cited by Moriera et.al (2016) study on the self-perspective of caregivers of children with DS QoL, called on help from health professionals desiring to know more about DS. In Ilacqua and colleagues' (2020) study on caregivers of adults with DS and Alzheimer's QoL, a portion of the research was on caregiver knowledge. Caregivers could in general answer two of the three questions correctly, which shows empirically that there is still a need for them to know more about the disability their loved ones are diagnosed with. The desire to be more informed is also supported cross culturally. In Seangpraw and Ong-Arborirack (2020) study, part of the study was on the QoL of family caregivers of the elderly with high blood pressure in Thailand; these caregivers had low to fair levels of knowledge in care-recipients medication and diagnosis.

Caregivers are also requesting support from the government. Researchers in Xie and colleagues' (2016) study on the health related QoL of Chinese family members caregiving for their elderly called upon the government to assume "responsibility for implementing existing public policies and for extending those that target the prevention of health-related complications" (p. 7). This finding was verified by Seangpraw and Ong-Artborirack (2020) who also called for government assistance. Not only is there a call for caregivers to be supported, but there is also a need for caregivers to be equipped to support themselves. In Ilacqua's (2020) study, caregivers did not utilize the resources available, and the ones they primarily used (i.e. brochures, pamphlets, and handbooks) were deemed inadequate and not really useful. These caregivers said, "they would be most willing to use DS advocacy groups, brochures, education workshops and science literature" (p. 9). This claim was supported by Yazdanmanesh et.al (2023) and Oliveira et.al (2020) who both did studies on support groups and found them effective for caregivers, which falls under the theme of resources. However, Hewitt (2014) as cited by Hodapp et.al's (2016) study "Family Caregiving of Aging Adults with Down Syndrome," noted a key point that "Across the United States… only 25% of all adults with intellectual disabilities receive state run disability services, whereas 75% do not" (p. 2). This therefore begs the question: If only a quarter of the eligible population is utilizing services, why does the majority not take advantage? One also wonders, to what extent are people knowledgeable about the services available.

The literature review highlights a theme of a need for adult services and a theme of a need for caregiver support. Caregivers are struggling with mental health and although some resources (i.e. support groups) seem beneficial, others are underutilized or not useful. Caregivers of the elderly and young children with DS are calling for assistance from the government and professionals, but there is no empirical evidence saying what informal caregivers for the aging and elderly population with DS are asking for and what exactly is the state of their QoL. Therefore, the current study proposes to ask some important questions. The first step before implementing services to improve the QoL of caregivers is determining which areas of QoL are being affected, then matching the needs with services to effectively address and improve their QoL for caregivers.

Chapter Three: Methodology

The participants of the current study are informal caregivers of aging and elderly adults with Down syndrome. The inclusion criteria to be a participant of this study was that informal caregivers provide a minimum of 10 hours of care weekly and were untrained. In this study, aging adults with Down syndrome are between the ages of 30-39 and elderly adults with Down syndrome are 40 and above. These age ranges are chosen because people 33 and above face unique challenges because they were born before the ADA was enacted. However, the 30s and 40s age group have different health concerns (Cabrera et.al 2022), and health is a key aspect influencing QoL. This established three cohorts: aging adults with DS (30-39), adults with DS born before ADA (33+), and elderly adults with DS (40+). With these three cohorts, different trends can be established and compared between the caregivers who care for these individuals. Additionally, QoL can be further determined to help these three cohorts.

To begin, an IRB approval was obtained (see Appendix A). Then, a Qualtrics questionnaire (see Appendix B) was formed by the co-investigator that includes:

- The Explanation of Research with a participant signature guaranteeing they read the full statement.
- Two questions to sort the participants into caring for an aging or elderly adult with DS before or after the ADA was enacted.
- The WHOQOL-BREF Demographic Information
- The WHOQOL-BREF Questionnaire
- Optional Zoom interview question with preferences

The demographic portion of the WHOQOL-BREF has no identifiable information, this establishes anonymity. However, if the caregiver desired to participate in the Zoom interview, an email and first name was asked, this information would not be released to the public. The WHOQOL-BREF was requested from the WHO and was given permission to the co-investigator to use. The WHOQOL-BREF was chosen, because it is a reputable QoL survey, created by the World Health Organization (WHO), and is of manageable length for caregiver to complete. The questions on the WHOQOL-BREF correlate to the four domains of QoL, which made it clear to see the trends in the QoL domains. The optional interview was included because QoL is a holistic matter and can also be qualitative. An interview gives participants a chance to express their thoughts outside of a quantitative questionnaire as well as gave a space for caregivers to offer their input on services they desire. The two questions that were chosen to guide the Zoom interview included:

1. Would you like to elaborate on any questions in the WHOQOL-BREF survey?
2. What resources do you desire to help support you as an informal caregiver?

To recruit participants, caregivers were contacted via DS Associations across the United States. Upon contact, the DS Associations agreed to share the informational flyer and questionnaire link with potential participants. However, no volunteers came forth to be interviewed, so the protocol is saved for future research iterations.

Chapter Four: Results and Discussion

There were 60 respondents to the survey; however, only nine qualified as informal caregivers of elderly and aging adults with DS. Of the nine participants, three were informal caregivers of elderly adults with DS and six were informal caregivers of aging adults with DS. Of the total nine, four were informal caregivers of individuals with DS born before the ADA was enacted (three elderly informal caregivers and one aging informal caregiver). This led to establishing three cohorts: informal caregivers of elderly adults with DS (Elderly), informal caregivers of aging adults with DS (Aging) and informal caregiver of adults with DS born before the ADA was enacted (Before ADA). The results show that informal caregivers who care for elderly adults with DS had the lowest QoL (3.07) in comparison to the Aging (4.03) and Before ADA cohorts (3.4). This information is displayed in Table 1.

The results also showed that the QoL determined by averaging all the questions was lower than participants personal rating of their average QoL. The largest difference was in the Aging cohort (difference: 0.65) and the least difference was in the Elderly cohort (difference: 0.26). The numbers are displayed in Table 1.

Table 1: Average Quality of Life

Category	**Elderly**	**Aging**	**Before ADA**
Average QoL	3.07	4.03	3.4
How participants rated their average QoL	3.33	4.67	3.75

Tables 2 through 5 display the average QoL of each domain (physical, social, psychological, and environmental) for each cohort to address Research Question 1: What are the trends in the four domains that influence Quality of Life, both positively and negatively, of informal caregivers of aging and elderly adults with Down syndrome? The average QoL for each domain was taken by using the WHOQOL-BREF analysis form which separated each question into the four domains. The Elderly cohort had the strongest QoL in the physical domain and weakest QoL in social domain. The Aging cohort had the strongest QoL in the environmental domain and weakest QoL in the physical domain. The Before ADA cohort had the strongest QoL in the physical domain and weakest QoL was in the social domain.

The results are shown in Tables 2 through 5.

Table 2: Physical Domain QoL

Elderly	3.48
Aging	3.71
Before ADA	3.536

Table 3: Psychological Domain QoL

Elderly	2.88
Aging	3.91
Before ADA	3.33

Table 4: Social Domain QoL

Elderly	2.25
Aging	3.94
Before ADA	3

Table 5: Environmental Domain QoL

Elderly	3.13
Aging	4.35
Before ADA	3.531

For the Research Question Two: What supports do caregivers of aging and elderly adults with Down syndrome want to improve their own Quality of Life, the results were inconclusive. Unfortunately, no Zoom interviews took place because only one individual requested a Zoom interview. However, no response was received to accept the Zoom in calendar.

Discussion of Findings

Since the sample size of nine participants is quite limited, the results are not statistically significant. Nonetheless, the findings can bring some clarity to an under-researched issue. The findings hinted at a decreasing QoL as the age increased of the person for whom care is being provided. This finding is shown by the decrease in average QoL in each domain in each progressively older cohort, from highest to lowest: Aging, Before ADA, and Elderly Cohorts.

When looking at Tables 2 through 5 and analyzing which QoL domains were strongest and weakest, both cohorts Elderly and Before ADA had the same results: the highest QoL domain was the physical domain and the lowest QoL domain was the social domain. This may be a result of three out of the four participants in the Before ADA cohort were also in the Elderly cohort: hence influencing the findings. These cohorts revealed that the lowest QoL was in the social domain seconded by the psychological domain suggesting a need for a social support circle for this cohort. These findings are like those of the informal caregivers of the elderly, in Xie et.al (2016) study where the findings showed that caregivers physical health was better, but mental health was lower. Also in agreement is the Sacco et.al (2022) study, since they also found that there were profound negative effects on mental health. Additionally, the need for a stronger support circle is supported by the voices of caregivers themselves in *The National Down Syndrome Newsletter* (Miller 2020) as well as Vos et.al (2021). In both pieces, caregivers wanted people to support them alongside in their caregiving journey and longed for people to listen and share their questions, situations, and concerns.

For the Aging cohort, the results differed. The strongest QoL is in the environmental domain, and the weakest is in the physical domain. This provokes interest since the weakest QoL is the opposite of the Elderly cohort (which is supported by Xie et.al 2016). For the aging cohort, physical self-care is necessary, thus possible supports could be free self-care outlets that provide respite care. Lastly, an unexpected finding appeared. The average QoL of each cohort was lower than their self-stated average QoL. No research has been done on the difference between one's perceived QoL and actual QoL with this demographic, and caution is recommended with this since QoL is subjective. However, this finding is important to note. Since caregivers are sharing their struggles and research is hinting at a lower QoL, the difference heightens the validity to these statements since the research is showing an even greater need than what the caregivers are expressing.

Chapter Five: Conclusion

This study helps to shine a needed light on the QoL of informal caregivers of aging and elderly adults with DS. The results showed that the Elderly cohort, caring for elderly adults with DS, followed a similar QoL trend to caregivers of the elderly. These individuals had a stronger physical QoL and lower social/psychological QoL. Recommendations to address this need include creating spaces as social support circles with respite care, so caregivers can have a community to walk alongside them through the journey of caring for those they love. Unique findings occurred in the QoL trends of aging adults with DS. These results differed from the Elderly cohort since their physical QoL domain was lowest while their environmental QoL domain was the strongest. Suggestions to help these caregivers include providing physical self-care groups/activities with respite care to support these caregivers in administering self-care. However, it is positive that the highest QoL domain for the Aging cohort is environmental. This suggests that our society is shifting to provide more support for this cohort. Yet, there is still a gap between the Aging cohort and Elderly cohort, emphasizing the need of services that extend the lifetime to be implemented immediately.

Limitations and Suggestions for Future Research

The current study sheds a light into the QoL of caregivers of aging and elderly adults with DS. While these results highlight similarities and difference to previous research, the cohort size was too small to be statistically significant. While possible trends are highlighted, because of small sample size, the study cannot be considered statistically significant.

For future researchers, opening the survey and sending reminders for an extended period (i.e. year or two) could reach a larger cohort and meet the minimum number of participants to have statistical significance. Additionally, acquiring funding would open the possibility to providing incentives to participate increasing caregiver participation. Another recommendation is to plan interviews to coincide with a convention or gathering of a professional organization to perform the interviews. Having the interviews in person and providing respite care might be a great incentive, too, so that caregivers can more accessibly provide their opinions.

Further research is suggested in this niche to continue finding statistically significant correlations between informal caregivers of aging and elderly adults with DS QoL. While research is showing growth in our community in supporting informal caregivers of aging and elderly adults with DS, there is still more to do. Creating spaces of support, providing respite opportunities, and continuing research in this field are only a few of the opportunities that may be taken to confine making positive strides in caring for our caregivers of aging and elderly adults with DS ensuring a better quality of life for all parties involved.

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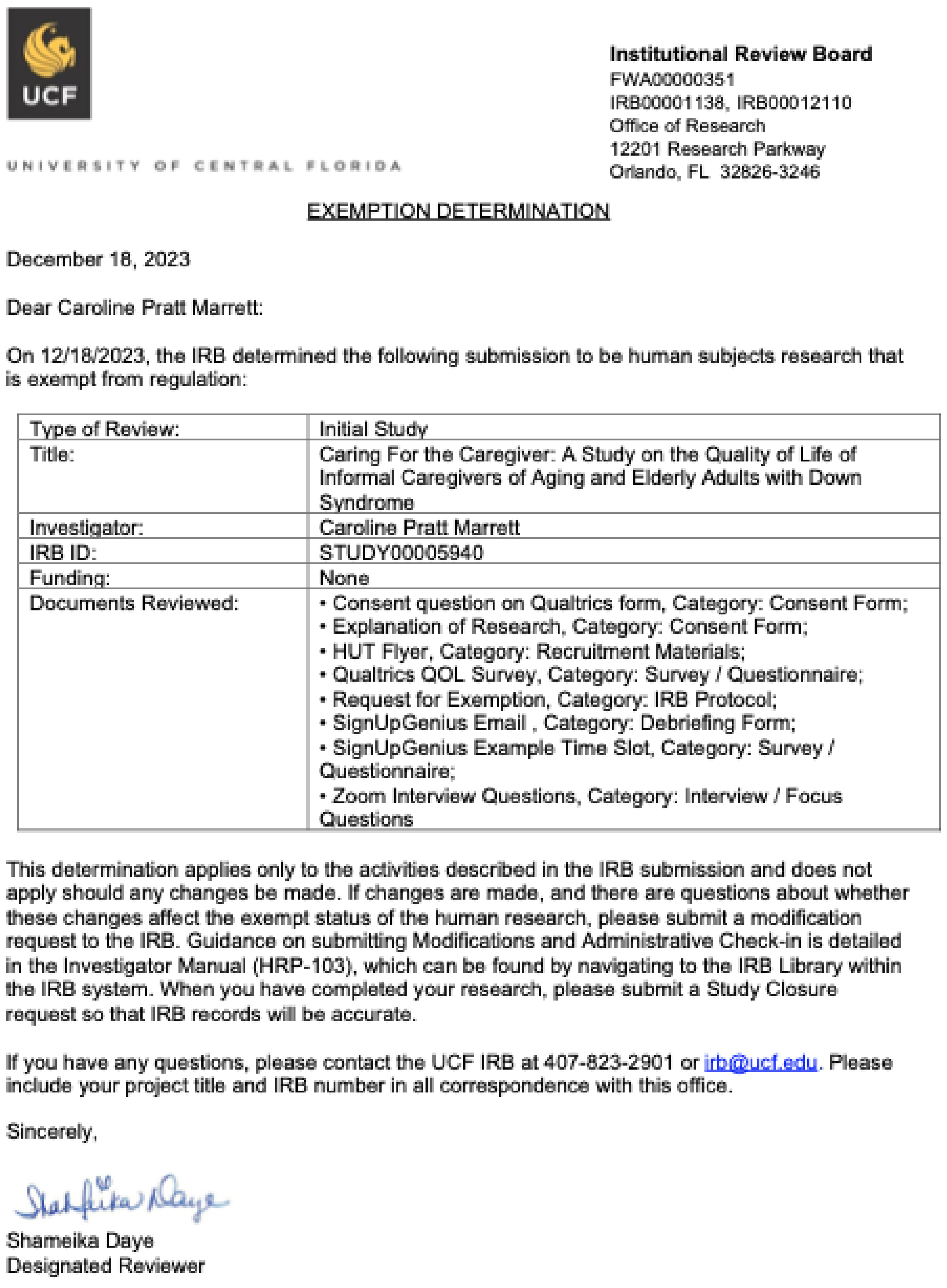
Appendix A: IRB Approval form



UCF
UNIVERSITY OF CENTRAL FLORIDA

Institutional Review Board
FWA00000351
IRB00001138, IRB00012110
Office of Research
12201 Research Parkway
Orlando, FL 32826-3246

EXEMPTION DETERMINATION

December 18, 2023

Dear Caroline Pratt Marrett:

On 12/18/2023, the IRB determined the following submission to be human subjects research that is exempt from regulation:

Type of Review:	Initial Study
Title:	Caring For the Caregiver: A Study on the Quality of Life of Informal Caregivers of Aging and Elderly Adults with Down Syndrome
Investigator:	Caroline Pratt Marrett
IRB ID:	STUDY00005940
Funding:	None
Documents Reviewed:	• Consent question on Qualtrics form, Category: Consent Form; • Explanation of Research, Category: Consent Form; • HUT Flyer, Category: Recruitment Materials; • Qualtrics QOL Survey, Category: Survey / Questionnaire; • Request for Exemption, Category: IRB Protocol; • SignUpGenius Email , Category: Debriefing Form; • SignUpGenius Example Time Slot, Category: Survey / Questionnaire; • Zoom Interview Questions, Category: Interview / Focus Questions

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 changes affect the exempt status of the human research, please submit a modification request to the IRB. Guidance on submitting Modifications and Administrative Check-in is detailed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Shameika Daye
Designated Reviewer

Appendix B: WHO-BREF Qualtics Questionnaire (WHO, 1998)

The WHO-BREF from the World Health Organization (1998) is embedded in this questionnaire, as explained in the Methodology.

Caring for the Caregiver

Start of Block: Explanation of Research

Q60 Explanation of Research
Please download and Read the Explanation of Research in completion.

End of Block: Explanation of Research

Start of Block: Block 7

Q57 I am an informal caregiver of a/an ____________________

○ aging (30-39 years old) adult with Down syndrome (1)

○ elderly (40+) adult with Down syndrome (2)

Q58 I am an informal caregiver of an adult with Down syndrome that was born before July 26, 1990.

○ Yes (1)

○ No (2)

End of Block: Block 7

Start of Block: WHO BREF- Demographic Questions

Q4 ABOUT YOU
Before you begin we would like to ask you to answer a few general questions about yourself: by

circling the correct answer or by filling in the space provided.

Q3 What is your gender?

- ○ Male (1)
- ○ Female (2)

Q9 What is your date of birth?
Day/Month/Year

____

Q10 What is the highest education you recieved?

- ○ None at all (1)
- ○ Primary School (2)
- ○ Secondary School (3)
- ○ Tertiary (4)

Q11 What is your marital status?

- ○ Single (1)
- ○ Maried (2)
- ○ Living as married (3)
- ○ Separated (4)
- ○ Divorced (5)
- ○ Widowed (6)

Q12 Are you currently ill?

- ○ Yes (1)
- ○ No (2)

Q13 If something is wrong with your health what do you think it is?

____

End of Block: WHO BREF- Demographic Questions

Start of Block: Block 5

Q61 You are now entering the WHOQOL- BREF Questionnaire

End of Block: Block 5

Start of Block: WHO-BREF

Q14 Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks, a question might ask:

Do you get the kind of support from others that you need?

1. Not al all
2. Not much
3. Moderately
4. A great deal
5. Completely

You should circle [click] the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

Do you get the kind of support from others that you need?
1. Not al all
2. Not much
3. Moderately
4. A great deal
5. Completely

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks. Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

End of Block: WHO-BREF

Start of Block: THE WHOQOL-BREF

Q16 How would you rate your quality of life?

- ○ 1. Very Poor (1)
- ○ 2. Poor (2)
- ○ 3. Neither poor nor good (3)
- ○ 4. Good (4)
- ○ 5. Very Good (5)

Q17 How satisfied are you with your health?

- ○ 1. Very dissatisfied (1)
- ○ 2. Dissatisfied (2)
- ○ 3. Neither satisfied nor dissatisfied (3)
- ○ 4. Satisfied (4)
- ○ 5. Very satisfied (5)

Q18 The following questions ask about how much you have experienced certain things in the last two weeks.

____

Q19 To what extent do you feel that (physical) pain prevents you from doing what you need to do?

- ○ 1. Not at all (1)
- ○ 2. A little (2)
- ○ 3. A moderate amount (3)
- ○ 4. Very much (4)
- ○ 5. An extreme amount (5)

Q20 How much do you need any medical treatment to function in your daily life?

- ○ 1. Not at all (1)
- ○ 2. A little (2)
- ○ 3. A moderate amount (3)
- ○ Very much (4)
- ○ An extreme amount (5)

Q21 How much do you enjoy life?

○ 1. Not at all (1)

○ 2. A little (2)

○ 3. A moderate amount (3)

○ 4. Very much (4)

○ 5. An extreme amount (5)

Q22 To what extent do you feel your life to be meaningful?

○ 1. Not at all (1)

○ 2. A little (2)

○ 3. A moderate amount (3)

○ 4. Very much (4)

○ 5. An extreme amount (5)

Q23 How well are you able to concentrate?

○ 1. Not at all (1)

○ 2. A little (2)

○ 3. A moderate amount (3)

○ 4. Very well (4)

○ 5. Extremely well (5)

Q24 How safe do you feel in your daily life?

○ 1. Not at all (1)

○ 2. A little (2)

○ 3. A moderate amount (3)

○ 4. Very much (4)

○ 5. Extremly (5)

Q25 How healthy is your physical environment?

○ 1. Not at all (1)

○ 2. A little (2)

○ 3. A moderate amount (3)

○ 4. Very much (4)

○ 5. Extremely (5)

Q26 The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

____

Q28 Do you have enough energy for everyday life?

- ○ 1. Not at all (1)
- ○ 2. A little (2)
- ○ 3. Moderately (3)
- ○ 4. Mostly (4)
- ○ 5. Completely (5)

Q29 Are you able to accept your bodily appearance?

- ○ 1. Not at all (1)
- ○ 2. A little (2)
- ○ 3. Moderately (3)
- ○ 4. Mostly (4)
- ○ 5. Completely (5)

Q30 Have you enough money to meet your needs?

- ○ 1. Not at all (1)
- ○ 2. A little (2)
- ○ 3. Moderately (3)
- ○ 4. Mostly (4)
- ○ 5. Completely (5)

Q31 How available to you is the information that you need in your day-to-day life?

- ○ 1. Not at all (1)
- ○ 2. A little (2)
- ○ 3. Moderately (3)
- ○ 4. Mostly (4)
- ○ 5. Completely (5)

Q32 To what extent do you have the opportunity for leisure activities?

- ○ 1. Not at all (1)
- ○ 2. A little (2)
- ○ 3. Moderately (3)
- ○ 4. Mostly (4)
- ○ 5. Completely (5)

Q33 To what extent do you have the opportunity for leisure activities?

- ○ 1. Very poor (1)
- ○ 2. Poor (2)
- ○ 3. Neither poor nor good (3)
- ○ 4. Good (4)
- ○ 5. Very good (5)

Q34 The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

Q35 How satisfied are you with your sleep?

- ○ 1. Very dissatisfied (1)
- ○ 2. Dissatisfied (2)
- ○ 3. Neither satisfied nor dissatisfied (3)
- ○ 4. Satisfied (4)
- ○ 5. Very staisfied (5)

Q36 How satisfied are you with your ability to perform your daily living activities?

- ○ 1. Very dissatisfied (1)
- ○ 2. Dissatisfied (2)
- ○ 3. Neither satisfied nor dissatisfied (3)
- ○ 4. Satisfied (4)
- ○ 5. Very satisfied (5)
- ○ Somewhat dissatisfied (6)

Q37 How satisfied are you with your capacity for work?

- ○ 1. Very dissatisfied (1)
- ○ 2. Dissatisfied (2)
- ○ 3. Neither satisfied nor dissatisfied (3)
- ○ 4. Satisfied (4)
- ○ 5. Very satisfied (5)

Q38 How satisfied are you with yourself?

○ 1. Very dissatisfied (1)

○ 2. Dissatisfied (2)

○ 3. Neither satisfied nor dissatisfied (3)

○ 4. Satisfied (4)

○ 5. Very satisfied (5)

Q39 How satisfied are you with your personal relationships?

○ 1. Very dissatisfied (1)

○ 2. Dissastified (2)

○ 3. Neither satisfied nor dissatisfied (3)

○ 4. Satisfied (4)

○ 5. Very satisfied (5)

Q40 How satisfied are you with your sex life?

○ 1. Very dissatisfied (1)

○ 2. Dissatisfied (2)

○ 3. Neither satisfied nor dissatisfied (3)

○ 4. Satisfied (4)

○ 5. Very satisfied (5)

Q41 How satisfied are you with the support you get from your friends?

- ○ 1. Very dissatisfied (1)
- ○ 2. Dissatisfied (2)
- ○ 3. Neither satisfied nor dissatisfied (3)
- ○ 4. Satisfied (4)
- ○ 5. Very satisfied (5)

Q42 How satisfied are you with the conditions of your living place?

- ○ 1. Very dissatisfied (1)
- ○ 2. Dissatisfied (2)
- ○ 3. neither satisfied nor dissatisfied (3)
- ○ 4. Satisfied (4)
- ○ 5. Very satisfied (5)

Q43 How satisfied are you with your access to health services?

○ 1. Very dissatisfied (1)

○ 2. Dissatisfied (2)

○ 3. Neither satisfied nor dissatisfied (3)

○ 4. Satisfied (4)

○ Very satified (5)

Q44 How satisfied are you with your transport?

○ 1. Very dissatisfied (1)

○ 2. Dissatisfied (2)

○ 3. Neither satisfied nor dissatisfied (3)

○ 4. Satisfied (4)

○ 5. Very satisfied (5)

Q46 The following question refers to how often you have felt or experienced certain things in the last two weeks.

Q45 How often do you have negative feelings such as blue mood, despair, anxiety, depression?

○ 1. Never (1)

○ 2. Seldom (2)

○ 3. Quite often (3)

○ 4. Very often (4)

○ 5. Always (5)

○ Somewhat negative (6)

Q47 Did someone help you to fill out this form?

____

Q48 How long did it take to fill this form out?

____

Q49 Do you have any comments about the assessment?

____

Q50 THANKS FOR YOUR HELP

End of Block: THE WHOQOL-BREF

Start of Block: Block 6

Q52 You are now exiting the WHOQOL-BREF Questionnaire and entering the optional interview question.

End of Block: Block 6

Start of Block: Interview

Q53 Would you like to participate in an optional Zoom interview scheduled at a later time. In the Zoom interview these two questions will be asked:

1. Would you like to elaborate on any question in the WHOQOL-BREF survey?
2. What resources do you desire to help support you as an informal caregiver?

○ Yes (1)

○ No (2)

Q55 ***ONLY FILL OUT IF YOU WILL DO A ZOOM INTERVIEW***

What is your first name?

____

Q56 ***ONLY FILL OUT IF YOU WILL DO A ZOOM INTERVIEW***

What is you email address?

____

End of Block: Interview