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THE EXPERIENCE OF HAVING PRIMARY CAREGIVING RESPONSIBILITIES FOR
AN
ADULT SIBLING WITH
DOWN SYNDROME
BY
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Dedication

This dissertation is dedicated to people with Down syndrome and the siblings who love and care for them throughout their lives.

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS.....	3
DEDICATION.....	6
ABSTRACT.....	10
I. INTRODUCTION.....	11
Aim of the Study	
Phenomenon of Interest	
Research Question	
Justification for Studying the Phenomenon	
Relevance to the Discipline of Nursing	
II. LITERATURE REVIEW.....	17
Down Syndrome	
Sibling Relationships in Adulthood	
Adult Siblings as Caregivers	
III. METHODOLOGY.....	23
Researcher's Approach and Rationale	
Researcher's Stance	
Assumptions, Biases, and Beliefs in Phenomenology	
Assumptions, Biases and Beliefs on a Personal Level	
Trustworthiness	
Participant Recruitment	
Protection of Human Subjects	
Data Collection	
Data Analysis	
IV. INTRODUCING THE PARTICIPANTS.....	41
Participants' Stories	
V. FINDINGS: GROWING UP TOGETHER.....	45
Noticing the Difference	

Learning to Protect
 What about Me?
 Inside World/Outside World

VI. FINDINGS: BECOMING THE CAREGIVER.....53

Winning the Prize
 “There really was no choice”
 Lack of Planning
 The Transition
 Adjusting to the Role

VII. FINDINGS: BEING THE CAREGIVER.....62

Everyday Life: “A juggling act”
 a. Caregiving Responsibilities
 b. Medical issues
 c. Transportation
 d. Socialization
 e. Dealing with “The System”
 f. Readyng for change: “no change, ever, ever, EVER!”

Making Tough Decisions: “Always Second Guessing”
 “Always on my Mind”
 Benefits: “How I’m Changed”

VIII. FINDINGS: PASSING THE TORCH.....84

“I Know I Need to Plan But...”
 One Day at a Time
 An Uncertain Future

IX. SUMMARY, DISCUSSION, AND IMPLICATIONS.....89

Summary of Findings
 What this Study adds to the Literature
 Prior Studies related to Adult Sibling Caregivers
 Protection from Stigma
 Socialization Skills
 Gender and Caregiving
 Difficulty making Decisions
 Medical Issues
 Future Planning
 Implications for Practice

Nursing
 Social Studies
 Future Research

X. REFLECTIONS.....	113
Participant Reflections	
Thoughts about Mothers	
“Don’t Forget the Siblings!”	
Researcher Reflections	
“Writing It Up”	
The Interview Process	
Final Thoughts	
XI. REFERENCES.....	121
XII. APPENDICES.....	128
A. RECRUITMENT FLYER.....	128
B. TENTATIVE INTERVIEW GUIDE.....	129
C. INFORMED CONSENT FORM.....	130

Abstract

Background: The current generation of adults with Down syndrome is living longer and is likely to outlive their parents. Siblings have been identified as the likely future caregivers for adults with Down syndrome, yet little is known about what the experience is like for those who are currently caring for their siblings. It is necessary to gain an understanding of what the service needs are for this population in order to assist sibling caregivers.

Objectives: To explore and describe the experience of being an adult who is partially or fully involved with primary caregiving responsibilities for a sibling with Down syndrome.

Method: Using a phenomenological approach, interviews were conducted with seven participants who were either partial or full caregivers for their siblings who had Down syndrome. The interviews were audiotaped, transcribed, and analyzed using qualitative techniques. Themes were identified and described and the experiences of the participants were presented in narrative format.

Results: Participants assumed the caregiving responsibilities for their siblings upon the disability or deaths of their parents. The transition was difficult since no prior planning had taken place. Caregiving has taken over every facet of their lives and requires juggling and coordinating on a daily basis.

Conclusions: There is a need to promote communication about future planning among family members to provide for a smooth transition of caregivers upon the disability or death of the parents. Implications for nursing, social services, and future research are addressed.

Key Words: Down syndrome, adults, siblings, caregiving, future planning, phenomenology

Chapter I

INTRODUCTION

Aim of the Study

The aim of this study is to explore and describe the experience of being an adult who is partially or fully involved with primary caregiving responsibilities for a sibling with Down syndrome.

Phenomenon of Interest

Cumming and Schneider (1961) contend that sibling solidarity is second only to the bond between a parent and a child. Sibling relationships are of a longer duration than other family relationships and are bonded not only by genetics, but also by a shared family history. There is evidence to suggest that this bond continues throughout life, persists even after death (Cumming & Schneider, 1961) and is no less enduring when one sibling has a disability (Degeneffe & Burcham, 2008). The normal sibling relationship is identified to be egalitarian, mutual, and reciprocal; however, when one sibling has a disability, an unequal relationship is created, and this unequal distribution of abilities may require a repatterning of the normative sibling connection during the life course (Seltzer, Greenberg, Orsmond, & Lounds, 2005). Nondisabled siblings are a valuable family resource throughout the lifespan because they act as companions and resources to the disabled sibling as well as to the aging parents and will most likely replace the parents as primary caregivers to the disabled sibling in the future (Griffiths & Unger, 1994; Pruchno, Patrick, & Burant, 1996).

The phenomenon of interest is the experience of being an adult who is partially or fully involved with primary caregiving responsibilities for their adult sibling who has Down syndrome. Although there is much discussion in the literature about adult siblings becoming future primary caregivers for siblings with intellectual disabilities (Hodapp, 2007; Hodapp, Glidden, & Kaiser, 2005; Seltzer et al., 2005) little is known about what happens when these siblings do step in and provide primary care to their adult siblings with Down syndrome. This study explores the experience of being a caregiver for an adult sibling with Down syndrome from a phenomenological perspective in order to derive the true essence of the meaning of what it is like to be living this experience. This study will add to the knowledge base about being a sibling caregiver and provide a better understanding of siblings' needs.

Research Question

What is the experience of being partially or fully involved with primary caregiving responsibilities for an adult sibling who has Down syndrome?

Justification for Studying the Phenomenon

Down syndrome is the most common genetic disorder among all the 750-1,000 genetic-chromosomal disorders that cause intellectual disabilities, and has a unique research history that dates back to the 1860s, coinciding with the history of human genetic studies (Patterson & Costa, 2005). Down syndrome occurs in approximately one out of every 692 live births and accounts for approximately 15% of the current population of individuals with intellectual disorders throughout the world (National Down Syndrome Society [NDSS], 2011). According to the NDSS (2011),

approximately 400,000 families in the United States include someone who has Down syndrome as well as one or more typical children. These statistics are generated from state and national membership lists of Down syndrome societies. All families may not be members of these associations, so the actual numbers of affected individuals and families may be much higher. There is no national registry of people with Down syndrome in the United States, so it is difficult to ascertain the exact number of individuals who are siblings of someone with Down syndrome (Skotko, Levine, & Goldstein, 2011).

The incidence of Down syndrome is expected to rise due to the recent societal trend of couples who delay parenting until later in life (NDDS, 2011). The lifespan of individuals with Down syndrome has doubled over the past 30 years (Bittles & Glasson, 2004) and one might expect that the body of knowledge would be rife with literature about these individuals and their families. Unfortunately, this is not the case and large gaps remain in family studies involving Down syndrome (Hodapp, 2007). Research has not kept current with the changes involving these families and there is little information about these families across the lifespan (Hodapp et al., 2005).

Since the passage of the Education for All Handicapped Children's Act of 1975(PL 94-142), children with Down syndrome have received more services and have been much less segregated in educational settings and in everyday life. Individuals with Down syndrome are mainstreamed into regular school classrooms and are living and working out in the community. Less than 20% of individuals with intellectual and developmental disabilities live in out-of-home placements (Stancliffe

& Lakin, 2004) and most remain living at home throughout their entire lives (Davenport & Eidelman, 2008) and rely on family members or community health agencies for support and services (Fisher, 2004).

Due to the generally inadequate system of formal adult care in the United States, adult siblings will be expected by society to fulfill caregiving requirements (Burke, Taylor, Urbano, & Hodapp, 2012; Hodapp et al., 2005). Between 2 and 2.4 million individuals across the U.S. are on waiting lists for supports and services (National Council on Disability, 2005). Since state services vary but are also on the decline, numbers of adults on these waiting lists may double over the next 20-30 years (National Center for Family Support, 2000). Siblings who expect that supports will be available may be dismayed when they find that they will be expected to fulfill more caregiving responsibilities than they had anticipated.

Relevance to Discipline of Nursing

Since the 1960s there has been a movement towards deinstitutionalization in the United States which has led to a steady decline in the availability of residential placements (Fisher, 2004) as well as a decrease in access to appropriately trained, experienced health care professionals who are well-versed in communicating with and treating individuals with intellectual and developmental disorders (Bittles & Glasson, 2004). State systems of adult services are poorly equipped to serve the needs of intellectually disabled adults, making future planning an important issue at the forefront of family services (Heller & Caldwell, 2006; Hodapp, 2007; Thompson, 2001). The majority of adults with Down syndrome will continue to live in the home

setting with family members, leaving caregivers to struggle with trying to figure out what support services are necessary, what services are available, and how to gain access to these services (Van Riper, 2000). Families now provide more life-long supports to children and adults with disabilities than any formal service system (Swenson, 2005). The “indentured servitude of families” (Swenson, p. 365) is the unofficial term for the formal systems that are in place now which rely on the assumption that families will keep providing care for intellectually-disabled adults and siblings will step in to continue to provide the care when the parents are no longer able to do so. Adults with Down syndrome are not only living longer lives, but are also living with concurrent medical and psychological conditions associated with aging that make caregiving more challenging for the family (Hodapp, 2007; Torr, Strydom, Patti, & Jokinen, 2010). It is certain that families will need supportive care from nurses as they attempt to provide care for their family member who has Down syndrome. It is imperative that nurses are aware of the complexities of these family relationships, especially as they pertain to healthcare decision-making and care planning.

Results of the two-year collaborative initiative of the Robert Wood Johnson Foundation (RWJF) and the Institute of Medicine, *The Future of Nursing: Leading Change, Advancing Health* (2010) calls for the transformation of health care delivery in the United States at all levels and specifically calls for advanced practiced nurses (APRNs) in all specialties to deliver more primary care in the community as opposed to specialty care in acute-care settings (IOM, 2010). Since more and more adults with

Down syndrome will be living in the community with families, these nurses will come into contact with families of people with Down syndrome on a regular basis. Nurses can play vital roles in providing care, education, support, and coordination of services to assist with future planning and improve the quality of life for these families (Fisher, 2004).

Chapter II

LITERATURE REVIEW

Down Syndrome

Down syndrome is a genetic disorder that is characterized by having an extra twenty-first chromosome, referred to as Trisomy 21—instead of having 46 total chromosomes, individuals with Down syndrome have 47; a method of preventing this genetic flaw has not been discovered (Patterson & Costa, 2005). Babies born with Down syndrome have diverse physical and cognitive abnormalities associated with the genetic defect (Cohen, 1999). The incidence of live births of infants with Down syndrome declined significantly throughout the 1970s after the introduction of prenatal screening and increased access to medical termination of pregnancies. The incidence has remained consistent or slightly increased in most developing nations during the past 30 years (Bittles & Glasson, 2004).

There has been a marked increase in survival among individuals with Down syndrome with life expectancy increasing by 0.94 life years per calendar year over the past 50 years (Bittles & Glasson, 2004; Hodapp, 2007). The current population of adults with Down syndrome is likely to outlive their parents and require significant care and resources (Bittles & Glasson, 2004; Cuskelly & Gunn, 2003; Dyke, Mulroy, & Leonard, 2009; Hodapp, 2007). As of 2003, approximately 710,000 adults with disabilities lived at home with caregivers aged 60 and over (Braddock, Hemp, & Rizzolo, 2008). This population is anticipated to reach 1.5 million by 2030 (National Center for Family Support, 2000). Siblings have been identified as the most likely

future caregivers for their disabled siblings when parents can no longer function in the role (Cuskelly & Gunn, 2003; Greenberg, Seltzer, Orsmond, & Krauss, 1999; Griffiths & Unger, 1994; Heller & Caldwell, 2006; Heller & Kramer, 2009; Hodapp, 2007; Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997); however, up to this point in time, little is known about the lives of siblings who actually do assume caregiving responsibilities.

Sibling Relationships in Adulthood

There is a dearth of research describing relationships between adults and their siblings with Down syndrome. Only one qualitative study was found that examined an adult sibling relationship when one sibling had Down syndrome—a phenomenological case-study of the life experience of a 39-year-old female sibling of a 35-year old brother who had Down syndrome (Flaton, 2006). This study described the participant's experience throughout her entire life and how this experience shaped her identity, experiences, and life choices. Themes that emerged from this study were self-perception, perception of family members, and a realization of the impact the experience had on her life. The participant provided primary caregiving for her brother with Down syndrome throughout their lives because their mother suffered from various illnesses and eventually died when both siblings were young adults. Due to severe aggression problems in his early teens, her brother had been put into residential care. The sister remained a constant presence in his life and brought him home for weekend visits until he decided he would rather remain at the residential home so he would not miss social activities. She reflected upon how all of her major life choices—

her choice of a profession in Special Education, her choice of a spouse, and her choice to reside in the family home after she married so when her brother came for weekend visits he would be in familiar surroundings—were all made with the welfare of her brother in mind. This sister believed her life has been enriched because of her brother having Down syndrome. Of course being a case study, this information cannot be generalized to other siblings of adults with Down syndrome, but it does provide some insight into what the experience of being an adult sibling caregiver to a sibling with Down syndrome is like from an adult perspective.

Adult Siblings as Caregivers

Siblings of children with mental retardation are socialized in childhood to become caregivers for their disabled siblings (Begun, 1989; Stoneman & Berman, 1993); however there were no studies found that specifically investigate the experience of being an adult sibling caregiver for a sibling with an intellectual disability. One unpublished doctoral dissertation was found that explored the experience of 17 primary caregivers of adults with intellectual disabilities (Morgan, 2010). Among the 17 participants were two adult siblings who were primary caregivers for their siblings. One sibling caregiver was a 60-year-old younger brother of a 63-year-old male sibling with an intellectual disability since birth. The other sibling caregiver was a 63-year-old twin sister of a sister with an intellectual disability acquired at birth due to oxygen deprivation. There were several similarities between these sibling caregivers: both were Irish/Catholic, were the only sibling of the disabled sibling, became schoolteachers, never married, and lost their fathers early in life. Each

felt from an early age that they had to help their mothers with the disabled sibling, since they had “mothers who worried” (p.101) about the responsibilities related to the disabled sibling’s care. They learned from their mothers how to care for the sibling and “...to do whatever was necessary to keep their siblings safe, happy, and healthy” (p. 110). They recalled from their earliest memories spending much of their time with their sibling. The brother remembered always doing things together with his brother and the sister’s parents encouraged her early on in the “guardian” (p.100) role and referred to her as the “lifeguard” (p.100) of her sister. Over time, caretaking activities gradually increased to include partial or full “intimate, personal care” (p.111) and eventually taking over the primary caregiver role from the parent. Both of these caregivers reported that they never married because they knew they would ultimately be the sole caregiver for their sibling when the mothers could no longer perform the role. The brother remembers telling his mother not to worry about what would happen to his brother in the future, “...as long as I’m here, don’t worry about it...I’ll be here” (p.99). Both of these sibling caregivers reported having no relatives to assist with caregiving, or for respite from caregiving duties, and both worried about the future of their siblings if the disabled sibling should outlive them. The brother laments, “...what can I do, except I pray I’ll outlive him...it wouldn’t be the ideal, to send him to a group home...” (p,.99).

Summary

Studies indicate that even in childhood, some siblings express the intention to care for their disabled brothers and sisters when they are adults and their parents are no longer able to care for them (Bigby, 1997; Burke et al., 2012; Greenberg et al., 1999; Griffiths & Unger, 1994; Harland & Cuskelly, 2000; Krauss, Seltzer, Gordon, & Friedman, 1996). Yet even in adulthood as the parents age, there still is a lack of communication about future planning between adult siblings who intend to become caregivers and their parents (Heller & Arnold, 2010; Heller & Caldwell, 2006; Heller & Kramer, 2009; Hodapp et al., 2005). Overall, there is a dearth of literature about sibling relationships in families of people with Down syndrome throughout the lifespan and a need for research that investigates barriers to future planning in these families (Hodapp, 2007; Hodapp et al., 2005).

Adults with Down syndrome are living longer due to advances in medical technology, but are living with the complications of normal aging combined with additional health issues related to having Down syndrome (Bittles & Glasson, 2004; Hodapp, 2007). The majority of these adults are still living at home with their aging parents (Braddock, Hemp, & Rizzolo, 2008) but when their parents eventually become unable to care for them due to disability or death, their adult siblings will be the likely caregivers (Hodapp et al., 2005). At the same time that they are called upon to be caregivers, these siblings may be sandwiched between caring for their aging parents and juggling their own health issues and personal work and family responsibilities (Hodapp, 2007). It is a certainty that these siblings will need some type of assistance

and support in order to fulfill these caregiving roles. In order to provide the necessary resources, it is important to understand what is necessary from the perspectives of these caregivers.

Up to this point in time, there have not been any studies found that have specifically examined what life is like for adults who have assumed caregiving roles for their siblings who have Down syndrome. Little is known about the challenges sibling caregivers face as they assume these caregiving responsibilities (Hodapp, 2007). Learning about the experience of caregiving from the perspectives of those who are doing it will help to better understand what it is like when a sibling must take over for a disabled or deceased parent in the caregiving role. Results of this study can provide information that can be used to enhance the understanding of what this experience is like and help to develop education and resources to make performing this role easier and more fulfilling for these caregivers and ultimately enhance the quality of life for adults with Down syndrome and their families.

Chapter III

METHODOLOGY

Research Approach and Rationale

Phenomenology attempts to describe a phenomenon under study from the perspective of those experiencing it and has been referred to as “the science of examples” (Munhall, 1989, p. 25) because the phenomenological description should contain vivid examples that allow the reader to visualize the in-depth features of the experience as described by the person living it. The aim is for a deeper understanding of the meaning of the human experience (Munhall, 1989). Phenomenology is a natural fit for studying the experience of being an adult sibling caregiver to someone who has Down syndrome because “lived experiences gather hermeneutic significance as we reflectively gather them by giving memory to them...we assign meaning to the phenomena of a lived life” (van Manen, 1990, p.37).

Streubert and Carpenter (2011) identify phenomenology as an appropriate methodological approach when there is inadequate in-depth information known or published about a phenomenon of interest. There has been no published research found to date that explores the phenomenon of having primary caregiving responsibilities for an adult sibling with Down syndrome. The use of descriptive phenomenology in this study elucidates the lived experience of being an adult sibling who is partially or fully responsible for primary caregiving responsibilities for a sibling who has Down syndrome. The information obtained from these siblings

provides nurses and other health providers with an enhanced understanding of the feelings and needs of the adult sibling caregiver population.

Researcher's Stance

Prior to beginning a qualitative study, it is necessary for the researcher to reflect upon and clarify personal biases about the topic. This is most often done by bringing into the forefront of one's consciousness one's own thoughts and ideas by writing them down. This awareness helps to ensure that questions being asked are not leading the participant towards one's own beliefs about the topic. If personal beliefs are not acknowledged, the researcher may lead the participants to validate his or her own ideas about the experience rather than discover the meaning of it for those who are living it. The researcher must always be careful to bracket their thoughts and beliefs throughout the interview process in order to remain open to what they are hearing from the participants. The story should be that of the participants, not of the researcher (Streubert & Carpenter, 2011). I believe this was especially important for me when I began this study.

I am the mother of a 27-year-old daughter with Down syndrome as well as two typical sons, ages 29-years and 24-years. There seems to be an unspoken solidarity between my sons that they will be caring for their sister in some way when their parents can no longer do so, but this subject has not been openly discussed in our family. The literature cites many reasons for the lack of future planning discussions in families, such as fear of mortality, parental fear of burdening the typical siblings, or of being told "no" by the typical siblings, and then having to search for other options, and

lack of resources to assist with future planning. I can only speak for myself when I say that I do not like to speak about what will happen to my daughter when I am no longer alive, because I cannot bear the thought of it. I often say “I cannot close my eyes on this earth and know that she is still here without me.” I feel that no one can love her, care for her, and protect her like I can. Of course the alternative would be for her to die first, and that is unfathomable to me as well.

My next choice of primary caregivers for Christina when my husband and I are no longer here would be her brothers. However, realizing the restrictions I have had on my life because of caring for my daughter, I feel I would not want them to be burdened throughout their lives in the same way. I feel now that she is an adult, I am more restricted than when she was younger. Younger children are restrictive on parents anyway—it is the normal course of life. You have to make sure they are cared for by someone or take them with you everywhere. When they grow up, they are on their own, and the parents then have freedom to reconnect with each other as a couple. My husband and I do not have that now, and probably never will. We are a trio—the *Three Musketeers*—which is fine for us, but will it be for my sons? Should they have to live their lives with this burden when they have their own families? I am not sure I would want this for them, yet I have no idea if they think of their sister as a “burden.” I have not had the courage to ask them.

This being said, the thought of calling my daughter a “burden” does not please me. She has always given all of us immense joy and unconditional love. All of our children have always been close to each other. When our youngest son was born, our

daughter was not yet walking well or talking fluently—she learned everything along with her baby brother. Soon enough the “baby” brother took the lead in all areas of development, but he still allows Christina to call him her “baby brother” and she still thinks *she* is watching *him* when they stay alone together. All three of my children have different personalities, capabilities, and talents. Both of my sons have excelled academically—one with an MFA in English and the other with a BFA in dance. I remember always trying to make sure I did things separately with each of my sons so they knew how precious they were to me individually. Although I encouraged all three of them to care for each other, I was always cognizant about not making the boys feel that Christina received special attention, or that they were any more or less responsible for her than any brothers would be for their sisters. I have always observed them giving and receiving love and affection to and from each other and I hope this will continue throughout their lifetimes. I never want my boys to feel that Christina is a burden to them or to be burdened by the thought of having to care for her in the future.

Both of my boys are now grown and have moved out of our family home. On a daily basis, Christina will freely ask about “big brother” and “little brother”. It is clear that there is still a lot of emotional connection between them and they love, care, and respect each other very much. Although the boys do not care for Christina on a regular basis, they have taken care of her when needed. My husband and I still remain Christina’s primary caregivers. Between the two of us, we juggle her day-to-day caregiving responsibilities, plan her social activities, and coordinate our work schedules so that one of us is available to transport her to and from where she has to

go, and that one of us is home with her at all times. We rely on no outside sources of assistance with caregiving or respite care besides our sons. We have not put any formal plans in place as to what will happen in the future when my husband and I are no longer able to fulfill the responsibilities of primary caregiving.

This is not to say that we do not have informal family discussions about it. My oldest son has made comments that he would be glad to take on the responsibility for handling any of the financial decision-making related to Christina's care in the future. He contends that my younger son has more patience in dealing with the day-to-day issues of caregiving for Christina and admits that he does not have the amount of patience he believes it takes to care for her on a daily basis. My younger son freely accepts this arrangement and talks often about how he wants to be settled into his career so he can have a place where Christina can live with him. Both of them express that they enjoy spending time with Christina. They are aware of Christina's likes and dislikes, many of her rituals and routines, and most of what she needs assistance with on a daily basis. We are all mindful that the caregiving discussions we do have are abstract and while no concrete legal plans have yet been made, at this point we see no urgency in doing so.

When I first started planning this study, I wondered about siblings who *intended* to become caregivers for their brothers and sisters with Down syndrome. I wanted to know how they came to make the decision to become one, and if they made preparations in their lives early on to better prepare them for the role. I knew my sons both intended to care for my daughter, but I didn't see them doing anything different

in their lives at this point to prepare to do so. As the proposal for that study evolved, it became evident that I should really talk to siblings who were already *doing it*. I had no idea what interviews with these brothers and sisters would reveal. I wanted to find out what it was like to transition from the sibling role into the caregiver role, so I could see the future and what it may be like for my sons one day. I knew what it was like for me, the parent, to be the caregiver for my daughter as an adult, but I had many years of caring for her as a child to get acclimated to the role. These siblings may have had to become caregivers suddenly upon the deaths of their parents, or some may not even want to be the caregivers. I knew it might be emotional for me to hear some of the thoughts of these participants about being caregivers. I imagined it would be a transition for both the typical sibling and the sibling who has Down syndrome. I knew how difficult it is to get someone with Down syndrome to accept even minor changes in their lives, so I wanted to see how they adjust to major changes like the loss of their parents and moving to another place to live and having a sibling now become their caregiver. This was uncharted territory for me, and I was expecting I would be taken to places that I was not sure I would want to go, but I knew I had to in order to find out what this experience is like for these siblings, and ultimately, for my own children.

By interviewing brothers and sisters who are already performing primary caregiving responsibilities for their siblings with Down syndrome, I hoped to learn what suggestions for resources they feel are needed to help future sibling caregivers better fulfill these roles. People with Down syndrome are living longer and have medical issues related to normal aging as well as those related to having Down

syndrome. I know that nurses can offer a lot of assistance to family caregivers, but it is impossible to provide resources to help plan for the future if it is not known what resources may be required and by whom. Findings may reveal issues that can enhance nurses' understanding of the needs of siblings who handle these types of caregiving responsibilities. I am hoping that my own experience of caring for my daughter throughout her life will help me to better understand and empathize with the sibling participants as they share their personal experiences with me. Finally, I hope to be able to pay tribute to these siblings by accurately and sensitively portraying their experiences in this study.

Assumptions, Biases, Beliefs in Phenomenology

Van Manen (1990) refers to phenomenology as the study of the *lifeworld* of the person as they experience it, with the aim of gaining a deeper understanding of what the experience is like for an individual (p.9). When entering the *lifeworld* of the participants, the qualitative researcher attempts to do so with a heightened awareness that preconceived notions could hold the potential to bias one's own perspectives. However, being familiar with the phenomenon of interest is not a hindrance as long as acknowledgement of this pre-existing knowledge is made explicit by the researcher (van Manen, 1990). The personal experience can be used as the *ego-logical starting point* for the phenomenological study (van Manen, 1990, p. 54). Van Manen (1990) also describes phenomenology as a "pure description of the lived experience" (p. 25) but notes that both descriptive and interpretive components are included in the term *description*.

Assumptions, Biases, and Beliefs on a Personal Level

I planned this study with the preconceived knowledge of what it is like to be a parent and primary caregiver for an adult child with Down syndrome. I know that for me, living the experience can be at times challenging and stressful. I think it is because it seems outside of the normal cycle of life for a parent to live with, and need to take care of, a child throughout adulthood. It is not what I envisioned my life would be like at this point in time when I first thought about having children in the early days of my marriage. It might also not be what brothers and sisters would have envisioned for themselves in adulthood. I thought that I would find that siblings would be resentful about having to fulfill these roles. I do not believe my own experience would be a disadvantage for me when I conducted the interviews.

According to Giorgi (1985) *bracketing* (p.90) requires the researcher to confront one's own assumptions and beliefs and put them aside in order to be receptive to the thoughts and feelings of others. As I proceeded with the interviews, I made a conscious effort to keep myself open to receive the new thoughts and ideas of the participants (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991; Giorgi, 1985). On a regular basis throughout the progress of the study, I bracketed my assumptions, beliefs, and feelings by writing in my reflective journal, keeping field notes, and writing analytic memos to help me remain open and responsive to what the participants were telling me about their experiences. I was careful to base my responses and inquiries on their thoughts and topics rather than ideas I thought were pertinent to the experience of being a caregiver to an adult who has Down syndrome.

According to Earle (2010) one must keep in constant check because prior knowledge is likely to resurface. I had written a comprehensive researcher's stance in my research proposal and read it over frequently throughout the study period. I was dedicated to keeping a reflective journal updated on a regular basis throughout the progression of the study, making reflective notes and analyzing my own feelings about topics that came up in interviews that were difficult for me to hear about as a parent. One of the first topics five out of the seven participants spoke about was how their mothers were advised to put their sisters into institutions immediately after birth, but they chose to bring them home and raise them the best they could themselves. I thought about how these siblings were now living with the legacy of their mothers' choices. None of the siblings brought up feeling resentful about this. I realized, I *am* one of those mothers. I wondered if they had not shared their true feelings with me because of my status as a mother of a child with Down syndrome who did the same. Did they even feel like this at all? As the interviews proceeded with each participant, there were more such incidents, and I had to make notes in the reflective journal to confront my thoughts and feelings in order to help me keep these feelings in perspective.

Trustworthiness

The concern for trustworthiness should be embedded through every step of the qualitative research activity (Ely et al., 1991). Trustworthiness is established by grounding the research based on high ethical standards, being cognizant of bracketing one's own thoughts and beliefs, and being cautious and conscientious about how the

data is collected and analyzed (Ely et al.,1991). The goal of rigor in a descriptive, phenomenological study is for the researcher to be able to accurately represent the lived experience of the participants (Streubert & Carpenter, 2011). Solicitation for participants in this study focused on finding individuals who were either partial or full primary caregivers for their adult siblings who had Down syndrome and wanted to tell their stories. Lincoln and Guba (1985) developed a set of terms to describe the operational techniques that support the rigor of qualitative research: *credibility*, *transferability*, *dependability* and *confirmability* (p. 328).

Credibility requires activities that increase the probability that credible findings will be produced, such as prolonged engagement with the participant, returning to the participants to verify that the transcribed information is true to their experience, and the use of multiple methods of data collection to confirm findings (Lincoln & Guba, 1985; Streubert & Carpenter, 2011). In this study, three interviews, each lasting between 60-90 minutes, were conducted with each participant. These interviews allowed enough time to develop a trusting relationship that allowed a sharing of personal information, as well as time to conduct informal *member checks* to verify information that was shared during each of the interviews (Lincoln & Guba, 1985, p. 328). The audiotapes were transcribed verbatim by the researcher and in between interviews the transcripts were analyzed to identify topics that warranted clarification or further discussion. The third and final interview allowed participants to reflect on and validate the meaning of the information provided in the two prior interviews. This reflection and validation added to the credibility and trustworthiness of the data.

Transferability is also referred to as *fittingness* and refers to the probability that the study findings have meanings to others in similar situations as well as to other researchers (Lincoln & Guba, 1985; Streubert & Carpenter, 2011). In this study, the life experiences of the participants are written with thick, rich description to allow the reader to have enough information to be able to make connections that could easily be transferred to others in similar situations. It is hoped that some of the findings of this study can be used as an impetus for other researchers to conduct future studies with sibling caregivers. *Confirmability* and *dependability* relate to the process of the study and include the use of an *audit trail*—a tracking of the activities of the researcher over the duration of the study—that helps to illustrate the evidence and thought processes that lead to the conclusions of the researcher (Lincoln & Guba, 1985; Streubert & Carpenter, 2011). Using methods such as the use of a reflective diary of the researcher's experience and field notes and observations of each interview enhances the rigor of the study (Ryan, Coughlan, & Cronin, 2009). The audit trail for this study consisted of field notes about the interactions with the participants, audiotapes of the verbal interviews, transcripts of the written interviews, analytic memos of the analyzed transcripts, and finally a reflective journal that helped me to keep track of the progress of the study and bracket my thoughts and feelings about topics discussed and any biases that I may have had about them.

Solicitation

Participants in qualitative research should be purposefully selected because of their first-hand experience with the phenomenon of interest (Streubert & Carpenter,

2011). Siblings who were either partial or full caregivers for their adult siblings with Down syndrome were recruited via networking through personal and professional contacts of the researcher. Recruitment flyers (Appendix A) were sent out via mail by the researcher to members of the alumnae association of a school for children and adults with intellectual disabilities. A connection was made with the executive director of the ARC of Somerset County, New Jersey, through a friend of a professor at Seton Hall University. This executive director of the ARC agreed to be the gatekeeper for her agency and distributed flyers to eight siblings of clients served by her agency. She also emailed the flyer to executive directors of the ARC in Union and Hunterdon counties in New Jersey. Two caseworkers (one from the northern part of the state and one from the southern part of the state) for Neighbours Inc., a social service agency that provides self-directed, “Real-Life Choices” services to adults with intellectual disabilities, agreed to ask their supervisors if the flyer could be distributed via email to clients. Sibling caregivers who were interested in participating were asked to contact the researcher via email or phone for more information.

The first two participants were referred to me through a former professor at Kean University and the third participant was put in touch with me through a student at Monmouth University. The fourth participant was referred to me by a registered nurse who works with the residents at the Somerset ARC. Her son is also a member of the McAuley School Alumnae Association and she had heard about the study from that route. Two other participants contacted me after receiving the flyer from their Neighbours Inc. caseworkers. I was put in contact with the final participant through a

student at Seton Hall University who had been told about the study by a professor at Seton Hall University.

Once the initial contact was made and verbal consent was obtained, the first appointment was scheduled for the interviews to begin.

Data Collection

The most commonly used data collection strategy in qualitative research is the open-ended interview (Ryan et al., 2009; Sandelowski, 2002). Data collection for this study was accomplished through the use of three 60-90-minute, in-depth, semi-structured interviews with each participant, scheduled approximately one-to-three weeks apart from each other (Seidman, 2006). The three interviews were guided by a tentative interview guide (see Appendix B) of broad, open-ended questions that provided some structure, but enough flexibility to allow for spontaneous issues brought up by the participants to be explored (Ryan et al., 2009; Seidman, 2006; Weiss, 1994).

Informed consent forms (Appendix C) were signed prior to beginning the interview at the first meeting for those participants who were interviewed face-to-face. Three of the participants were interviewed via telephone interviews; one due to participant preference, and the other two due to convenience because of the traveling distance and work scheduling conflicts. For these three participants, consent forms were emailed to the participants and returned signed via email to the researcher prior to beginning the telephone interviews. At the beginning of each telephone interview, the participant was reminded that the telephone conversation was being recorded and

permission was asked to record the conversation. One of these interviews was conducted via Face Time, a software application that permits video phone calls. This method of interviewing proved ideal, as it combines the intimacy of face-to-face conversation with the timely convenience of a phone call, excluding the usual obstacles of geographic distance and work-schedule conflicts.

Historically, the main argument against using telephone interviews in qualitative research has been the risk of loss of visual cues resulting in data loss or distortion. In a review of the literature consisting of eight articles from 1988-2007 comparing the two modalities, Novick (2008) found that there is little evidence to support this suspicion; moreover, participants that interview via telephone may disclose personal information more freely than during the face-to-face mode of interviewing. Several studies note that the final analysis of data did not reveal any noticeable differences in the quality or quantity of information obtained (Chapple, 1999; Fenig, Levav, Kohn, & Yelin, 1993; Sturges & Hanrahan, 2004). That was the case in this study whereby the first three participants were interviewed face-to-face. The fourth participant asked to be interviewed by telephone after cancelling our scheduled face-to-face appointments several times over a six-month period. The duration of his interviews and the quality of the information shared with me was similar to that of the three prior participants who interviewed via the face-to-face mode. Prior to interviewing him, the participant who was interviewed via Face Time, and the one other participant who was interviewed via telephone due to geographical distance, I communicated via several emails and at least one phone call to establish

rapport and gain trust prior to starting the series of interviews (Burke & Miller, 2001). The duration of all of the interviews and the quality of information obtained did not appear to be affected by the method of data collection. Data saturation was achieved after interviewing seven participants.

Each of the three interviews was audio-recorded using a digital recording device. The participants were identified by a pseudonym during the interviews. Each interview was guided with the focus questions planned for that interview and questions were added or modified depending upon the responses of the participants. At the end of each interview, the audiotape was transcribed prior to meeting again for the next interview. In the interim, the transcripts were reviewed to identify potential topics that could be expanded upon or clarified during the next interview. As soon as possible after each interview, I wrote down observational field notes pertaining to the interview and kept a reflective journal about my thoughts related to what happened and what was discussed during each interview. At the completion of the final interviews, I clarified contact information and asked permission to contact the participant when and if I needed further clarification of information at a later date when I was analyzing the data and writing up the study's findings. All of the participants agreed to be contacted again if necessary.

Protection of Human Subjects

Institutional Review Board (IRB) approval from Seton Hall University and Monmouth University were obtained prior to data collection. Participants in the study were given a full explanation as to the nature of the study and the format of the

interview process. Participants were given time to reflect on whether or not they wanted to participate. Written consent was obtained just prior to the first interview for the participants who were being interviewed face-to-face. For those participants who were being interviewed via face-time or telephone, the consent form was reviewed via telephone and signed and returned to me via email prior to the telephone call scheduled for the first interview. The participant was reminded at the start of the phone call that the call was being recorded and permission to record the phone call was asked for and received from the participant. The privacy and confidentiality of the participants were protected by not disclosing their identity in the interviews and using pseudonyms in the interview transcripts, field notes, logs, and reflective journals. Participants were assured that there was no penalty for early withdrawal from the study and that they had the right to refuse to have any data they have previously shared with me withdrawn from the study.

Interview tapes, transcripts, field notes, analytic memos, and reflective notes contain no identifiable features and pseudonyms were used to protect the identity of the participants. Only I had access to the identifying information; however, my Chairperson had access to the interview transcripts and analytic memos. All data, including interview tapes and flash drives containing the transcribed data and field notes are stored securely in a locked file cabinet in my home and will be kept there for a period of at least three years after the conclusion of the study. After that time, all electronic data will then be deleted and/or destroyed. Signed informed consents are being kept separately from the interview data in a locked file cabinet in my home and

will be kept there for a period of at least three years after the conclusion of the study and then shredded and discarded.

Data Analysis

Several methods of analyzing qualitative data have been noted in the literature. All these methods speak about reading the data as a whole, sorting the data, coding the data, separating the codes into categories, and finally identifying subthemes and metathemes that truly describe the experience being investigated in the richest possible way (Ely, Vinz, Downing, & Anzul, 1997; Tesch, 1990; van Manen, 1990).

The audio-taped interviews were transcribed verbatim by the researcher. The accuracy of the transcripts was checked by listening to the taped interviews while reading and rereading through the transcripts. Any errors in the transcription were corrected prior to starting data analysis. Data analysis began as soon as the first interview was transcribed. The transcripts were read and notes were made in the margins of the transcripts considering the simple question suggested by Tesch (1990), “what’s going on here?” I then read through the transcripts again, putting notes in the margins detailing my thoughts about the topics discussed. Any topics that needed further clarification or that I wanted to have expanded upon were asked about during the next interview. This type of analysis continued throughout the data collection period for all interviews with all participants.

I followed the process of interpreting the data that is outlined in Ely et al., (1991). Once I had all the interviews transcribed and reviewed with the initial topics coded in the margins of the transcripts, I wrote analytic memos for each participant

using the topics outlined in the margins as categories in the memos. I rearranged the categories in the interviews to try and link them to each other. I kept in mind Ely's advice of "being open to revising the categories" (Ely et al., 1991, p. 145) until all of the information was categorized. I then looked at all the analytic memos and found ways of linking all of the categories into one large analytic memo that captured the essence of the experience for all of the participants combined. Van Manen (1990) describes a theme as "the experience of meaning, of focus, of point... capable of capturing the phenomenon one tries to understand" (p.87). *Theme analysis* refers to the process of recovering themes from the data that evolve into meanings and imagery representing the phenomenon of interest (p. 78). I then began the search for themes by trying to again collapse these categories by linking them together into an outline. I read through each category to find statements that stood out as being particularly expressive or reflective of what that category contributed to the story. I continued to collapse the categories in the outline, and as I did so, themes began to "lift" from the categories. According to Ely et al. (1997) "all analysis is basically sorting and lifting" (p.162); I continued this sorting and lifting process until all the themes had been isolated into a final outline to guide the writing of the findings of the study.

Chapter IV

INTRODUCING THE PARTICIPANTS

The seven participants in this study are all adult siblings of women with Down syndrome; six of them are female, one is male. Three live with their sisters and are primary caregivers as well as legal guardians. Two of them share caregiving duties with their mother, who works full-time. The remaining two have their sisters in residential care settings, though they retain legal guardianship. Of these latter, one's sister has recently moved into an apartment setting, while the other's sister has been in residential care for over 30 years.

The following are short introductions to the participants in this study. The full stories of all the participants will unfold throughout the chapters of the findings. At the start of the first interview, each participant chose the pseudonyms to be used for themselves and their sisters. They were asked to choose names that were easy for them to remember as we proceeded with the interviews.

“Lynn”, age 25 years old, and “Elizabeth”, age 33 years old, are the sisters of “Neenie” who is 30 years old and has Down syndrome. All of the sisters live at home with their mother and Jasper, the family cat. They have one 28-year-old brother who was recently married and lives nearby. They are a very close-knit family, especially since their father died suddenly nine years ago. Elizabeth and Lynn work part-time and provide partial care and companionship for Neenie while their mother works full-time. Both of them are still single and envision that when they do find someone to

have a committed relationship with, that person must be accepting of Neenie and their role in her life.

“Anne” is the 68-year-old sister of “Carol” who is 67 years old and has Down syndrome. The family in which they grew up consisted of Anne and Carol, who were only thirteen months apart in age, and a younger sister who is currently 62 years old. Anne’s husband died in 1995 of a sudden heart attack at 51 years of age. They had a happy marriage and raised three children together, all of whom are married. Anne has been the legal guardian and primary caregiver for Carol for the past 15 years. Both sisters are finding life a bit more difficult recently due to the onset of chronic health issues. Currently they live together in the neatly kept, ranch-style home where Anne and her husband raised their children.

“Philip” is the 48-year-old brother of “Charlotte” who is 47 years old and has Down syndrome. He and Charlotte are the only two siblings in the family. Their parents divorced when they were both in their late teens and their father remarried. After the divorce, their mother, Philip, and Charlotte continued to live in the family home that Philip resides in today. He applied for legal guardianship of Charlotte shortly after their mother’s death at age 69 in 2000. His father was still alive but did not contest Philip’s plea for guardianship. He is 83 years old now and does not participate in Charlotte’s daily care, nor does he support her in any way financially. They have no extended family to assist with Charlotte’s care. Currently she lives in a supervised apartment, but Philip retains guardianship, and has full authority over all decisions regarding her care. He speaks to her on the phone multiple times daily.

“Marie” is the 52-year-old sister of “Ann” who is 38-years old and has Down syndrome. Marie has three grown children—two sons, one of whom is married and has three children, and the other who is still single—and a daughter who is married with no children. Marie is married to her second husband who is also the father of two grown children. Marie and Ann are members of a large Irish-American family of eleven children, six boys and five girls, and Ann is the youngest. Out of the group, Marie was designated by her parents early in life to be the caregiver for Ann in the future because she has always had an “understanding and an appreciation of her my whole life.” The family has always referred to Ann as “the Prize,” and Marie officially inherited the Prize and became Ann’s legal guardian after both parents passed away in December, 2005. At that time, Ann moved from the family home in Pennsylvania to live with Marie and her husband in southern New Jersey. In addition to being Ann’s primary caregiver, Marie works full-time outside the home.

“Tara” is the 39-year-old sister of “Marie” who is 42 years old and has Down syndrome. Tara’s mother was chronically ill and hospitalized for a period of nine years prior to her death in 2006. During that time, Tara became the legal guardian for Marie along with their father. Tara has been married to her husband for eight years and at this time they have no children, but have been trying to start a family. They share a two-family home with Tara’s father and Marie; Tara and her husband live upstairs, and the father and Marie live downstairs. In addition to being Marie’s primary caregiver, Tara works full-time as an administrative assistant and attends community college part-time in the evenings.

“Kathy” is 10 years older than her sister, “Sally” who has Down syndrome. The two sisters also have two other siblings, one younger sister who lives in New Jersey and is also active in Sally’s life, and a brother who is the oldest sibling in the family and lives in Indiana. Sally was first placed in residential housing about 30 years ago by their mother. Kathy became Sally’s legal guardian at the request of their mother when her health started to fail and she moved into assisted living about nine years ago; she is now deceased. Kathy is married to her high school sweetheart and has two grown sons who no longer live at home. She is still working full-time as a special education teacher for blind and visually impaired middle school students. She and her husband live in Baltimore, Maryland and Sally lives in a group home in New Jersey.

Chapter V

FINDINGS: GROWING UP TOGETHER

All of the participants spoke about their memories of growing up with their sisters, although the amount of time spent talking about these memories varied depending upon the age difference between the siblings and the age of the siblings at the present time. Those participants who are younger now in chronological age and grew up closer in age to their sisters had more vivid memories to share about the feelings they had growing up. Those participants who were older or who had a greater age difference between themselves and the sister with Down syndrome had fewer distinct memories of their early lives together; however, all participants described noticing the difference between their sisters and other children and learning that they needed to protect their sisters from being teased because of these differences. Those participants who were close in age to their sisters also spoke about feeling not as important as their sisters because they did not have disabilities.

Noticing the Difference

All of the participants spoke about realizing that their sisters were *different* from an early age, but not being told directly that they had *Down syndrome*. The condition was never clearly explained to them by their parents. Some recalled memories of realizing something was different about their sisters themselves and “evolving” into realizing what the difference meant as life went on.

Anne, the oldest participant in the study, recalled when she and her sister Carol were in school in the 1950s, Carol was referred to as being “mentally retarded” or

“mentally impaired.” The first time she heard her sister referred to as having Down syndrome was when she applied for legal guardianship of Carol in 1997 and the physician doing the physical examination for the application told her he wrote it down as Carol’s diagnosis on the form. Most of the participants noted that the differences they perceived in their sisters were related to their physical and mental development and one spoke about her sister’s appearance. Kathy was 10 years older than her sister, Sally, and remembers her being “very, very cute” but that she did not reach the developmental milestones like walking and talking when other children her age reached them. Philip remembers his sister was “a little different...but I think sometimes I try to block that out.” Tara and Marie are only 2-1/2 years apart in age and their mother had them involved in many of the same activities because she wanted Marie to grow up having as many of the same experiences in life as Tara. The difference between them was evident to Tara when they were doing school work or activities like sports and Marie could not do the things she could do. Tara asked her mother why Marie seemed to be “stuck” at the same level and not moving along. Her mother explained that Marie was different and had a disability, but never referred to it as Down syndrome. She told her Marie would always be this way and would always need additional help and support.

Learning to Protect

Closely associated with realizing that there was a difference with their sisters was the realization that other people noticed the difference too. The siblings quickly learned that they had to protect their sisters from the taunts of other children and they

feel they still have to protect them now. Anne concluded very early on that “kids are cruel” after trying to convince her classmates in school that it was unkind to make fun of her sister. She remembers feeling upset for her sister and hoping that she did not hear the comments and wanting to protect her from them. Now her sentiments have evolved into “people are cruel” because she says people still stare because they just do not know any better. Philip also believed growing up that “kids are cruel” because he had to defend his sister Charlotte when other children made fun of her on the school bus for the things she said or did. He still has a hard time admitting that he was embarrassed by her behavior and tries to “block out” thoughts about her being “a little different.” Children also taunted other participants’ sisters for no reason, and the typical siblings were determined to protect their sisters from being hurt by these comments. Elizabeth remembers “clear as day” being in first grade and riding home on the school bus. She saw her mother and sister, Neenie, coming to meet her at the bus stop. Neenie was running ahead of her mother and someone on the bus shouted, “oh look at that retard run!” Elizabeth recalls:

I think it was the first time that I realized it that people are going to be mean to her and at that moment it was the older sister—protective—like, what do you meant? She’s not a *retard*, she’s my *sister*. So I think that was really the first moment, it was like that *awareness*, that o.k., not only is she *special*, and I know what she has, I know she has Down’s, and I know that like, I know people are going to be *mean* to her, this is *real*, it’s no longer just the family.

All of the participants had to defend their sisters from teasing, and divert them from noticing the stares of people. “Other people, strangers or whatever, they always, and to this day, they stare because they don’t know, I mean obviously they don’t know, so their natural reaction is to stare at somebody which is pretty rude, but they don’t know” (Tara). Marie occasionally encounters “little minded people” in the small community in which they live and agrees it is hurtful, but “you don’t become sensitive because it’s not often.” As people get to know Ann, they realize she has much to offer, and they are generally so good to her that it touches Marie’s heart. “I think she teaches people a lot. She’s doing a great job educating our little world about the Down’s community.”

What about ME?

Several of the participants remembered feeling that their needs were not as important as that of their sisters and feeling “left out” in some sense because of this. Elizabeth recalled being “dumped off” at babysitters’ homes while Neenie went off to her therapy sessions with their mother. She remembers feeling jealous of Neenie for much of their early lives, but she has never told anyone in her family how she felt. To give an example of how she felt as a child, and why, in one of our interviews Elizabeth described a therapy session where she watched Neenie play in a room through a one-way mirror with her mother and therapists:

I *hated* it, I hated *her* because she always gets to play and everyone’s so interested in *her* playing and nobody wants to see *me* play, and after it was over, they let me go in the room and play, but it was over. So I was very

jealous of her for a very long time growing up because she got to do all these fun things and nobody cared about, *I could stack the blocks too!*

Another feeling expressed by two of the participants who were the lone siblings of sisters with Down syndrome was that the parents tended to focus on the sister with Down syndrome and push them aside and consider their needs afterwards. Philip did more activities with his father because his mother “always paid more attention to Charlotte because she figured I was O.K.” He recalls this made him feel “not as important” as Charlotte. Tara always felt like “second best, second fiddle” like she was “not good enough” because she was the “normal” child and her sister was the one with the disability. Tara tried to excel in both academics and sports to make up for her sister’s disabilities, but she felt that none of the extra effort she put in was ever recognized by her parents or other family members. It has always bothered her, but she has never mentioned it to her father because she feels he has been through enough because of her mother’s chronic illness and death. She has mentioned it to her aunts and uncles and the response she received from them was surprise, “you’re *crazy*, that was *never* the case, how could you feel that way?” She had been plagued by thoughts of this lack of acknowledgement throughout her life, and she only had the courage to mention it to them after seeking therapy for her feelings and coming to terms that her feelings do matter. In congruence with what she had always observed being done in her family, she pushed her feelings to the background because she believed taking care of her sister’s needs was the priority:

I just felt like it was never, like it was never good enough, because it was like it was always about my sister and the fact that she had a disability, and the care always had to be turned towards her and stuff like that...and I guess maybe that's what bothers me is that my feelings were never acknowledged, that it was just pushed aside, so I guess in some sense that's why I pushed it to the side and never dealt with it.

Well-meaning extended family members and friends can make the situation worse by commenting that the sibling is “special” and treating them differently than the other children in the same family. Giving praise that is deemed to be “over and above” what is warranted for similar accomplishments that the other siblings have achieved have caused resentment. As an example, Lynn and Elizabeth and their sister Neenie were all lectors in their church. When they served together, Elizabeth or Lynn would get everything ready for Neenie and all she had to do was read one passage and one psalm. They did all the rest of the work. For a time, after her first few masses, the congregation would give Neenie a standing ovation. After a while, that stopped—much to the relief of her sisters—but the congregation continued to line up to congratulate Neenie at the end of each mass.

Elizabeth thinks it was because they did not expect that she could do *anything*, but neither she nor Lynn ever received any type of praise for what they did during the mass or for helping Neenie complete her responsibilities:

We'd sit there like “are you kidding?” Like she read one stinking thing, one thing, that's it, it was a paragraph and she's *amazing*? And I know it's cause

they didn't expect it of her but it's so...there's *so many things* that would just drive me crazy that ...and so of course, you know by the time we got home we'd be like, 'you're not *that* good, you know, like you're really not, you did nothing.' Just once I'd like—and *you* did a good job! (Elizabeth)

Inside World/Outside World

All of the participants spoke about how *inside* their immediate families their sisters with Down syndrome were not treated any differently than the other siblings in the family by the parents, and definitely not by the other siblings themselves. There was not much thought put into their sisters being different on a daily basis. There were typical sibling rivalries and jealousy spoken about in all of the family relationships. All of the siblings played together, had chores around the house the same as the others did, and were teased and fought with by the other siblings equally. The older siblings in the family played pretend "school" games where they truly were their sister's first teachers. It was here that the sister's learned the alphabet, numbers, colors, and basic drawing and coloring skills. Elizabeth remembers how impressed the teachers were at her sister's kindergarten admission meeting because she knew all of these things, although at the time Elizabeth did not realize why everyone was making such a big deal out of her knowing all of this. Tara said her mother always kept the two of them involved in the same activities because "she always tried to keep us together because we were sisters and she wanted to provide my sister with a *normal* life, the life that I would have, and she always wanted to continue that as we grew up." Marie expressed

the sentiment that best summarized this for all of the participants, “Ann was *our normal*, that was *our life*, there wasn’t a lot of thought put into how she was different.”

When the siblings ventured into the *outside* world to go to school and church and interact with extended family members, only then was the significance of the difference realized. All of the participants talked about “stares” from people outside of the family and when they went out in public. This was particularly evident when they ventured out into the school setting where the disparity of their sisters was made more evident because of the separation that was forced on them. None of the siblings attended school with their sisters; even if they were at the same school, the sister was in special education classes, so they did not see each other during the school day. This being apart during the school day created a chasm for the siblings. Their lives were totally disconnected during school days, and then they came home to the family in the evenings and resumed their “normal” lives. The typical siblings had to learn early in their lives how to navigate between the *inside world* and the *outside world* to sustain their relationships with their sisters. They continue to do so today.

Chapter VI

FINDINGS: BECOMING THE CAREGIVER

Winning the Prize

All of the female participants in the study spoke about how they knew ahead of time that they would be their sister's caregiver in the future. The one male caregiver in the group never envisioned himself in the role, even though he was the only sibling. Philip's thoughts on the topic were, "not at all, I actually thought I was gonna go be on my own somewhere, get married...I didn't really give it any thought because, like hey, I had two parents and that's not my job." When Anne and Carol's mother was dying in the hospital, Anne's husband made her a deathbed promise that they would take care of Carol. Anne believes this made it possible for her mother to "let go—so my mother could, I guess, close her eyes and that was it." Marie was chosen, out of nine other children, by her parents to "inherit" Ann—"the Prize"—and be her caregiver in the future because of an "understanding and an appreciation of her my whole life." Tara is the only sister of Marie, so she knew she would have to take care of her in the future, but she did not think the *future* would be so soon. Kathy was always involved in her younger sister's life and believes her mother asked her to be the guardian because she is a special education teacher and knew a bit about the legal aspects. Whatever the circumstance, once the sibling became the caregiver, adjusting to the new role took time and effort for all of them.

“There really was no choice”

Some of the participants specifically talked about having no choice in the decision to care for their sisters. Two of the participants were the only siblings of their sisters, so they were the likely choices. Philip, the one male participant in the group, expressed his reason for becoming his sister’s caregiver, “I did it because she’s my sister. You know like I couldn’t change the cards I was dealt. If it was the other way around I’d pray Charlotte would do it for me, but it’s not. I can’t change this, so in my mind I just did what I had to do because I thought it was the right thing to do.” Philip already knew his father was not going to take care of his sister because of a letter he had received years prior from his stepmother telling him that neither he nor his sister would ever be welcome to live in their home. He applied for guardianship shortly after his mother died. His father was alive and was sent a letter in case he wanted to contest Philip’s application. Not only did the father not contest the guardianship, he did not even show up in court that day. Philip was awarded guardianship but says, “it just kind of happened, my Mom died and that was that, it wasn’t like I had a real choice.”

Other participants who had other siblings in the family knew they would be the caregiver for different reasons. Anne *always knew* she would be her sister Carol’s caregiver when their parents died because their younger sister “never seemed situated enough” to take care of her. When their mother died, the younger sister was going through a divorce, so “there really was no choice.” Marie knew for a long time that she would be the one to take on the responsibility for Ann’s care. Even though Ann did not get along with Marie’s husband, he never challenged the decision, “he knew

there was never a choice, it wasn't a choice, I didn't have a choice to make, so therefore don't put me in the middle." It seems that these siblings had an innate allegiance to the commitment to become caregivers for their sisters that was non-negotiable and on which they could not renege.

The participants talked about how when they were young they took care of their sisters. They spoke about protecting their sisters from being hurt by teasing from peers in school and from the stares of strangers as they grew older. They all grew up witnessing their mothers advocating for their sisters in the school setting and caring for their sisters throughout their lives. They spoke highly about the care their mothers gave their sisters and credit their mothers with making their sisters so independent and easy to get along with, making their lives as caregivers easier now. Although many of them say they had "no choice" but to become their sisters' caregivers, they actually did have a choice. They could have chosen not to become their sisters' caregivers, but they made the choice to do so. For some reason, whether or not they ever envisioned themselves in that role, when they were called upon to fulfill the responsibilities of primary caregiver for their sisters upon the disability or death of their mothers, all of the participants did so immediately and without reservation.

Lack of Planning

The two participants who are only partial caregivers at this time spoke freely about how they are planning to incorporate the care of their sister into their future lives. In their interviews, although their planning is well-intended, it is spoken about in the abstract. Both of them are still living at home and their mother is still the primary

caregiver. Neither of them is in a serious relationship at this point. A common theme among the participants in the study who are now the primary caregivers is the lack of concrete planning for being the caregiver on the part of the siblings who intended to care throughout their lives. Although in the back of their minds they knew they intended to be the one to care for their sister, they continued to live their own lives and interact with their sisters only on a social basis because their parents were doing the primary caregiving. In some cases, they were living apart for decades, some in other states. When the mother died, they stepped back into the life of their sister to become the caregiver. They knew nothing about the day-to-day activities of being the caregiver.

Only Marie's family actually held regularly scheduled "Ann planning meetings" as part of the regular monthly meetings held for the family business. Although this family held meetings, they really made no plans for Marie and Ann during the meetings, they just designated that Marie would be the sibling who would be the caregiver in the event the parents could not care for Ann any longer. Marie spoke about what went on at those meetings:

We used to talk about it as if it was in planning, as if it wouldn't be real, no one really could imagine my parents not being here, so knowing that I got 'the Prize' was very different than when it actually happened and it was like 'oh no now what?'

Although Marie freely accepted the role, she really had no understanding of what being the primary caregiver meant and regrets she had not used the planning

meeting as an opportunity to ask her parents important information about Ann's day-to-day life:

Ann was part of that discussion and yeah, yeah, yeah, that's my job, I got it, and I welcome it, but I really had no idea what it meant. If I did, I would've been taking copious notes about who was who in her life, because even anything as far as a resource. I was a sister, I didn't do any of the structure, so I didn't know anything about...I just knew her as a sister.

The Transition

For these participants, going through the process of obtaining legal guardianship for their sisters upon the disability or death of their mothers marked the true transition from sibling to primary caregiver, with the legal document and title serving as a concrete sign of passage into this role. Those participants who have legal guardianship have retained it even though their sisters are in residential housing so they can have control over the decisions regarding their sisters' care. However, it was also at this point that many of the participants really acknowledged that they had no idea what to do to move forward in the role. All of the mothers were the primary caregivers for their daughters until they became too ill to do so anymore, and they died without leaving any definitive instructions as to either who would continue to provide the required care, or even what that care consisted of. Three of the participants had been living on their own away from their parents and sisters for decades and had no idea what they needed to do to care for their sisters. The general feeling expressed by all of the participants who are now the primary caregivers was that it was not their role

as siblings to know what had to be done for their sister, so they never really had to pay attention to what was going on when their mothers were alive.

Adjusting to the Role

This change in role from siblings to caregivers required major transitions for both siblings and their families. Most of the participants took these changes in stride and made the necessary adjustments, even though some had to make major life changes. Some of the participants felt the transition more difficult than others. The amount of physical change varied from participant to participant depending on the living conditions of the sister with Down syndrome at the time they became legal guardians. Those participants whose sisters were already living with them or in residential care felt the change of becoming the legal guardian in gradual ways as they started to do more decision-making for their sisters. Two of the participants had to move their sisters into their family homes which required much more of an adjustment for everyone involved.

Anne continued to work full time after moving Carol into her home and paid for a homemaker to come in daily to spend the days with her while Anne was at work. Anne had a fulfilling social life with her co-workers, the flexibility to leave work to take Carol to physician appointments, and extra money to spend on Carol to treat her to beauty salon treatments. Shortly after Carol came to live with her, however, Anne's children convinced her to retire because she had some serious health issues. Anne confesses this is not the retirement she envisioned for herself because she is always with Carol. Since she is no longer working, she cannot afford to pay for help with

Carol and has lost the social contacts she had at work. *Retirement* now means she has 24-hour caregiving responsibilities for Carol. She feels she has more responsibility on her now than ever and that her life is not her own.

Marie had to make the most dramatic changes by moving her sister from the family home in Pennsylvania to live with her in New Jersey, change all the state resources, and find new social services and medical resources for her sister because of the move. Adding to this was the fact that her sister Ann had never really been fond of Marie's husband, and now they were going to be living together, which created a moderate amount of anxiety in Marie. She was committed to making the change work and hold true to her promise to care for her sister. She did not want everything in Ann's life to change, so in order to keep some semblance of routine, Marie arranged for her to keep working in the family business in Pennsylvania two days a week. This means that a rotation of family members take turns picking Ann up in New Jersey on Mondays and she goes up to Pennsylvania to work in the family business on Tuesdays and Wednesdays, then Marie or her husband pick her back up on Wednesday evenings and drive her back home to New Jersey for dinner. This allows Ann to continue to see the siblings that she left in Pennsylvania and work in a familiar environment. It was supposed to be a temporary arrangement, but it was started eight years ago when Ann first moved to live with Marie, and they are still doing the routine. Marie works full-time herself and feels she is lucky she has a job that provides her with the flexibility to care for her sister.

Tara had an easier transition because it happened gradually over the nine years her mother was ill and Tara describes it as moving into a “different phase.” She and her father officially became the co-guardians for Marie, although Tara is the one who coordinates all the resources and does all the planning for Marie’s life. Tara married near the end of her mother’s illness and she and her husband moved into the family home which had been converted into a two-family residence so Tara and her husband could live downstairs and her father and Marie could live upstairs. Tara schedules all of Marie’s activities and leaves a detailed calendar on the refrigerator in her father’s apartment. He makes sure Marie gets ready for the bus on time and out to where she is supposed to be each day. Tara has hired a homemaker to be there in the evenings to help her father with Marie’s care needs. The homemaker is the same woman who worked for them when their mother was ill, so she is like “another mother” to Marie. Tara is grateful for all this assistance because she feels it takes “many hands in the cookie jar” to care for her sister.

There was a gender difference noted in perception about the life changes because of becoming caregivers. Philip did not have any physical changes to coordinate because of his becoming the legal guardian. He remained in the family home where he had been living with his sister and continued doing the things his mother had done for her using the resources already in place set up by the mother. However, he believed his life had changed in “just about every way” since he became Charlotte’s caregiver because being her primary caregiver made dating very difficult. He had not yet married by the time he became Charlotte’s caregiver and every woman

he met asked him what he was going to do with his sister. He feared at the time he would never find a woman who would understand and accept his life situation. Then he found one who he thought was perfect because she had a nephew with “special needs.” They dated for four years and became engaged, and in that time she insisted that Philip put Charlotte into residential care twice; the first group home did not work out, and now she is in supervised apartments. The fiancé has since left him and he is now alone in the family home he once shared with Charlotte.

Chapter VII

FINDINGS: BEING THE CAREGIVER

Everyday Life “A Juggling Act”

Once the participants were settled into their roles, the first thing they had to do was to figure out how to deal with the challenges of everyday life. The siblings of five of the women with Down syndrome who were born between the years of 1945-1974 talked about how their mothers were advised at their sister's births that they should consider putting their newborn babies into institutions, but the mothers made the choice to bring them home instead. All of them seemed proud of their mothers' choice to bring their sisters home and raise them along with the rest of the siblings and spoke positively about their mothers' contributions to their sisters' development. They described their sisters in positive ways, such as, high functioning, easy-going, sociable, and outgoing. They all spoke about how they believe they are “lucky” because they have seen others with Down syndrome who appear much harder to handle. They all credit their mothers with raising their siblings to become as self-sufficient and independent as possible in the early years of their lives so that taking care of them now is less challenging than it might have been.

Caregiving Responsibilities

Those participants who live with and take care of their siblings full-time spoke about how their daily caregiving responsibilities have taken over every facet of their lives. Marie describes the experience as being like “caretaking of a dependent, it's high maintenance, it's a lot of appointments, and it's a lot of juggling and

coordinating.” The level of care varied dependent upon the age and health needs of their sisters and had to be incorporated into their own daily lives. Most of the women with Down syndrome are able to perform simple activities of daily living like bathing and dressing themselves and making light meals or snacks without the use of the oven or microwave. They know the basic rules of safety such as not opening the door of the home for strangers and calling 911 for emergencies. Although the participants describe their sisters as being “high functioning,” none of them feel it is safe to leave their sisters alone in the home for long periods of time, meaning that arrangements must be made so someone is always home with them.

For the two participants who are partial caregivers (Lynn & Elizabeth) the day-to-day caregiving responsibilities are slightly different, but highly comparable to those of the primary caregivers. They live with their sister Neenie and since each of them works only part-time, they are home during the day to stay with Neenie and help with her care needs. They provide both emotional support and social support to their sister and also perform tasks like taking Neenie to doctor appointments because their mother works full-time during the day. There are times when they have to talk to Neenie about sensitive topics such as the need to take a shower if she’s gone too long without one. When their mother returned to work last year after Neenie’s brain surgery, both sisters helped take care of her during her convalescence. Over the years, Neenie has lost contact with the friends she went to school with because they lived a distance away from their home. Lynn takes it upon herself to make sure that Neenie has activities to keep her busy by including her in her own social life. She takes Neenie on

errands with her to get her out of the house and the two of them do the weekly food shopping together. Neenie is also involved in some formal evening social programs, so both Lynn and Elizabeth make sure she has transportation to those events. Lynn admits that sometimes she feels that she cannot fully live her own life because she always thinks about what Neenie is doing; “it’s not fair that I have to accommodate for her all the time, sometimes I just want to go and hang out with my friends without feeling guilty that my sister is sitting home doing nothing.” While it appears that Neenie is comfortable at home doing her normal routine of “playing with her cards, watching her DVDs, and sitting in the *same* chair at the *same* table” Lynn does not understand how Neenie can be happy doing that every day, so she tries to take her out socially with her every chance she gets and when Neenie agrees to go.

Medical Issues

The participants feel that taking care of their sisters’ medical care is a huge responsibility. All of the women with Down syndrome were living with some type of chronic health issues, the most common of which were hypothyroidism and obesity. Other chronic issues were insulin-dependent diabetes, peripheral neuropathy, and Alzheimer’s disease. The medical disorders require consistent medical oversight to ensure that the conditions are not worsening, and if medications are being given, that they are at the proper dosage. Trying to control the obesity condition is a constant battle for the caregivers, since it is hard to convince their sisters to eat correctly and exercise regularly. One family has had success with Weight Watchers and their sister

lost 60 lbs., but was only after “scaring her” about what could happen to her if she did not lose weight.

The caregivers who live with their sisters are responsible for making the appointments and transporting them to and from these appointments. They must be at the appointments to speak with the healthcare providers and plan all of the medical care. They must make medical decisions for their sisters, manage their medications and complete the medication refill paperwork with Medicare. When possible, the participants maintained the same type of medical routine that was established by their mothers. Tara takes her sister Marie to the same primary care physician and dentist that her mother did, but has not taken her for a gynecological exam because “my mom never did, so I kind of never continued it, or started up.” Tara makes the appointments, but her father takes Marie to them during the week because she works.

When Anne first took over Carol’s care, she took her for a full medical exam to find out what medical issues Carol had because she had no idea when her mother had last taken Carol to a physician. Carol has developed type II diabetes and is now insulin dependent and Anne must oversee her blood sugar readings and insulin administration. Carol has also developed peripheral neuropathy and has become very unsteady on her feet, so Anne does not leave her alone at all anymore because she’s afraid of her falling. Anne has had to retire because of her own cardiac and cancer-related health issues and now “there are days when I just can’t take care of myself that I feel so tired, so that’s where it’s hard for me too.”

Marie had to establish an entirely new medical routine for her sister, Ann, because she moved her from Pennsylvania to New Jersey, and also because her mother passed away without leaving much of a medical history for her to follow up on with Ann. She chose to take Ann out to a major center for the care of children and adults with Down syndrome in Baltimore, Maryland to have her examined from “head to toe” and find out exactly what resources Ann would need to get and stay healthy. She found out her sister had several medical and mental health issues that needed to be addressed and she had to follow up with medical professionals in her home state. Marie estimates “I think it probably took a good 3-4 years to get a good core of support people that now I know where to go to when I have an issue.”

A common problem mentioned by the caregivers is that their sisters rarely tell them when they are feeling sick or in pain. Some of the participants say their sisters seem to have a very high tolerance for pain because they never complain. They believe that because they know their sisters so well, they have developed a 6th sense about knowing when something is wrong with them. Anne believed at the time of our interviews that there was something wrong with Carol because there was a “spot” on her femur that her physicians were watching to see if it develops into anything. She was going to be asking her physician to do a “body scan” on Carol to check for cancer because she was convinced that Carol was not acting like herself and was much more tired than usual. Marie equates being Ann’s caregiver during times of illness to being like a “detective” trying to figure out what is wrong with her because the only information she will contribute is “I feel fine,” which are apparently her code words

for, “I am sick.” Tara spoke about having to spend last Thanksgiving in isolation away from the rest of the family because Marie was diagnosed with “walking pneumonia.” Tara says Marie had not even shown any signs of severe illness except for a slight cold and cough that had resolved with over-the-counter products. When Marie suddenly lost her balance, Tara felt something must be seriously wrong and had her father take her to the physician the next day and she was diagnosed with the pneumonia.

Those caregivers who have retained legal guardianship of sisters who live in residential housing do not have to accompany their sisters to medical appointments, but are consulted about what goes on during the appointments and about any changes that occur with their care. Kathy tries to visit her sister Sally as much as possible because about a year ago she was diagnosed with Alzheimer’s disease. Kathy thinks that Sally knows something is wrong with her although she is not sure what. The first signs of the disease were problems with her memory. Kathy is fearful of the future and what medical decisions she will have to make for her sister because of the progressive nature of Alzheimer’s disease. When his sister was still living at home, Philip took care of all of Charlotte’s medical needs including taking her to her gynecological examinations and “talking about all that woman stuff that guys don’t usually want to hear about or know about, a lot of different things, but I knew if I didn’t do it, it wasn’t gonna get done.” Charlotte has recently been placed in a supervised apartment, but she has some incontinence and obesity issues, so Philip is anticipating that he will have to make decisions about putting her on a low-calorie diet and increasing her level

of care because of these medical needs. Philip recalls his ex-fiancé warned him, “Philip, you’ll never be free of this...this will always be your responsibility.”

Transportation

Transportation was an issue for all of the participants because they had to arrange their schedules or ask their spouses or other family members for assistance with transportation in order to accommodate their sisters’ schedules. None of the women with Down syndrome can drive or use public transportation independently, so they rely on their caregivers to provide transportation to anywhere they need to go. Tara has transportation arranged for Marie to get back and forth to her day program and to some social programs, but says it is hard to find safe, reliable transportation services for evening social events. She juggles her own schedule and gives up her own social engagements to drive or pick up Marie as opposed to risking her being put in an unsafe situation. She does admit though that at times it is an inconvenience to her if she is in the middle of something herself:

I have to stop what I’m doing or not go to an actual event so I can pick her up, and again it’s my fault because I involve her in these activities, but sometimes last minute things come up at work or something and people want to go out and I can’t because I have to be home (Tara).

Socialization

Closely tied in with the transportation needs are the social lives of the women with Down syndrome. Many of them went to schools that were far from their homes and have lost touch with friends because of distance. Some are at the age now where

they have lost touch with friendships they had in Special Olympics or other social clubs because of the passage of time. They also may have lost touch with other friends because of moving from where they used to live. If they do still have contact with these friends, they have to be transported to see them, and the distance prohibits their caregivers from doing so on a regular basis. There are local social organizations that sponsor programs for adults with intellectual disabilities, but some of the participants feel that their sisters do not see themselves as fitting in with other adults with intellectual disabilities, so they do not want to attend any social activities organized by these groups. However, they do not fit in with typical adults their age either, so they are socially isolated. No matter what the reason, a common problem mentioned by the participants was the lack of friends for their sisters which in turn affected them:

She really doesn't have anybody, which, sometimes I do forget. I'm sitting there—do something—but she doesn't have anyone to do it with. I can call up my friends—let's go do something—and it's easy, she can't do that. She doesn't have anyone that she can go walk to someone's house and go hang out [with] for the day, so she does rely a lot on us, and that's another reason why I try and do so much for her because I don't want her sitting in that chair (Lynn).

In most cases, because their sisters did not have their own social contacts, the caregivers felt obligated to incorporate them into their social circles by taking them out with them wherever they went or just staying home to avoid leaving their sisters. This meant that the participants had restricted social lives, causing them to feel socially isolated. Anne said her sister Carol “never had any friends” growing up and

basically only went places with their parents all her life and socialized with them. Carol does not like to be left at her daughter's home when Anne goes out to socialize with her friends. Carol will say, "that's not right!" So Anne will often just stay home to avoid hurting Carol's feelings, "sometimes when I see my friends going here and there and the other where, it does bother me, but what are you gonna do? She's my sister."

Dealing with "The System"

All of the women with Down syndrome are recipients of some type of formal government services such as Social Security, Medicare and/or Medicaid. Once the participants became legal guardians of their sisters, they had to submit proof of guardianship to these entities to act on their sister's behalf. This process went more smoothly for some than others. The fortunate participants had services already set firmly in place by their mothers and they just had to submit the guardianship papers. For two of the participants, the process did not go smoothly and they are still trying to work out errors in "the system" even years later. This has resulted in many visits to state agencies and much frustration on the part of two of the participants.

In Marie's case, her sister was under her father's medical insurance as a dependent when he died. Marie kept Ann under COBRA insurance for 36 months while she coordinated all of the other aspects of the move and getting Ann acclimated to her new environment. When Marie found out she was supposed to apply for Medicare for Ann, she was accepted as a "late entrant" because she was supposed to apply by 18 months after the death of the father, just like a spouse would have to do.

Now Ann gets a \$75 penalty fee deducted from her social security check each month because of her late entry into Medicare. Marie appealed the decision but lost and was told she could get a lawyer and fight it further, but she would have to use her own funds to do this. The reason Marie had not enrolled Ann is because she did not know she was supposed to do it, “there is no guidebook for siblings about what to do.” She is also trying to get Ann Medicaid-eligible because of a new ruling that says Ann must be Medicaid-eligible in order to continue to participate in services offered by the Division of Developmental Disabilities (DDD), which offers social programs for adults with intellectual disabilities, such as the Real Life Choice program that she had already been participating in. Marie waited an hour and a half one day for a ten-minute interview and to hand in a large packet of her bank statements and other qualifying materials to her local social security office. After not hearing from them for several weeks she called multiple times and finally was told “somebody probably trashed” the entire packet and could she please bring in another one. This resulted in another hour long wait during Marie’s work day. Marie had these thoughts:

I don’t know how it can be streamlined, but it’s so frustrating. Should there be any question a Down syndrome, a 38-year old Down syndrome is eligible, she’s under the DDD umbrella, they have everything, that makes me crazy, it’s not logical, it’s not easy, but it’s necessary, so that type of stuff sends me over the edge a lot more than any of the caregiving frivolities.

Anne has had different experiences but the same feelings of frustration. When her father died, her sister Carol was under his social security number as an “adult

dependent child.” She never had her own social security number. Because she is his dependent and not receiving her own social security benefits, she makes \$300 over the monthly limit to qualify for Medicaid and the services provided by the DDD. This is a disadvantage to Carol and Anne has tried to protest this with the social security administration but her appeal has been denied because she was told there is no such category as “adult dependent child.” She has been told she can get a lawyer and “fight it” but she feels she does not have the mental and physical strength or the personal funds to do so at this point in her life. Anne also manages a “special needs trust” for Carol which is a large responsibility and causes her much stress because she must account for the money used from the trust, “I have to show where every dime of that money has gone and if it’s not in there on March 31st they can put a thing out for my arrest.” She also has to pay for the trust to be bonded every September “so I don’t abscond with it.” So far Anne has had to use funds from this trust for special shoes, dentures, and medical supplies for Carol, and at the time of our interviews, she was contemplating using the funds to pre-pay for Carol’s funeral expenses in case she dies first, so her children will not have to be burdened with this.

Readying for Change: “No change, ever, ever, EVER!”

All of the participants spoke about how their sisters are resistant to change and how much they value their everyday routines. As caregivers, they have all learned that in order to work change into their sister’s lives, it must be gradually introduced, and the change must seem like their own idea. When this has to be done on a daily basis for minor changes in routine it can be annoying, but when it must be done for major

life changes such as those that were being contemplated by some of the participants at the time of our interviews, it seems to require strategic planning—and patience.

Lynn complained that Neenie's adherence to her own routine and rituals and her resistance to change are things that annoy her most about her sister. "She's so BORING, she's the most boring person I've met in my entire life, she LOVES her life and that's great, I look at her and I'm like I don't know how you live like this." At the time of our interviews, Lynn was seeking full-time employment and was planning on moving out of the family home to live with her girlfriends. Neenie did not take it well when any of her siblings moved out of the family home to attend college or when their brother moved out after getting married last year, and she's not likely to take this change well either. Lynn has been prepping her already by telling her she will have her own room now, control over the television, and other "perks", but so far she has not succeeded in getting Neenie to think it is a good idea.

The participants spoke about how they must balance doing the things they want to do for themselves along with the things they must do for their sisters. They also cannot help but worry about how any change is going to affect their sisters. Marie stressed about how her sister Ann did not like change, "ever, ever, ever, EVER!" and said that the two of them argue over even changing the bedspread on Ann's bed or the carpet in her room. At the time of our last interview, Marie and her husband had just purchased a retirement home in Florida and were trying to slowly coax Ann into agreeing that she wanted to go and stay there too. "I'm working on Ann now, look we took some pictures, you've got a really nice room, you'll be able to walk to some

shops, and she's like, 'I'm not ready for that,' and I was like, I know, but by the time the winter comes you will be." Anne is planning on selling the small ranch house to move to a senior citizen development with Carol. This is a sad time for her because it is the house where she raised her children and the last thing she owned together with her husband. Anne just feels that the ranch is too much for her to handle now that her health is not good and she has to go up and down the stairs to do her laundry. She feels Carol will be alright with the change as long as she is with Anne. Tara and her husband have been trying to have a baby, and Marie is excited to become an aunt and help Tara with the baby. Tara is worried about how she will manage taking care of Marie along with taking care of the baby, but her husband has reassured her that they will manage and they cannot put off doing the things they want to do in their lives because of being Marie's caregivers.

Even the two participants who have their sisters in residential care are undergoing the uncertainty of change at this point. Philip wonders if he made the right decision putting Charlotte in the apartment at the insistence of his fiancé. He and Charlotte had talked about her moving out one day, but she did not agree with the move at this point in time, so maybe this was not the right time to do it. She was in the apartment only about a month at the time of our last interview, so he was still not sure how she was adjusting. Kathy is worried that the Alzheimer's disease will progress and she will be asked to take Sally out of the home. She does not have the resources to care for Sally in her home and the only other choice would be a nursing home that accepts Medicaid.

Making Tough Decisions “Always Second Guessing”

A large responsibility of being the legal guardian is making difficult decisions for their sisters, having to live with the consequences, and “always second guessing” themselves. The participants spoke about their personal struggles with trying to balance doing what is right for their sisters while recognizing that their sisters are adults and really should have some say in decisions concerning their lives. Keeping this in mind is difficult because their sisters often act like children. Marie tried to describe it, “in my mind Ann is 12 years old most of the time, a pre-teen that is fun to have around, makes you laugh, a little bit sneaky, thinks she knows it all, because I can equate that to my children growing up and that’s kind of where I place her,” but when it comes to making decisions concerning Ann’s life, “the worst is my own confidence, it’s a balancing act, do you force her to do things, even though she likes it when you do, or do you respect her decision making?” Marie raised three children and never felt she had the same trouble making decisions as a parent as she does when making decisions for Ann, “I’m always on the fence.”

Anne feels that this is a major reason that caregiving for Carol is so “sad and stressful” for her at times is because, “you have to make major life decisions and you second guess yourself...then you think to yourself am I doing the right thing...what else could you possibly do that could help this person?” Anne also believes that society does more for other vulnerable populations such as the elderly and indigent than for people with mental handicaps, and that frustrates her, “every time you take two steps forward somebody’s telling you that you have to take two steps back which

isn't good either." She spends a lot of time and energy advocating to get the services that her sister needs and feels that she gets nowhere for her efforts.

Philip also mentioned second guessing himself over the decision to put his sister in residential housing at the request of his fiancé. After he had secured an apartment for Charlotte, and even before he moved her in, his fiancé broke up with him. Now Philip is alone in the house and Charlotte is having trouble adjusting to her new home. At the time of our final interview he was seriously considering whether he made the right decision moving Charlotte out of the family home and into the apartment:

I'm supposed to be guardian and I'm a mess, I let a woman change everything about my life, my house, my home, my sister, the whole nine yards, and what kind of mistake did I make, did I do the right thing? To this day I don't know. You know what I mean?—like um, I really don't know (Philip).

The participants also struggle with reminding themselves to respect their sisters and not to treat them like children. Lynn talks about how her sister, Neenie, hates being treated like a child. When they have arguments, Neenie reminds Lynn that she is Lynn's older sister, and an adult, and she does not like being treated differently. Lynn's perspective is:

I know it's true, we do kind of treat her like a little kid, we don't really, I guess, give her the respect of treating her [like] her age and she hates it, she HATES it, and it's not that we do it on purpose, but that is definitely her big

fight and that's what she gets upset most about is, 'I'm an adult, treat me like an adult' but sometimes she acts like a child so I'll treat her like a child (Lynn).

“Always on my Mind”

All of the participants had some negative things to say about being both partial and full caregivers for their sisters. Overall the most frequently voiced complaint was that it puts limitations on their lives, most often because of the consideration that their sisters always require someone to be there with them. As Marie pointed out, unlike raising children, being the caregiver for a sibling with a disability is not a situation that has a predicted end. This is a lifelong commitment. Several of the participants are at points in their lives where they are making life changes, and because their sisters are part of their lives, they will be making the changes with them. Both their everyday life and long-term plans are restricted in some sense because of their considerations for the needs of their sisters.

Lynn feels her life would be “a little easier” if Neenie did not have Down syndrome. She feels that she is “always thinking of two, not one” whenever she makes any plans and that Neenie is *always* on her mind. She worries so much about Neenie that it holds her back from doing things and feels “it’s a little sad that my life couldn’t be lived to the fullest.” Her older sister, Elizabeth, has friends that have siblings that are close in age and compares their relationship with hers and Neenie’s and wishes things could have been different for them:

I hate that the life that I could have had doesn't exist, I *hate* that, it's always that *what if?* What if she was just like every other person, every other sibling,

we'd have the same interests, we'd have maybe the same friends, we'd hang out, we'd go out together, share clothes, all these things I see people are able to do that I'm not able to do, so I hate that, I hate that life that could have been was never given the chance (Elizabeth).

Anne feels that she has limited freedom to do the things she wants to do because of taking care of Carol. Anne's children are planning a trip to Disneyworld, which Anne thinks would be "the highlight of my life." They want her to join them, but she has no one to take care of Carol. Anne says, "you say to yourself sometimes, why me?" Marie had the same feelings, "it limits, it limits." This is the time in Marie's life when she and her husband should be free to go and do whatever they want, their children are grown and are no longer living at home, but instead they have Ann. She feels she has given up her freedom, but feels bad about complaining, "that sounds terrible, doesn't it?" Tara feels limited in the sense that she cannot just get up and leave when she wants to go off and do something. She always has Marie in the back of her mind, when she makes plans. If Tara wants to go out alone with her husband she feels guilty unless Marie is occupied doing something. She has to make sure if she is going somewhere that she has something planned for Marie or she has care arranged for Marie. If she was not Marie's caregiver, she and her husband would have a much more spontaneous lifestyle.

Besides the limitations, Marie thinks the hardest thing about being the caregiver is, "the time commitment is enormous!" Marie feels it is impossible to fulfill the responsibilities of the role unless you have a job that affords you flexibility or you

have a personal assistant. She pointed out that taking care of her sister is similar to raising children, but, “if you have a toddler, those things change, but this will never change, it’s a constant, in fact, it could get worse.” She is starting to see signs of aging in her sister and she believes Ann is going through menopause and is starting to become forgetful. As her needs change, it frightens Marie that she could become even more dependent.

Benefits: “How I’m Changed”

Despite all of the negative aspects of being caregivers for their sisters, the participants also spoke about the positive things they get in return from their sisters. There was quite an array of emotions as the participants spoke about their sisters and how their smiles can light up the room “like Christmas morning.” They spoke about the “unconditional love and loyalty” they have always received from their sisters even when they do not believe they are deserving of it. One of the participants says she knows her sister appreciates all she does for her because she spontaneously says, “I’m happy, I’m happy” for seemingly no reason and her happiness “rubs off on people.” She knows what she does is appreciated, and that is all she needs as “payment” for the trouble she goes through juggling her schedule for her sister. Marie feels that she did truly inherit “the Prize” when Ann came to live with her because she is a blessing. “I believe Ann is a gift to my life and to our family. She has an incredible sensitivity that blows my mind, a perception that I think operates above the rest of us. I’m in awe a lot of times just interacting with her and it, *I get it*. It warms my heart when other people have that moment where *they get it*.”

Anne insisted there was “nothing, nothing” positive about the caregiving experience, even when prompted several times during one of her interviews. On that particular day, I was to meet her sister after the interview. When the time came for me to meet Carol, the change in the Anne’s face, voice, and demeanor was clearly evident as she proudly introduced her sister to me. She told me about how the two of them keep each other company and talk over dinner in the evening about the “old times” when her sister was still living at home with their parents and she was off and married. Her sister fills her in on family history she missed. She then admitted, with tears in her eyes, that if anything happened to her sister, “it would be like losing my right arm.”

The participants feel that growing up with their sisters and witnessing their struggles and the prejudices against them has made them more empathetic and understanding of people with all types of disabilities. They have learned valuable life lessons like how to take life more slowly, how to look for humor in situations, how not to take life so seriously or get excited about things, and the value and necessity of patience. Those participants who had raised families and had grandchildren spoke about how over the years they had included their sisters in their children’s and grandchildren’s lives and feel they have been enriched by interacting with their aunts. They feel their children and grandchildren are much more empathetic as well. They spoke about how amazing and bittersweet it was to watch their children and grandchildren grow up and progress from being playmates, to peers, and then to surpass their aunts in development, only to realize as they grew up what valuable life lessons they had learned from their interactions. All of them have “an appreciation” of

their aunts and of people with disabilities in general. Anne's children are already pledging to care for her sister, Carol, after Anne dies. Anne spoke at length about the ways her children and grandchildren have always included her sister in their lives and have grown up with the same protective instincts as she did when she was younger because of witnessing the stares and hearing the comments of strangers. In ways, caring for the person with Down syndrome is a "family affair" and in this family, the caring seems to be passed down through the generations:

My kids always say to me, 'Mom what did she ever do to have all this sickness come to her? She never did anything to anybody.' They feel as though she was given a raw deal in life because first she was—the way she was born—and then the way things, she was when she was growing up, and now all her health issues. They just feel that she, it's been hard for her, and I think the same thing, she never did anything to deserve all this (Anne).

Some participants told about how their sisters have brought joy and humor into their lives just by being themselves. Lynn said that her sister Neenie gets herself into comical situations just because of the "innocence of her" and says, "it's been fun growing up with her, fun and then not so fun at times too, but yeah, she's too funny, too, too funny." Marie says a big plus about having Ann in her life is that she makes her laugh. Marie told a comical story about Ann sneaking out of the house with an inappropriate outfit peeking out from underneath other more appropriate wear. One evening Ann was headed to a local bar to hear music play. Marie noticed a gold metallic belt hanging out from underneath a huge sweatshirt. Apparently Ann had

some sort of skimpy outfit on under the sweatshirt. When Marie asked her what was hanging from her shirt she said flatly, “nothing.” Another time, Marie was taking a stroll with her grandchildren in their small shore town and saw Ann coming down the street in very tight, short spandex shorts and a very short cropped top. Marie did not know where to run. Ann is “very obese” but when Marie pressures her about losing weight, Ann remarks, “I don’t want to lose weight and look like Twiggy!” Marie laughs when she tells these stories. Marie said Ann has a very healthy self-image and does not seem to understand that there is “about 200 lbs. between her and Twiggy!” Marie has also learned the value of acceptance, tolerance, and “picking your battles” and takes life a little slower now than she did before Ann came to live with her because she has no choice, but she does not consider this a bad thing.

On a more serious note, Tara feels that she has been able to come to terms with the anger she felt about her mother’s illness by becoming Marie’s caregiver. During her adolescence, Tara went through a very turbulent time, and she and her mother were not close. They were just starting to rekindle their relationship when her mother became ill. Tara had a very hard time dealing with the anger she felt over her mother’s illness and subsequent death. Tara even admitted being angry at God for allowing it to happen. She believes that somewhere out there her mother and grandmother are able to see what a good job she has done with her sister and that her sister is happy and thriving under her care:

I know overall she’s happy just because she tells me and I can see it, I just wish my Mom...I wish my Mom and my grandmother could see it, that I

changed my life, and that I stepped up, and that, she's doing good, they didn't get a chance to see all that (Tara).

Chapter VIII

FINDINGS-PASSING THE TORCH

“I Know I Need to Plan But...”

Since a big focus of discussion was about how their parents had not given them direction or made any plans to help guide them with what to do with their sisters once they became caregivers, it would make sense that this group of caregivers would be doing some sort of planning for the future in the event that they could no longer care for their sisters—that they would have some sort of back up person or plan—but that was not at all the case. The participants have really not made any concrete plans for the future themselves. They are caring for their sisters now and most say that they are so absorbed in taking care of the day-to-day responsibilities that they have not had time to think about who they will pass the torch to if anything should happen to them and they cannot care for their sisters anymore.

Tara, who used to work in the life insurance business, says she is normally a “planner” in all other aspects of her life, but when it comes to thinking about her sister Marie’s future care she finds it very difficult:

I have enough money [life insurance] to bury myself and pay off my house, but I have to think about what will happen to Marie...It’s just something that I *have* to do but I just don’t *want* to do, it’s just something that I can’t *imagine* doing cause I always think that her and I are gonna live forever, or she’ll die before I will and I won’t have to deal with that preparation but, I don’t know...

Elizabeth believes families do not talk about future planning because “you don’t want to think about the day when you don’t have parents.” After her family lost their father, they realized how important this type of planning really is. They have already made funeral plans for their mother and Neenie so they do not have to think about that topic again until the inevitable time comes. Elizabeth thinks parents do not want to talk to their other children about who will care for their disabled children after they die because they are afraid of what they will say:

I don’t think they want to know if their other children *want* their sibling, you know what I mean? How would you feel if you talked to your children and ‘well I don’t want to take care of them’ that’s gotta be heartbreaking. If we had said to my mother, that we don’t want Neenie, she’d be heartbroken, what would she do? So I think maybe there’s that fear that their other children don’t want them, and then so it’s almost better off not knowing.

This may be what the sibling caregivers feel also, and therefore, the legacy of not planning for the future is perpetuated in these families. No one wants to face their own mortality, and planning for what happens after one’s own demise is a verification that this event will happen.

One Day at a Time

As irritating as it was to them that their parents had not made plans for who was going to take care of their sisters when they died, these participants have fallen into the same pattern—some say they are so absorbed in getting through all of the responsibilities they take it “one day at a time” and do not have time to consider

making these types of future plans. Marie thinks that concentrating on the present is where the time and energy must be expended because it is required there, “it’s not that you choose to, but she [Ann] needs a support or an advocate everyday.” Others do not plan because of practical reasons; they simply do not have anyone to leave their siblings with if they cannot care for them any longer. A couple of the participants are the only other sibling in the family and have limited or no extended family members who they can entrust with the care of their sisters.

Philip has one friend from childhood that he has legally entrusted with the financial aspects of Charlotte’s care, but this person has a wife and children and cannot provide care for her on a regular basis. He has no one to ask to check on her and provide her with companionship:

If I die right now she’s in that place [the supervised apartment] and she’s kind of screwed, I mean, forgive me for saying that, but whatever they determine for her is what’s gonna be, I mean, nobody else is gonna be involved, maybe my buddy might from a financial perspective, but from an everyday *carer*, she’s gonna be on her own.

Tara tries instead to focus on the happy times she is having in her life now and the plans she is making with her husband and Marie rather than planning for an uncertain future. “It’s not like I have another sibling...I might have to put her into a group home or something like that, which is something I never wanted to do, but I don’t have anybody that would care for her.”

Even the participants who do have people who could possibly be the caregivers for their sisters have not made definitive plans. Anne feels her own health is worse than Carol's because of her cardiac problems and thyroid cancer history, but as far as talking to her daughters about officially becoming Carol's future caregivers, "that is something we've talked *around* not *about*." Anne's children have reassured her that they will take care of Carol and that they know what to do. Anne really does not want her children to have to bear the burden of taking care of Carol, but she is grateful that they are offering to do so. Marie, who is 14 years older than her sister Ann, has several other siblings who can possibly assume care, but expressed her thoughts about why she has not done any planning as to who will take over Ann's care when she is not able to do it anymore, "I think we just trudge along, day in, day out. I'm not sure *what* I should, *how* I should be planning my older years or my retirement years, I'm assuming that I'm going to live longer than Ann, but that might be a bad assumption, right?" Marie concludes her thoughts about the future with a simple statement, "I see Ann with us forever."

An Uncertain Future

Ironically, it is not that the participants are ignoring the inevitable. Kathy has a medical directive in place for the health care issues of her sister Sally in case she is hospitalized when Kathy is not there to make the decisions. She and her mother had this directive put in place after they had a bad experience when the father was in the hospital with Alzheimer's disease. They felt his death process was prolonged because of all the unnecessary medical interventions done to him. They did not want the same

thing happening to Sally. Kathy also has started a funeral account for Sally with the money their mother left for her when she died. She adds to the account monthly with the excess from Sally's social security money. Anne is also in the process of starting a funeral account for Carol with money from the special needs trust. Anne feels it is important to plan Carol's funeral so her children will not have to bear the burden of this responsibility. It is interesting that this type of planning seems to be easier for the caregivers to think about doing because it does not involve asking someone else to assume the duties they are currently performing for their sisters.

Only one participant did speak about trying to actively plan for the future, and being told that the future was not able to be planned for because the progression of her sister's Alzheimer's disease was too unpredictable at this time. Kathy believes that her mother may have put her sister Sally in the group home years ago to avoid Kathy and their younger sister from being burdened by having to care for Sally as she aged. The plan did not work though—Kathy is Sally's legal guardian even though she is in residential care—and Kathy is worried about what may happen to Sally if the Alzheimer's disease progresses. It seems like Kathy summarizes the feelings of all the participants about the future when she admits that the long-range future is uncertain and basically out of her control so she tries to "take it one step at a time...it's unknown."

Chapter IX

SUMMARY, DISCUSSION, AND IMPLICATIONS

This chapter summarizes the purpose and the findings of the study. The findings of the study are then discussed in comparison to the current literature. The discussion includes the contribution that this study makes to the body of knowledge about sibling caregivers and the implications of the findings for practice and future research.

Summary of Findings

The participants spoke about growing up with their sisters and living between two worlds. In the inside world of their home lives, their sisters were perceived as “different but normal for us” and treated just like all the other children in the home, while in the outside world their sisters were considered “different from normal” as perceived by society, and treated with stares and insensitive comments from which they felt responsible for protecting them. The participants learned to straddle both worlds in order to be accepted by society and also be loyal to their sisters.

The participants who became primary caregivers for their sisters immediately stepped in to assume the role upon the deaths of their parents, and their lives were instantly transformed as a result. Overall, families had not made prior plans for the siblings to become caregivers. The transition from sibling to caregiver was difficult. There was no guide to follow as they assumed their new roles. Even if a care plan had already been established by their mothers, the caregivers had difficulty finding health information and social resources. There was a lack of direction from formal social

service agencies, resulting in costly errors and frustration. Dealing with medical appointments and health issues became a large part of the daily routines, with these challenges expected to increase over time as both siblings aged. The time commitment required to perform all the tasks of caregiving was described as “huge,” with daily responsibilities such as ensuring socialization opportunities, transportation, activity involvement, and dependable supervision for their sisters putting limitations on the caregivers’ lives.

Adaptation to their new lives took resilience and negotiation on the part of the caregivers. The women with Down syndrome functioned best when they adhered to set routines, with any change requiring preparation and coaxing on the part of the caregivers. The women with Down syndrome also had limited social lives, which made their caregivers feel obligated to include them in their own social activities. Moreover, making decisions for the adult sibling was difficult and resulted in feelings of uncertainty and inadequacy in the role because participants found it challenging to negotiate the discrepancy between the chronological age of the sibling and her social and developmental level.

Despite the negatives, all of the participants felt they get back unconditional love and loyalty from their sisters and are more empathetic to people with all types of disabilities because of their caregiving experience. They accept that being a caregiver for their sibling is a lifelong commitment that can only end in death. Although all of the participants agreed that future planning is important and wished that their parents had planned better, they have not made concrete plans as to who would succeed them

if another caregiver is necessary for their sisters. Those participants who are partial caregivers now are already making abstract plans to have their sister live with them in the future, and participating in the study has made them more cognizant of the things they need to do to adequately plan for the inevitable.

What this Study Adds to the Literature

This is the first study that investigates the experience of being a partial or full primary caregiver for an adult sibling who has Down syndrome. It is also the first study that includes a male sibling in the role of primary caregiver for a sister who has Down syndrome. Since the study was conducted via a phenomenological approach, it was possible to discover a deeper level of meaning about the experience from the perspective of those who were living it. The topics that were addressed were those that were important to this group of participants and the findings were expressed in the words of the participants to avoid changing the meaning through paraphrasing the information. This study adds information to the body of knowledge about sibling caregivers of adults with Down syndrome. The findings present implications for nursing and social service professionals about the perspectives of these caregivers and their needs. It is the hope that this information can assist service providers to direct these important caregivers to the resources they need to fulfill their roles, as well as suggestions for future research.

Prior Studies Related to Adult Sibling Caregivers

The topic of sibling caregiving when one sibling has an intellectual disability has been understudied. There is a gap in the literature where the topic had been studied back in the late 1990s and is recently being investigated. Studies were found about adult siblings who were assisting their parents with some aspects of caregiving for their siblings with chronic disabilities such as mental illness and mental retardation (Bigby, 1997; Pruchno, Patrick, & Burant, 1996), their intentions to assume care for their siblings in the future (Freedman, Krauss, Seltzer, 1997; Griffiths & Unger, 1994; Krauss, Seltzer, Gordon, & Friedman, 1996) and, more recently, the role of the siblings in assisting with future planning for their siblings (Chou, Lee, Lin, Kroger, & Chang, 2009; Heller & Kramer, 2009). Some of these studies did predict that females in the family would be the most likely future caregivers for their siblings, especially those who still live in or close to the family home (Bigby, 1997; Greenberg, Seltzer, Orsmond, & Krauss, 1999; Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997). In the present study, six of the participants were female, but the one male participant is the only sibling, and he is fulfilling the role in the same manner as the sisters.

Although all of the participants in the present study knew on some level they would be the caregiver in the future, when their mothers were still able to provide the primary care they were only involved emotionally and socially. Most of them were off building and living their own lives, some states away from their parents and siblings. They did not reconnect to provide any of the primary caregiving for their sisters until the disability or deaths of their mothers.

One study found in the literature portrayed what it was like to be an adult sibling of someone with Down syndrome (Flaton, 2006). In this phenomenological case study, the one participant spoke about what it was like to grow up with her brother and how the experience shaped her life. There were some similarities between her experience and that of the participants in the present study. She involved herself in his care from a very early age and was very protective of him. Overall she felt she was a more empathetic person because of growing up with her brother. There was also one unpublished dissertation found in the literature that examined the experience of caring for an adult family member with an intellectual disability that included a total of 17 family caregivers, only two of whom were siblings (Morgan, 2010). The two participants who were sibling caregivers had experiences similar to those of the siblings in the present study in that both siblings became protectors of their siblings very early in their lives. As life went on, the caregiving activities they performed for their siblings increased to the point of them becoming fully transitioned into being the primary caregivers upon the deaths of their mothers. Differences with these siblings were that they never married because they had mothers who very early on impressed upon them that they would be their sisters' caregivers.

While there were no prior studies found that specifically investigate what it is like to be a caregiver for an adult sibling who has Down syndrome, there were studies found that shed additional light upon some of the findings of this study. What follows is a discussion of the literature about some of these key findings.

Protection from Stigma

Goffman (1963) speaks about the “protective capsule” (p.32) that families construct around the child to filter out the stigma that surrounds a salient intellectual disability such as Down syndrome. Todd and Shearn (1997) found that parents of adult children with intellectual disabilities felt that the “toxicity” of stigma was so great that they had to protect their child from it. It may be that these sibling caregivers have the same protective feelings. All of the siblings in this study talk about learning about the need to protect their siblings from the effects of the stigma of society very early in their lives. Stalker and Connors (2004) specifically discuss how siblings of children with disabilities are well-versed at mediating the world of the “normals” (p.227) as well as the world of the disabled because they spend time in both places. They are well aware of society’s view of *difference*, which tends to convey the meaning of *abnormal*, and their need to push the boundaries of social acceptance to include their siblings. In fact, the adult siblings in the present study described their sisters as “different but normal for us” which is almost exactly the way children in the Stalker and Connor’s (2004) study described their siblings. This need to protect the siblings has continued into adulthood and has evolved into being not only protectors from the stares and comments of unkind strangers, but also being advocates for them in their daily lives when dealing with healthcare and service professionals.

McGraw & Walker (2007) conducted a qualitative study with ten women that explored how nondisabled sisters understand themselves and their disabled sisters “within sociocultural systems that dictate what it means to be a ‘good’ woman and a

‘normal’ person” (p.475). Findings suggest that being a “good” sister to someone with a developmental disability involves portraying the normality and exceptionality of the sibling rather than the negative traits. All of the siblings in the present study spoke highly about their sisters’ positive traits. They described their sisters as being “high functioning,” “easy going,” and “very independent.” All of them felt they were “lucky” because they have seen other people with Down syndrome who were not as easy to deal with as their sisters. Some challenged the dominant definitions of normality altogether by creating their own definitions of *normal* to describe their siblings’ behaviors, such as saying the behaviors were “normal for her.” They positioned their siblings on equal footing with the other siblings in the family by emphasizing that they were all treated equally by their parents in the home.

Socialization Skills

Many adults with intellectual disabilities do not perceive themselves as different, mainly because they lack the mental capacity to understand the difference. Basically, they are not aware of the social standards by which they are judged. They define themselves by what they see others in their worlds doing, which are primarily the actions of their siblings (Davies & Jenkins, 1997). Most of the participants in the present study spoke about how their sisters want to make friendships with people in the siblings’ social circles and in general do not want to associate with other adults with intellectual disabilities. They assimilate themselves with their typical siblings, rather than with other adults with intellectual disabilities. It is evident from the stories about the women with Down syndrome in the present study that they lack social

support, since they have lost ties with their friends from their school days, but they may not fully understand how to develop relationships if and when they are exposed to social situations. It is not sufficient to just expose these adults to others with similar disabilities in social situations and expect friendships to form (Jobling, Moni, & Nolan, 2000).

In comparison to non-disabled peers, many adults with Down syndrome lack peer friendships and romantic relationships (Jobling et al., 2000). As a consequence of this, many of them resort to watching excessive amounts of television or movies on DVDs and develop “friendships” with these program personalities that become very real to them, often replacing the need to make authentic friendships (Jobling et al., 2000). This was a common finding in the present study also. One of the participants complained that her sister would rather watch her DVDs than go out socially with her and this caused much frustration for the caregiver because she did not feel this was a healthy way for her sister to be spending her time. There is a need for formal education to assist adults with intellectual disabilities to learn how to socialize with the goal of forming friendships (Jobling et al., 2000) and the present study identifies the need to help family members understand more about how these individuals can be helped to socialize more effectively and appropriately.

Only one participant in the present study stressed that her sister did not have any problems with her social life or with establishing friendships. She attends a daytime vocational program and is also enrolled by the participant in many evening and weekend social activities sponsored by her local ARC and through the Division of

Developmental Disabilities, Real Life Choice program. After her day program she calls her friends and select relatives on the phone to keep herself busy. Clearly, participation in many activities seems to be beneficial towards keeping her socially engaged, but the downside is that transportation must be arranged for all of these activities. Tara had her sister, Marie, enrolled in the day program right after she finished her school program at the age of 21 because of their mother's illness. At the time, she wanted to keep her sister out of the house during the daytime to avoid having her being exposed to her mother's erratic behavior. Perhaps the key is to provide resources to assist with keeping the adult with Down syndrome socially involved as much as possible after graduating from high school at age 21 to avoid this gap in socialization that the caregivers spoke about in their stories.

Gender and Caregiving

The sibling relationship when one sibling has a disability was examined from critical feminist and disability theorist perspectives and findings suggest that females in families take full responsibility for the caregiving of disabled family members and even make excuses for the men in the family for not helping more with the caregiving activities (McGraw & Walker, 2007). In the present study, one participant hired a homemaker for the time in the evening when she was not yet home from work or when she had to attend school in the evenings because, "it alleviates my dad from doing a lot of the stuff so he's more relaxed or whatever" (Tara). Kathy spoke about her brother who was 15 at the time of their sister's birth. He was never involved in her life and still is not to this day. He lives in another part of the country and Kathy thinks

his non-involvement may stem from his wife and their mother not getting along. She does not know for sure if it is her sister's condition that has made him distance himself from the family.

Philip is the only brother in the group caring for his sister, but even he makes excuses for his father's non-involvement. Philip is unique in that he is putting his sister in supervised housing at his fiance's request, but also because he has cared for his sister in all kinds of ways, including providing *intimate care* such as prepping her for a colonoscopy, "I had to do this twice, but...hey, yeah I was in an awkward spot, but no one else was gonna do it but me" and taking her to the gynecologist and speaking to the physician about female health issues, "talking about all that woman stuff that guys don't usually want to hear about or know about, a lot of different things, but like I said, I knew if I didn't do it, it wasn't gonna get done."

In contrast, Marie told her husband, "don't make me choose cause you'll lose" because the husband knew about the deal of her taking over Ann's caregiving before they married. In fact, all of the female participants in the present study have voiced their determination to care for their sisters despite the desires of their spouses or the significant others they have yet to meet in their lives. It seems their priority in life is to make sure that their sister is cared for, no matter what the cost to themselves.

Difficulty Making Decisions

Todd and Shearn (1997) found that parents had difficulty relating to their adult children with mental handicaps because they never achieved many of the typical experiences considered to mark maturity, such as more involvement with their own

peers and a separation from parents. They did agree that their adult children were not children because they were physically mature, even if they had childlike qualities, so they did not fit into either category. It seemed acceptable to place them as forever being in the adolescent stage of development because they tended to have resistance to parental authority over decision making and would never have adult responsibilities. The findings in the present study are consistent with these findings. Participants had difficulty making decisions for their siblings because of ambivalence about them being adults in chronological age but acting like children on many levels. Even when they made decisions, they often ruminated over those decisions and second-guessed themselves about whether or not they made the correct decisions.

When adults are in the decision-making phase, they actively consult with the other adult or adults whom the decision affects and obtain advice prior to making the final decision (Browder, 2002). In the type of caregiving relationship being examined in this study, the consultation is possible, but the meaningful feedback that provides for making the final decision is not always obtained, so the final decision often falls on the shoulders of the legal guardian. This can result in the feelings that the participants expressed—that of uncertainty, questioning the decision, and overall stress over the decision-making process (Browder, 2002). Marie feels fortunate that she is able to consult with her other siblings if she really feels uncertain about decisions she has to make about Ann and says they all are still involved in helping her:

But, BUT, they all feel free to give their opinion but always, always back off and say, ‘well whatever you decide.’ So she’s part of our family meeting, we

talk about Ann, so she's a discussion point, but they're all very respectful of the role and the life that we have you know with Ann living with me. Because they don't want that at all!

Other participants in this study do the same. Kathy consults with her younger sister who she says helps her with all of the decisions she has to make for their sister Sally. Tara consults with her father and husband, and Lynn and Elizabeth are not yet the primary caregivers for Neenie, so their mother still makes all of her decisions. The one person who feels he has no one to consult with is Philip. He does say that he always feels "on the fence," especially recently since he made the decision to put his sister into residential care and he is completely unsure as to whether he made the right decision.

Medical Issues

Longer life expectancies and less formal residential resources for people with Down syndrome mean that more family caregivers will be responsible for managing the many health care issues for their family members who have Down syndrome (Bittles & Glasson, 2004). People with Down syndrome are living longer, and medical technology is now more advanced, so this generation of sibling caregivers will be the first to manage a myriad of chronic health issues related to ageing in this population. Early-onset Alzheimer's disease is prevalent in the adult population of people with Down syndrome and has become the most concerning medical condition faced by family caregivers (McQuillan, Kalsy, Oyebode, Millichap, Oliver, & Hall, 2003; Toor, Strydom, Patti, & Jokinen, 2010). Regular medical screenings for health issues that are

prevalent in the population of adults with Down syndrome should be incorporated into the health care regimens of these adults in order to prevent exacerbation of conditions prior to their identification (Robertson, Roberts, Emerson, Turner, Grieg, 2011; Smith, 2001; Watchman, 2003). However, people with Down syndrome living at home do not often receive regular health screenings and definitely do not receive screenings that identify the early signs of Alzheimer's disease, which is highly prevalent at much earlier ages in adults with Down syndrome (Watchman, 2003).

Participants in the present study report that a large amount of their time is spent managing their sisters' medical care. Health issues currently being experienced by the women with Down syndrome were hypothyroidism, obesity, insulin dependent diabetes, peripheral neuropathy, urinary and fecal incontinence, obsessive compulsive disorder, colon cancer, and Alzheimer's disease. The youngest woman with Down syndrome had prior surgery for a benign brain tumor and the oldest woman had colon cancer surgery. All of the women were being managed medically by family physicians for their routine care. Only one woman had ever had a gynecological examination. The one participant who had taken her sister out to the major medical center in Baltimore, Maryland for her physical examination when she took over being her caregiver is in the process of trying to get her sister to agree to go back to have a sleep study done since obstructive sleep apnea is a common cause of sleep disturbance in adults with Down syndrome (Trois et al., 2009). One of the participants who has her sister in residential care is already dealing with the effects of Alzheimer's disease with her sister, and another who has her sister living home with her highly suspects that her

sister is showing early signs of Alzheimer's and she has been monitoring her "forgetfulness" herself for signs of it getting worse.

Some participants in this study complained that their sisters do not tell them when they are not feeling well, and in fact go to great extremes to deny feeling sick to avoid having to go to physicians. Tara told the story about how her sister had apparently had "walking pneumonia" for a while and did not even appear to be sick. The only way she knew anything was wrong was when her sister started to stumble around and act differently. She sent her to the physician's office with her father and a chest radiograph was done and it was positive for pneumonia. The only indication may have been a slight cough during the prior week. Since stories like this are common, scheduling regular screening examinations is imperative, and knowing the family member well and paying attention to the behavior of the individual is crucial since oftentimes that is the only indicator of illness.

In the current study, Anne has found that taking a proactive, preventative approach to healthcare for her sister Carol has been a much better tactic than waiting and treating disorders as they present themselves, since usually by that time, Carol has had the issue for a length of time. She learned this because of taking her sister to the physician upon becoming guardian and finding out she had diabetes and having had it now progress to her requiring help with insulin injections. She says Carol has always had a habit of not complaining and having a "high tolerance" for discomfort and pain, so she could not trust her to tell her when anything was wrong.

Future Planning

Many studies conducted with adult siblings focus on planning for the future care of the sibling who has a disability. Future planning for family members with intellectual disabilities has been studied from the perspective of all family members (Caldwell & Guze, 1960; Freedman, et al., 1997; Greenberg, et al., 1999; Griffiths & Unger, 1994; Grossman, 1972; Heller & Kramer, 2009; Krauss, et al., 1996; Schatz, 1983; Seltzer, Krauss, Hong, & Orsmond, 2001). Findings of these studies suggest an overriding theme of a general lack of communication about future planning among family members even if future planning was taking place in some form. In some of these studies (Griffiths & Unger, 1994; Heller & Kramer, 2009; Krauss et al., 1996; Schatz, 1983) siblings expressed the intention to become future caregivers for their disabled siblings, yet reported that parents had not approached them about it, nor to their knowledge had made plans for them to do so. Moreover, many parents reported that they desired the typical siblings to care for their disabled adult child, but had not expressed this desire to the siblings (Freedman et al., 1997). Bigby (1997) found that siblings stepped in to perform the role of primary caregiver for their adult siblings with intellectual disabilities when the parents could no longer fulfill the role because of disability or death, but no formal transition into the role had ever taken place.

The findings of this study are consistent with these prior studies. Even when one of the families had “planning meetings” no real planning went on and the sibling who was designated to be the caregiver was left with the feeling “now what?” when she took over guardianship of her sister. The transition for these siblings was when

they became legal guardians for their sisters, and that was not until their parents were disabled or deceased. One of the participants went into detail explaining why she believed her parents did not plan, and her reasons echoed those that were alluded to in the literature, fear of mortality, fear of being told “no” and having to make other plans, and not wanting to face the rejection of the disabled child by the other children in the family.

Perhaps perpetuating the tradition of not planning, these participants are doing little to plan for the future care of their sisters if anything should happen to them. Two of the participants have no other siblings, so planning is difficult since they feel they have no one to entrust with their sister’s care. Another participant has health issues and feels her sister may outlive her, so she has made her funeral plans and has talked “around not about” the subject of future caregiving with her adult daughters who have volunteered to take over their aunt’s care if necessary. No formal plans have been made for this arrangement. The other participants have not made any plans for anyone to step in as the caregiver. Marie has not thought about planning for someone else to take over Ann’s care because, “I’m assuming that I’m going to live longer than Ann, but that might be a bad assumption, right? Fourteen years apart. I don’t know what I should be doing now.” This is another area where education is necessary so that there are not gaps in care if another transition has to take place.

Implications for Practice

Where are the Nurses?

It was interesting that only one participant mentioned nurses being involved in the care of her sister, but it was not in a positive light:

I don't think nurses in the hospitals are as passionate as they should be. I think sometimes they're just there to get their things done and they're just out by the end of the day. You'll notice that even they, they don't treat patients that have certain disabilities the way they should be treated (Anne).

The fact that none of the participants even mentioned nurses seems to be an implication in itself that nurses should have more of a presence in the lives of adults with Down syndrome and their caregivers. The two participants who are partial caregivers for their sister did talk at length about how their sister had brain surgery and how their mother had to "sneak in and out" of the hospital early in the morning so the nurse manager would not know that the night nurse had let her stay in the intensive care unit with her sister overnight. Even though the mother did not have legal guardianship, their sister would not allow anything to be done without their mother present. The night nurses valued the mother's presence because she kept their sister calm during the night. However, before "management" came in for the day shift, they said their mother had to leave and go wash up in the ladies room. There is clearly a need for nurses to recognize the importance of parents and siblings in the care of adults with intellectual disabilities in the acute care environment.

One participant went to another state to have her sister evaluated so she could make sure she knew what care to provide for her; clearly the desire to give the best possible medical care to their sisters is at the forefront of their minds, but finding that healthcare is the challenge. Nurses can assist these families with access to the health education and medical care needed for adults with Down syndrome in their local areas. This care is needed as they progress through not only the normal issues of aging, but possibly the added complications of Alzheimer's disease. Participants in this study expressed the desire for more knowledge in general about the health care issues that affect adults with Down syndrome, and more knowledge in particular about the high incidence of Alzheimer's disease and the progression of the disease. The one participant whose sister was diagnosed with insulin dependent diabetes was sent home from the physician's office with a prescription for the insulin pen injections without assessment being done that would have determined that she was unable to administer the insulin to her sister because of her own fear of needles. Eventually her son taught the sister how to self-inject. When I heard this story, I immediately thought, where were the nurses? Nurses working out in the community and in physician's offices can assess the needs of family caregivers to determine what educational resources are necessary so the caregiver can feel confident about providing the required care.

One of the participants spoke about how her family loved the way her sister was treated by the neurosurgeon that operated on her for the brain tumor. He always spoke right to her sister and explained everything clearly so she could understand the

very complex procedure. She spoke about her perception of him and why she believes he may have been more empathetic to the needs of his patients:

He's amazing, he is just *amazing*, and it's funny like I saw—I don't know if I saw...I think I saw it after surgery when he came out to tell us—he has a scar, he had chest surgery, he had heart surgery, so it was almost like anybody who's had anything you are automatically more sympathetic to anybody who has had anything, so when you saw that it was like OK well he knows what it's like to be the patient you know so he gets it (Elizabeth).

Certainly it is not necessary for healthcare providers to experience being patients to be able to provide exceptional care to patients. It takes a desire to take the time to get to know and understand the individual patient and the needs of the entire family. This is something that nurses are trained to do for all populations of patients, and people with Down syndrome and their families are no different. There is a need for all nurses to be better educated in the treatment of adults with intellectual disabilities considering the number of these individuals who are living longer and requiring nursing care. Participants in this study expressed the need for healthcare professionals to speak to their sisters rather than to them, and to explain things in terms the caregivers could understand so they could easily interpret them for their sisters. One of the participants who takes her sister to the physician on a regular basis had this to say about encounters with healthcare professionals:

But the biggest thing I would say to healthcare in general—talk to *them*, treat them like they're people—so many times you go to a doctor's office or

whatever and they'll talk to *me* or they'll talk to *my mother*, or whoev...they don't talk to her—well, talk to HER, ask *her* what's wrong and she will tell you! Treat her like the patient, don't treat her like you know, a child, she's not a child, she's 30 years old. Talk to her, treat her like a person (Elizabeth).

One of the participants who is the legal guardian for her sister who lives in a group home has a medical directive stating what would happen in the event her sister was hospitalized. She feels this is especially important because her sister is living in the group home and she may not be immediately available if her sister is taken to the hospital. This medical directive was originally written when their mother was still alive because their father suffered in the last stages of Alzheimer's disease and the mother did not want the sister to suffer in the same manner. There is a need for nurses to encourage families to make advance directives during times when the person with Down syndrome is healthy, to avoid having to make difficult decisions during the stressful periods of illness.

Social Support Services

Due to better access in health care and advances in medically technology, adults with Down syndrome are predicted to live into their 50s and 60s and have parents who are about 30-40 years older, so this is the first generation who will be caring for their siblings after the deaths of their parents (Hodapp, 2007). Very few parents do anything in the way of preparing for the future (Heller & Caldwell, 2006) and there is a need to educate siblings who will be assuming the role of caregivers about what resources are available, what resources their sibling requires, and how to

access these resources (Hodapp, 2007). Part of the problem with finding and accessing resources may be that family support services vary across states, with the individual states determining how the funding allotted to the support services will be spent (Rizzolo, Hemp, Braddock, & Schindler, 2009). Caregivers need to be connected with a central resource agency to be able to find the best support services for their family member.

Access to a direct support person upon assuming guardianship would be the best way of being connected expediently to the resources needed to avoid some of the pitfalls experienced by participants in this study. If the resources were not already put in place by the mothers prior to their deaths, the participants in this study had a very hard time accessing resources in a timely manner. They complained that for sibling caregivers “there was no guidebook” for them to follow upon assuming guardianship. The most difficult task was navigating the social security system, with three of the participants having ongoing issues with this agency. When determinations were made that seemed nonsensical and were unacceptable to the caregivers, they were advised that they could “get a lawyer and fight the decision.” Surely there must be a better way of handling administrative issues than adding additional financial expense and mental stress to these caregivers’ lives. It was unclear why they had to “prove” via physical examinations and certifications from physicians that Down syndrome was a medical disability that would not change in order to keep receiving benefits. Since society can expect that more and more siblings of individuals with intellectual disabilities will be

assuming caregiving roles, there is a need to provide formal services specific to this group to make access to the resources more streamlined.

Future Research

This study presents many ideas for future research. During this research I had the opportunity to meet two of the participants' siblings and see the siblings together. Watching them interact and connect and tell me stories about their lives was truly heartwarming and inspiring. In the future I would like to do a participant observation study about the relationship between siblings when one sibling has Down syndrome. I would also like to study the sibling caregiver experience from the perspective of the sibling with Down syndrome. What is it like for them when they have to adjust to new living arrangements and now have the sibling that they once considered a peer become their guardian and "parent" or authority figure? Another interesting finding of this study was that, in families where there were multiple children, mothers seemed to choose the sibling whom they wanted to be the future caregiver for their adult child with Down syndrome. An interesting topic of future research would be to examine how they make these choices. What criteria do they use to determine to whom they will "pass the torch?" Finally, participants in this study brought up the topic of being fearful of having a baby with Down syndrome when they were planning to have children. In fact, the one participant who is trying to become pregnant at this time, and the two participants who have yet to marry, talked about the worry at length. Elizabeth puts her thoughts this way:

It terrifies me, it terrifies me, because I know how high functioning my sister is and I know how people she's gone to school with are not and it terrifies me that...if this happens am I gonna be strong enough? I've thought about it for years since I'm young enough or old enough, capable of thinking about a future for myself and having kids, it absolutely terrifies me because there's so many unknowns you know? You don't know how high functioning they'd be, you don't know what health restrictions they're gonna have. Who's gonna take care of them? There's just so many open-ended questions there's just no answers to (Elizabeth).

All of them wonder whether they would be capable of raising a child with Down syndrome from birth, despite being familiar with the syndrome and comfortable caring for their sisters. In this day and age, we are at risk for losing an entire generation of vibrant, productive people who make positive contributions to society everyday—people with Down syndrome—because of early prenatal screening (Chiang, Chao, & Yuh, 2006). I would like to one day speak with new mothers of infants with Down syndrome about how and why they chose to keep their babies and what they believe the future holds for them.

This study makes an important contribution to the knowledge base about the experience of being a caregiver for an adult sibling with Down syndrome. Although participants described caring for their siblings from an early age and expressing the intention to care for their siblings upon the disability or deaths of their parents, there had been no concrete planning done between the parents and caregivers that would

allow for a smooth transition into the role of caregivers. There is a need to discover why families do not make plans for this transition. Future research should concentrate on identifying factors that inhibit communication in families about the responsibilities of caring for someone who has Down syndrome and making concrete plans for the transition of care in the future. Notably absent from the literature is the voices of the adults with Down syndrome—how do they feel when their parents are disabled or deceased and they now have a sibling assume the parent role? It is important to include their perspectives in future studies. Many adults with Down syndrome have opinions about this and other issues, and their opinions deserve to be heard. There is also a need for longitudinal studies to follow families of infants with Down syndrome throughout the lifespan to identify the service needs of these families as the child with Down syndrome ages into adulthood.

Chapter X

REFLECTIONS

This chapter is about the reflections shared with me by the participants about being a part of this study and also my reflections about my experience as a novice qualitative researcher. The journey has taken me through a myriad of emotions. I will talk about the challenges and the lessons I have learned that I will take forward with me into future research endeavors.

Participant Reflections

Overall the participants felt that participating in the study was a positive experience for them. All of them said that this was the first time they were asked how they felt about being a sibling to someone with special needs and talking about it helped them come to terms with some of the emotions they had held in for their entire lives. It also raised their awareness of why they were caregivers for their sisters at all, especially since they spoke about how difficult it can be at times. Most of them shared unresolved feelings such as jealousy, resentment, and of being “second best” for years. Participating in the study gave them the time and opportunity for reflection about not only about what it was like to grow up with their sisters, but also what it was like to be called upon to later allow their sisters to virtually “take over” their lives when they became the caregiver when the mothers died. One of the participants felt this was a “cleansing” experience, since she had always felt guilty about the turbulent adolescent period she had gone through and had just started to grow out of when her mother became ill. Being able to think about, and reflect upon, some of the things she had

held in all of her life helped her to see things a bit more clearly and has freed her to be the caregiver for her sister that she knows her mother and grandmother would have wanted her to be. Another participant used the time to reflect upon her sister's life as it is and how it cannot be easy for her either, "it's been hard for her...she never did anything to deserve all this (Anne)."

Thoughts about Mothers

At times the participants speculated about what it was like for their parents taking care of their sisters. For many years, the parents had been the only companions for their sisters and some had no respite from the responsibilities. As difficult as they believed it may have been for them, all of the participants continue to care for their sisters in the same way they had observed their mothers care for them. Anne points out that what her mother experienced is similar to what siblings also experience as caregivers:

My Mom, I think sometimes she felt caged in. She didn't have an easy life but that didn't make it any easier for her either, so...it's hard, it's hard, and they say as you get older you take care—the kids take care of the parents as they get older—but some people don't realize that there are siblings too that need help.

Another participant feels there is much that mothers can do to help the siblings who will be future caregivers to be more prepared to assume the role. Although she helped her parents with transporting her sister to activities now and then and attended her sister's Special Olympics events, Marie was not involved in any of the activities of her sister's day-to-day routine, nor did she know anything about the special planning

required to obtain the support services that were utilized by Ann in her life. Marie had this advice for families of siblings who are planning to become caregivers in the future:

While their Mom's alive there's so much that that Mom could do to help pass on because even though you're doing, you're far removed. I didn't live that far from my parents so I would *do*...oh I could take Ann to swimming, I don't mind taking her, can I pick her up for you...you do *activities* but that's far different than being the *caregiver*. So if I could do it again I'd probably ask a lot more questions and take a lot more notes!

“Don't forget the Siblings!”

One of the participants had very strong feelings about how siblings should be included from an early age in all therapies and planning sessions. She believes that this way they grow up *in* the caring environment rather than viewing what their sibling is doing from the perspective of an outsider. Elizabeth believes if she had been included in the therapy sessions, she would not have experienced jealousy or resentment related to her sister's alone time with their mother. She had taught her sister the alphabet, numbers, and colors, so she always believed she could have helped her in her therapy sessions as well. Elizabeth thinks that the way she and her siblings have been raised may be the key to having siblings who are better equipped to care for their brothers and sisters with any type of disability because becoming a caregiver is an expected event rather than something that occurs upon the death of a parent:

If you start when they're young, from the beginning and well, and not even, don't even give 'em a choice, you start from when they're little, 'you know one day you're gonna have to take care of Suzie,' then it's just 'well that's what we're gonna do, well we're gonna take care of them' (Elizabeth).

Researcher's Reflections

The journey began with my search for participants, which was truly a search like none I have ever had to do before. When I wrote my proposal, I thought I had a surefire method of finding eligible, willing participants. I quickly found out how wrong I was. I wanted to find participants who were living with their siblings and caring for them in their homes, who lived close enough in proximity to me so I could accomplish three interviews in a timely fashion. As a mother of an adult daughter with Down syndrome, I knew many parents and siblings of people with Down syndrome. However, I did not want to interview anyone I knew well. Therefore, a large number of eligible participants in my social network were eliminated. I tried soliciting through my daughter's school alumnae association, but the only responses I had were from two elderly parents who were still the primary caregivers for their sons and daughters. They called to wish me luck and tell me if they ran into anyone who fit the qualifications they would refer them to me—so close, yet so far. Finally, I found the first two participants through a former professor and I set off to do my first two interviews—the next hurdle—I had never interviewed before. As I sat down to do the first interview, tentative interview guide in hand, all of my equipment at the ready, I stammered, I stuttered, I asked leading questions, I talked too much, I did just about

everything I read NOT to do when I conducted an interview. As each interview with each participant was conducted, I would like to be able to say I became much better at interviewing, and I truly *hope* I have. What I can say for certain is, that after reading and re-reading my interview transcripts, I now feel I have a much better idea of how to conduct multiple phenomenological interviews. I am sure that was one of the objectives of this process.

“Writing It Up”

As I started to finally begin actually writing this dissertation, I searched for books about how to do it, and found an excellent guidebook. As a starting point, Wolcott (2009) advises one to consider whether you are “essentially a reader or essentially a writer” (p.18) and to come to terms with the fact that few people can excel at both. I always thought I was a writer—I liked reading well enough, and goodness knows it is necessary in this profession—but I felt that writing was my strong suit. That is until I started trying to write up the findings of this study. Van Manen (1990) speaks about the responsibility the researcher has to tell the story of the participants in the way that best describes the lived experience. After interviewing this group of participants and hearing their touching stories, I realized this would be an overwhelming endeavor and one not easily achieved. Even though I could almost see all the transcripts in my head when I closed my eyes because I had read and reread them so many times, I wondered whether I was interpreting their meaning correctly. Did I have the most important themes extracted from the data? Did I winnow down the information in the best possible way and not eliminate any crucial information? All of

these questions almost paralyzed my writing at times. I felt like everything looked “messy” and not at all how I envisioned my dissertation to be. I learned that to be a qualitative researcher you must be an avid listener, an astute reader, and an *excellent* writer. The book *Doing Qualitative Research: Circles within Circles* by Ely et al. (1991) was one of the required texts in our qualitative courses. I realized how appropriate the title of the text was since I felt I was going in circles as I analyzed the data and struggled to find the best way to portray what this experience was like for the participants.

The Interview Process

Before each interview I shared with the participants that I was a nurse and a mother to an adult daughter who has Down syndrome. I wonder if this affected some of the content of the topics in the interviews because they may have been guarded about sharing certain opinions with me. For example, I know that living as a caregiver for an adult with Down syndrome has many challenges, some of which this study has brought to the forefront. I, as a mother of a child with Down syndrome, made the choice that their mothers made, to bring my daughter home to raise her to be the best she can be. These participants are now living the legacy of their mothers’ choices. They did not make the choice themselves, in fact, they felt they had no choice in the matter of being a caregiver—yet none of them expressed anger over being chosen and about the limitations it has put on their lives. Is it because I am a mother too? I’m not sure. I would like to think it is because they genuinely do not feel anger and that they only feel the unconditional love they talk about their sisters feeling for them.

At times these interviews were very emotional for me. One reason I chose this topic was because I wanted to see what siblings go through when they are caregivers for their siblings with Down syndrome when the mothers have died. Some talked about how their sisters have very vivid memories and truly recall times with their mothers and how their mothers are still “very real” to them, so they are very careful not to try and fill their mothers’ shoes. Knowing how people with Down syndrome are so resistant to change, I recognize that adjusting to the death of their mothers must have been difficult for the women, but the participants did not bring up this topic and I did not pursue it. This may have been because the topic is too “close” for me to talk to them about. I happened to be interviewing Tara during the anniversary of the month that her mother died. She stopped to cry several times during the interview as we talked about how Marie helped to care for her mother when she would become combative and how at those times Marie had more patience with their mother and Tara felt Marie was a better caregiver to her mother than she was. Tara wondered aloud if her mother knew that she “stepped up” and was now caring for Marie and that Marie was happy. I reassured her that as a mother myself, I can be certain that “somewhere out there” her mother knows and is at peace knowing that Marie is being cared for. Then we cried together. After the interview we sat together for a couple of hours just talking. I felt like I needed to spend more time with her before she left for the drive home. The next week Tara brought Marie with her to the interview. We had made a pact that neither of us would cry. We had talked about all the “heavy” topics. Seeing

Tara and Marie together and laughing as Marie told stories about their lives made up for all the sorrow and confirmed my belief that their mother must be resting in peace.

Final Thoughts

I feel that this “PhD journey” has culminated in a study that is the springboard for my future. I have so many ideas of where I want to go from here because there are so many ways that life can be improved for siblings who have chosen to follow in the footsteps of their parents and care for their siblings with not only Down syndrome, but other intellectual disabilities as well. I hope that other researchers who read this work can take ideas from it to further the research with this population and improve the lives for all of these families.

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Appendix A

RECRUITMENT FLYER

Invitation to Participate in Sibling Caregiver Research

- Are you a sibling to an adult with Down syndrome and have either partial or full caregiving responsibilities for that sibling?
- Would you be willing to participate in a study where you describe what this experience is like for you?
-

Patricia Sciscione, MSN RN CSN-NJ, a doctoral student in the Nursing program at Seton Hall University in South Orange, New Jersey, is seeking participants to enroll in a study entitled:

“What is the Experience of having Partial or Full Caregiving Responsibilities for a Sibling who has Down Syndrome?”

Participation consists of a series of three, audio-taped interviews lasting about 60-90 minutes each taking place over a flexible three-week timeframe.

Participation in this study is voluntary and you can withdraw from the study at any time.

All the information you share during the interviews will be kept confidential.

Your identity will only be known to the researcher. You will be referred to by a fictitious name during the interviews and all your audiotapes will be identified by a unique code number. All audiotapes will be transcribed by the researcher and kept on a secured data key. All study materials will be stored under lock and key to maintain strict confidentiality.

In order to participate in this study you must:

- Be over the age of 18
- Speak fluent English
- Be a sibling to someone who has Down syndrome and have partial or full caregiving responsibilities for this sibling

To hear more about the study, please contact the researcher at:

Patricia Sciscione, MSN, RN CSN-NJ

Seton Hall University

973-761-9306

Patricia.sciscione@student.shu.edu

Appendix B

TENTATIVE INTERVIEW GUIDE

Interview One: Getting to Know the Participant

Tell me about yourself...

Tell me about your siblings...

Tell me about your sibling with Down syndrome....

Tell me what it was like growing up with him/her?

What is your earliest memory of caring for your sibling?

Interview Two: Being a Caregiver

How did you come to be the primary caregiver?

What caregiving responsibilities do you perform for your brother/sister?

What is it like for you being the primary caregiver?

Interview Three: Effect on your Life

What effect has being a primary caregiver for your sibling had on your life?

Is there anything you want to add?

Appendix C

INFORMED CONSENT FORM

Informed Consent Form

Researcher's Affiliation

Patricia Sciscione, MSN RN, is a doctoral student at Seton Hall University College of Nursing. The study she is conducting is entitled, "The Experience of having Primary Caregiving Responsibilities for an Adult Sibling with Down Syndrome".

Purpose of the Study

The purpose of this study is to explore and describe the experience of being an adult who is partially or fully involved with primary caregiving responsibilities for a sibling with Down syndrome. The researcher wants to know what this experience is like for the adult sibling caregiver from his/her point of view.

Duration of Participation and Procedures

Participants will take part in three (3) interviews lasting approximately 60- 90 minutes each, scheduled about one-to-two weeks apart from each other. The interviews will take place at a mutually agreed upon date, time, and place that affords quiet and privacy. The interviews will be guided by several open-ended questions, for instance, "Tell me about yourself and your sibling with Down syndrome" and "Tell me what it is like for you providing care for your sibling". The interviews will be audiotaped using a digital recording device. You will not be addressed by your real name during the interviews. Fictitious names will be used for you and your sibling on both the recordings and the transcripts. The audio-recorded interviews will be transcribed exactly word-for-word by the researcher. The type-written copy of the interviews will be stored on an electronic file on a USB memory key. They will be kept in a secure, locked file in the home of the researcher. The researcher will have the only key to the file. No one except the researcher and her faculty advisor will have access to this data. Three years after completion of the study, all paper and audio-recording files will be destroyed and discarded by the researcher.

Voluntary Nature of Participation

Participation in this study is completely voluntary. You have the right to withdraw from the study at any time during the study and for any reason without penalty or loss of benefits to which you are otherwise entitled.

Anonymity

The researcher guarantees that no participant in this study will be identified by name. Fictitious names will be used to protect the identity of the participants and the siblings with Down syndrome.

Confidentiality

All materials collected during this study and records of the data will be kept confidential. All consent forms with identifying data will be kept separately from the interview data in a locked file cabinet in the researcher's home office. All information collected during this study will be stored electronically on a USB memory key and kept in a locked file in the researcher's home office. All audio-recordings will be kept in the same locked file. Fictitious names will be used to match the audio-recordings, paper transcriptions, and electronic files. No participant or sibling will be identified by name on any research documents.

Only the researcher and her faculty advisor will have access to the confidential research records. All results and findings of this study will be used for research purposes only. A report of the research findings will be made available to the public through scholarly presentations held at professional conferences and by publications in professional journals. Reports of findings will never use individual identifiers and confidentiality of all data is guaranteed. Three years after completion of the study, all paper and audio-recording files will be destroyed and discarded by the researcher.

Risks or Discomforts

This study involves no foreseeable risks, however, participation may cause you some emotional discomfort as you discuss the experience of caregiving for your adult sibling with Down syndrome. You may choose to not answer any questions that cause you discomfort and you may stop the interview at any time.

Benefits

There are no direct benefits to you for taking part in this study. However, participating in this study has the potential to increase knowledge about what this experience is like

for adult sibling caregivers. Information learned as a result of this study may be used in the future to help health care providers to better plan for supports for adult siblings going through similar experiences.

Compensation

There is no compensation or payment for participating in this study.

Contact Information

If you have any questions about the study, the principal researcher is: Patricia Sciscione, MSN, RN. She can be contacted via phone at SHU at 973-313-6040 by leaving a message and she will return your call or by email at patricia.sciscione@student.shu.edu. The faculty advisor for the researcher is Judith Lothian, RN, Ph.D, Dissertation Committee Chairperson. Dr.Lothian may be contacted at 973-761-9273 or via email at Judith.lothian@shu.edu. If you have any questions about your rights as a participant in this research, please contact the Director of the Institutional Review Board at Seton Hall University, Dr.Mary Ruzicka, Ph.D., at 973-313-6314.

Consent for Audiotaping

The audio-taped interviews will be transcribed exactly word-for-word by the researcher. No real names will be used to protect confidentiality and anonymity. Fictitious code names and related code numbers will be used to identify the information. The type-written copy of the interviews will be stored as a paper copy and as an electronic file on a USB memory key. They will be kept in a secure, locked file in the home of the researcher. The researcher will have the only key to the file. No one except the researcher and her faculty advisor have access to this data. Three years after completion of the study, all paper and audio-recording files will be destroyed and discarded by the researcher.

(Print name of participant)

(Signature of participant)

Date:

Consent to participate in the study is indicated by signing below:

(Print name of participant)

(Signature of participant)

Date:
