IMPACT OF A STUDENT-LED WELLNESS PROGRAM FOR INDIVIDUALS WITH DISABILITIES ON CAREGIVERS AND FAMILY MEMBERS

by

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(Under the Direction of Kevin McCully)

ABSTRACT

Few studies have addressed impact of participation in wellness classes on caregivers or family members of individuals with disabilities. This important aspect of program evaluation is neglected**.** **PURPOSE:** To evaluate effects of the wellness program on family members of caregivers of participants. **METHODS:** Eight program participants and nine respective family members or caregivers were selected for interviews. Interviews were then transcribed and analyzed into codes, categories, and themes. **RESULTS**: Five themes emerged from interview data: benefit of class to self, positive feelings about participation, relationship dynamic, importance of classroom interaction, and burden of class. Zarit Burden Interview scores indicated moderate burden in sample of caregivers. **CONCLUSION**: This study demonstrated effect of a unique program on the overall wellness of participants with disabilities and their respective caregivers or family members. Caregivers or family members do acknowledge benefits of the program to themselves. However, the program does not reduce caregiver burden significantly.

INDEX WORDS: caregiver, caregiver burden, disability, wellness program

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DEDICATION

I would like to dedicate this research to the caregivers of those who participate in our wellness class, as well as hardworking caregivers everywhere of individuals with disabilities.

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I would like to thank several individuals in both my academic and personal life that have contributed to my career, character, and work ethic. First and foremost, I would like to recognize Dr. Kevin McCully and thank him for his contributions to this thesis as well as my graduate career. He has been a most excellent advisor, and I could not have fulfilled a graduate degree without his guidance and support. Secondly, I would like to thank Dr. Gary Liguori for his continued guidance and support of my academic pursuits well beyond my undergraduate degree. I would not have made it to graduate school without his support, guidance, and encouragement. Last, but certainly not least, I would like to recognize my family, John, Rhonda, and Kelly Ware, for their continued support. Without their solid foundation, I would not be the individual that I am today.

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CHAPTER 1

INTRODUCTION

Disability was identified in about 12.6% of the United States population in the year 2012.[1] The definition of disability can be very broad. According to the ADA, an individual with a disability is defined as "a person who has a physical or mental impairment that substantially limits one or more major life activity".[2] With that definition in mind, the disabled status becomes very diverse. In accordance with the United States Disability Status report, the prevalence of the six disability types among persons of all ages in 2012 were reported as such: 2.2% reported visual disability, 3.4% reported hearing disability, 6.9% reported ambulatory disability, 4.9% reported cognitive disability, 2.7% reported self-care disability, 5.6% reported independent living disability.[1] Any, and all, forms of disability present unique challenges to those directly affected, as well as those who support individuals affected.

The poverty rate of working-age people with disabilities was 28.1% in 2012.[1] In the same year, the employment rate of people aged 21-64 with a disability was 34.6%.[1] Such a low employment rate can have serious implications on family income, exemplified by the poverty rate of individuals with disabilities. In 2012, the median annual income of a household with any working-age people with disabilities was $37.300.[1] However, these earnings do not necessarily translate into discretionary income, due to the expenses that individuals with disabilities incur. Costs related to disabilities can be numerous. Individuals with disabilities can find themselves paying out of pocket for many items, such as necessary medications, assistive devices, or therapy services. Home renovation costs to increase accessibility can be heavy as well, often leading to the selection of less effective, lower cost alternatives.

11.5% of the population in the state of Georgia reported disability status in 2014.[1] This is very close to the national percentage, stated above. Further, the employment rate for those with disabilities in the state of Georgia in 2012 was 29.8 %, as compared to the 75.7% seen in the non-disabled population.[1] The lack of employment for those with disabilities in the state of Georgia has economic implications similar to those stated above; however, it is important to keep in mind the socioeconomic status of those in Georgia as compared to the nation as a whole. Individuals in the state of Georgia with disabilities spent an estimated $10,444 in disability-related expenditures in the year 2006.[3] That is about a third of maximum estimated income level that a one-person household could receive before qualifying for Medicaid ($29,344) in the state of Georgia.[4]

Many individuals with disabilities have unmet healthcare needs due to lack of access.[5] Access takes many forms, from financial access to physical access to buildings that provide proper healthcare. Also, proper servicing can be difficult for individuals to find, due to different expertise and focus of different healthcare facilities. People with disabilities were more than twice as likely to find that healthcare providers were not adequately able to care for their needs, four times more likely to report being treated poorly by healthcare providers, and three times more likely to be refused care.[5]

In 2012, 86.7% of working-age people in the United States with disabilities had health insurance.[1] 34% of those individuals received health insurance from their employer or worker's union, while a combined 63.8% reported coverage by Medicare, Medicaid, or other government-funded assistance plans.[1] However, the exclusion or inclusion criteria in coverage programs can be overwhelming to an individual with a disability or a family of someone who has a disability. It can often be difficult to qualify, which leaves a portion of the population uncovered; if they are covered, there is a chance that there are limits on care or cost-sharing obligations. Vital areas of care for individuals with disabilities, such as medications, care coordination, dental coverage, vision coverage, long-term care, or medical equipment, could be dropped from coverage in certain plans; this is especially true of employer-sponsored health insurance.[6]

Wellness programs have been proven to be an effective tool for reducing health risks in the clinical population. Exercise in a wellness program environment has been shown to reduce risks for cardiovascular disease, diabetes, obesity, cancer, and sexual function among other physiological factors.[7-11]

Wellness programs for individuals with disabilities do exist; however, those programs are met with unique challenges. Costs for adaptive equipment, access costs for transportation, as well as the presence of an experienced staff increase the budget for such programs. Also, extra time might be spent for participants in the wellness programs to prepare for exercise, such as time transferring to and from an assistive device or time spent to cool down due to changes in physiological functioning. Factors such as these create unique challenges for scheduling and personnel needs. Group exercise is a barrier to wellness programs for those with disabilities, because the conditions of the individuals participating may vary too much to allow for one single activity to do together.

Ploughman et al. studied the effectiveness of such a program on mood, function, and exercise adherence in individuals with moderate to severe neurological disorders[12]. The exercise intervention lasted 10 weeks and was comprised of circuit training and introductory measures to increase affinity to a normalized gym setting. Objectives measured were functional mobility, endurance, health-related quality of life, and participation. The results indicated, for those who completed the intervention, quality of life measures related to health significantly increased.[12] At-home programs for exercise engagement are also viable, but could be more effective with some kind of support or assistance. A study by Froehlich-Grobe et al. compared the effectiveness of home-based programs with minimal support versus intensive support, meaning the presence of staff and supervision.[13] Both groups of participants were wheelchair users with significant upper body function, who reported spinal cord injury as the most common cause of mobility impairment. The intervention lasted 12 months, with instruction on self-managed exercise as well as specific exercise instructions. The main outcome measured was exercise adherence; secondary outcomes were physiological outcomes, such as strength and aerobic capacity. The results supported the use of staff-supported exercise, because the participants who received intensive support had higher rates of reported exercise time as well as increased aerobic capacity and strength when compared to the self-supported group.[13]

Young et al. outlined a program that takes place at the University of Georgia.[14] This program is student-led, and is funded by resources at the university.[14] Because of the funding source, the class has minimal cost for those who participate in it; the incurred cost of participation is mostly for transportation. Students, under the supervision of university instructors, act as wellness coaches to the individuals who participate, providing them with guidance for exercise. These classes also operate with multiple participants in the facility at one time, providing exposure to other individuals with disabilities as well as their caregivers or family members.[14]

There are close to 44 million adult caregivers in the United States.[15] A portion of those care for those with intellectual or physical disabilities. Caregivers of individuals with disabilities often face great challenges; this is defined by the term 'burden'. Based off of the hours spent providing care, 32% of caregivers report having high burden, while 19% report having medium burden, with more than 20 hours of care representing high burden.[16] Finances can be a source of distress for caregivers. Also, learning the skills necessary to properly care for the individual with the disability can be burdensome and time-consuming. In fact, caregivers have reported feeling underprepared and abandoned when taking care of the individual in question, especially when there are special procedures needed to provide adequate care.[16]

However, the implications of burden can extend far beyond providing for the needs of the individual with a disability. The health of the caregiver can be subject to the circumstances that he or she finds themselves in due to the burden of care. The health of the individual being cared for is dependent on the caregiver, and the reverse is also true; evidence shows that caring for a family member can have measurable negative effects on the health of the caregiver.[15] Depressive symptoms are often persistent for caregivers of those with disabilities.[16] Institutional care can and is used to take burden off of the caregiver, but institutional care could be inadequate to the needs of the individual being cared for; this possibility is often a source of worry and added stress on the caregiver.[15] The mental burden can manifest itself physically, resulting in fatigue, illness, or sleep disorder.

Problem Statement

Available research seems to evaluate the impact and effectiveness of these programs by using health-related outcome changes in the participants. Although this is a very important aspect of programs for people with disabilities, it is not the only aspect where impact and effectiveness can be evaluated. Family and caregivers are vital to the care of any individual with disabilities, and are often debited with high burden. Evaluating impact and effectiveness should extend to caregivers and family members of individuals with disabilities, because of the investment caregivers and family members have in said programs to improve outcomes for individuals with disabilities. Not enough attention is dedicated to the impact of these kinds of programs on caregivers and family members; this study seeks to do so.

Purpose

The purpose of this study is to evaluate the impact of the University of Georgia's student-led exercise class for individuals with disabilities on caregivers. Specifically, this project will address any kind of outside impact (occupational, social, etc.) of the class. This will be assessed through formal interviews with family members, caregivers, or social group members. Key outcomes are perceived caregiver burden, quality of life, quality of interaction with the participant in the class, and perceived changes in the life of the participant in the class.

Research Questions

The following are questions this study seeks to answer:

1. How do caregivers describe, with specific examples, the impact of this class on their support of the individual with disabilities?
2. If so, what kind of effect? (For example: Financial, Emotional, Physical)
3. What are the strength of the effects?
4. Can caregivers give specific examples of this effect?
5. How do interviews with participants corroborate or contradict the information provided by caregivers?

Significance

Physical or intellectual disabilities affect a significant portion of the United States population. These people have twice the health care costs of people without a disability, and yet have much lower income (when and if employed) and lower access to health and wellness services. Even more limiting, people with disabilities face discrimination, prejudice, stigma, and lack of knowledge from those without disabilities. Caregivers and family of individuals with disabilities also experience prejudice, stigma, discrimination, and monetary struggles. The development in the summer of 2012 and the subsequent continuation and exponential growth of KINS3450L (Practicum in Fitness Conditioning or Disability and Wellness) suggests that positive inroads can be made in healthcare available for those with disabilities; it also suggests that provisions could be made for expanding opportunities for not only the participants, but their families and caregivers.

This research is necessary to evaluate the impact of disability-serving programs within the department of Kinesiology. Furthermore, publication of this data would support the goal of expanding a program such as this to other universities. The benefit to those individuals with disabilities who participate in programs such as this is clearly visible; however, the benefit could also extend to the family members or caregivers.

Theoretical Perspective

Interpretive research is a practice within social science research that is invested in philosophical and methodological ways of understanding social reality.[17] It is widely used in a variety of research areas in the social sciences. Under its umbrella sits many other frameworks, as it serves as a focal point for research that seeks to further understand culture, thought, individuals, beliefs, etc.

Interpretive research is guided by the idea that understanding comes first, or *Verstehen.*[17] This idea drives the underlying goal of interpretive research, but does not determine the way in which understanding is established. Understanding is established by the researcher, and is shaped by the theoretical perspective that the researcher chooses. Each perspective-ethnography, ethnomethodology, phenomenology, etc.- brings with it different strengths and weaknesses.

For the purposes of this study, I will be using an interpretive methodological perspective. I seek to better understand the way that the exercise class impacts those who care for individuals who participate in it. I will not be narrowing my lens any further, however; I feel that leaving this study open to basic interpretation will best suit the goal of the study.

Functional and Technical Definitions

Code: direct quote pulled from participant interview transcript; serve to help develop categories

Category: organizational tool for grouping codes; serve to help develop theme

Theme: consistent, overarching consensus of interview data conclusions; made of categories

Class Participant: individual with a disability from the Athens community who participates in the wellness course

Student trainer: undergraduate student taking the wellness course for academic credit; usually are assigned to 1 or 2 participants per semester

Caregiver: individual who is the primary means of support (financially, emotionally, functionally, etc.) for a participant in the wellness course; primary caregivers were identified by class participants

Summary

Currently, little research exists that addresses impact of participation in exercise classes on caregivers or family members. Programs that are student-led at a college or university do exist, but the research to support the existence of such programs neglects the collateral impact. This study seeks to fill in this gap in the research. Filling in this gap could potentially lead to a different way of measuring economic impact of programs for those with disabilities, new validation for the existence of such programs, and expanding awareness of the impact that student-led exercise classes can have on those who participate as well as their family or caregivers. Accomplishing that task will require qualitative methods. Interviews will be the primary method of collecting data. Data will then be organized and analyzed for reoccurring themes.

CHAPTER 2

LITERATURE REVIEW

Introduction

For the purposes of this study, the works surveyed in this review covers the areas of: disability in family dynamics, and caregiver literature. These areas will be kept in broad perspective. This is so that the reader is able to reflect upon ties from the current literature base to the research questions.

Specific literature on the research questions is lacking. As previously mentioned, caregiver literature seems to place the caregivers or family members of those in wellness programs in the role of evaluator; this study seeks to discover if there is an indirect benefit for the caregiver or family member, and if programs like this can impact caregivers or family members. If so, how does it benefit or impact that group?

Disability in Family Dynamic

As expected, diagnosis of a disability does not affect solely the individual who is diagnosed. Those who support and surround that individual are inevitably affected. Typically, those supportive individuals are family members or close friends. Current literature addresses some aspects of the dynamic effects of disability in a family or supportive network. This review seeks to address those aspects that have already been examined, as well as identify gaps in the literature on this topic.

Relationship Dynamic

Romantic partners or spouses of people with disabilities can often be the anchor of support for the affected individual. For some groups, such as individuals with intellectual disabilities, relationships and sexuality can become quite a polarizing subject among family members; this could be because of a perception of individuals with disabilities as being permanent children [18]. There are many available resources on the topic [19-25].

An area of the research that is less covered centers around individuals with visual, hearing, and physical disability and their romantic relationships, particularly if those individuals are young adults. An attempt to characterize the romantic experiences of individuals of different genders and disability has been made. Individuals between the ages of 18 and 25 with either a hearing, visual, or physical disability were interviewed on the topic of sexuality, expression of sexuality, and partnership. Lack of encounters of this nature were reported by participants, with explanations of limiting beauty standards, overprotective parenting, stigmatization, lack of mobility, and feelings of inferiority. Interview responses also indicated differences in experience with relationship and sexuality between the different groups. Young adults with physical disabilities reported having fewer relationships, as well as later life sexual experiences. Young adults with hearing disabilities reported having more relationships, as well as earlier life sexual experiences. Overall, 90% of the participants had been in at least one relationship, with 70% of those reporting experiences of sexual intercourse. Sexual intercourse was more prevalent in female participants, while male participants reported more relationship experience [26]. These results do challenge a societal perception of people with disabilities as being incapable of sexual relationships as well as romantic relationships. Although these results were obtained in Germany and may not be directly translatable to young adults with hearing, visual, or physical disability in the United States, there are significant implications as to the experiences that this population group faces. Young adults with disabilities are engaging in romantic and sexual relationships, therefore, more education on the health risks of sexual relationships must be a priority. Also, empowerment of this population group should be a priority; in order to combat the feelings of inferiority, stigmatization, and limiting beauty standards that this population faces, research must be done to determine what this group feels is needed. Finally, these results indicate a need to examine the individual, to treat the individual, at a deeper level than what the societal perception would hold. Research could be done in areas of healthcare and education to see what improvement of perception could do for treatment, patient retention, and other variables. The results also have implications for caregivers of individuals with disabilities seeking romantic or sexual relationships. For caregivers who are also spouses, this realization could be quite powerful and relevant in respect to societal recognition of their position; for caregivers who are parents or siblings, this realization could produce a move toward more autonomy for the individual with a disability.

Seven couples in New Zealand were interviewed on the topic of dealing with partner multiple sclerosis (MS) and the challenges that come with it. Participant selection criteria were as follows: 1) participants had to have been diagnosed with MS long enough to be able to speak to the experience, and 2) participants had to have been diagnosed in a non-recent timeframe for the sake of not being too shaken by the diagnosis. Two themes emerged from the interview data, being coping together on a day-to-day basis and coping long-term. Day-to-day coping strategies centered around similarities in coping. Couples who did not have similar strategies reported some difficulty in relationship, as to be expected. However, support of the spouse and shared domestic responsibility was cited as being a way to overcome the difficulties. Understanding that the life of the couple is a shared life was also cited as a way to cope day-to-day. Coping long-term with MS was a more complex issue for the couples. Some couples explained the difficulty in dealing with the diagnosis, as well as the different perspectives taken on the matter. For example, members of couples would deal with the diagnosis as a set-back while the other would dwell on the diagnosis. Couples added that living in the immediate future was also helpful for coping with the diagnosis. Finally, fundamental faith in each other as well as one's self was shown to be effective for maintaining relationship [27]. These results were obtained from a sample of New Zealand citizens; however, they still present interesting observations about the fundamental nature of relationships in which a member has a disability. These results show that coping is not a single-person event. Instead, it is an event that couples experience together. More research needs to be done to demonstrate how these behaviors develop, as well as how these coping mechanisms can enhance or retract from the existing relationship.

Four partners were interviewed to discuss the effects of traumatic brain injury (TBI) on partnership and decision-making ability. All partners had been in committed relationships with the individuals with TBI for at least 4 years, and two of the couples were married. The majority of the couples had entered the relationship after the injury occurred. Partners also differed on the basis of gender identification, employment status, socioeconomic status, parenthood, availability of support, and sexuality. Interviews were in-depth, discussing topics such as decision-making processes with an individual with a TBI with examples of such instances. These interviews were transcribed and coded for common themes. The results indicated similarities between partner's strategies and environments for decision-making. Partners expressed critical features of the relationship that allowed decision-making to be a pleasurable experience, such as commitment to the individual despite the TBI, viewing the individual in a positive way, finding ways to effectively communicate, taking time to understand the implications of the injury on their partner's brain, and learning from previous experience with the partner. Overall decision-making processes did change from before the injury. Partners expressed that decision-making became more about leading on their part, initiating the decision point, remaining vigilant to allowing the individual with TBI to make as many of their own decisions as possible, taking time to critically reflect on the decision-making process, and emphasizing the choice to live with the outcome despite who actually made the decision. [28] Interview data may not be directly translatable to American populations because this study took place in Australia. However, these data suggests that partners had to develop these mindsets in order to combat the effects of their partner's loss of autonomy, but also to respect autonomy where it could take place. This data also emphasizes the role that partners or spouses play in critical decision-making on behalf of their loved one. Clinically, the relevance of this research should extend to the treatment of individuals with disabilities, as well as the understanding of the role of the spouse in treatment. Further research should be performed to identify if these patterns exist in other couples, and how those patterns of decision-making influence marital quality for spouses of individuals with disabilities.

Evidence of gender differences in partner support or strain effects were examined in 3,505 journals from 1,162 older adults with disabilities as well as spouses. Emotions such as happiness, sadness, worry, calm, and frustration were sought for in journal entries, along with overall negative and positive emotion evidence. These emotions were also examined with activity-related rankings that participants disclosed, mostly centered around activities of daily living. Also, relationship quality data were obtained on the topics of strain and emotional support. The results indicated a difference in response to emotional support or strain based off of gender. Women with significant disabilities reported increased feelings of calm when in a self-perceived supportive marital environment. Conversely, self-perceived supportive marital environment decreases feelings of calm and increases reports of frustration, sadness, and worry in significantly impaired men. If the relationship is also experiencing strain, men with disabilities may also become more susceptible to negative mood [29]. The implications of this research are key to understanding fundamental relationship dynamics when disability enters the relationship. As demonstrated here, men may respond to the decline in functional capacity in a negative way. It is imperative that spouses continue to communicate feelings and emotions with each other past the diagnosis for maintenance of the relationship. If female partners do not understand the origins of the negative mood or negative emotional reactions that males can have due to further disability, the male could be at risk for losing a partner or a caregiver. Future research should focus on the origins of such emotions- whether from loss of autonomy or something more- in order to best aid couples in effective communication and reduction of disability-derived relationship strain.

Family-Member Specific Literature

Fathers of individuals with disabilities have a unique perspective that has been explored in recent literature. Although they do not represent the majority of the caregiver population, some do assume a caring role [30]. A review by Davys et al. explores perspectives of fathers of children with intellectual disabilities[31]. The literature revealed that most fathers have a heightened sense of anxiety and sensitivity to depression in the time after diagnosis. Although those feelings seem to dissipate over time, fathers still report stress, sleeplessness, fatigue, anger, shame, and guilt [31]. These feelings could be hypothesized as the result of heightened demand that the child incurs, as well as remorse for feeling lacking at times; feelings such as these could be labeled as “crisis reactions” [30]. Fathers also reported fear for the future, which is a commonly cited source of anxiety in the literature. The future includes adequate care for the child, sexual practices of the child, finances for the child, and education of the child, among other variables. Work-related issues are also brought to light in the review; fathers feel that they are providers for the family, and report that, at times, having a child with a disability can make that difficult. Sharing the role of ‘carer’ with the mother of the child can create a difficult employment situation, despite the fathers’ drive to create stable and caring environments for their children [31]. Even though fathers shared these feelings with researchers, the literature states that fathers often neglected their own needs for the needs of their families. These needs are heightened by the additional need associated with caring for a child with a disability. Further research could pursue further the needs of fathers of children with disabilities, and solutions to meet those needs that fathers would deem as positive [31] [30].

Mothers of children with disabilities often express that they are primarily responsible for the caring of children with disabilities [30]. With the primary responsibility inevitably comes stress, emotional reaction, regret, and guilt. These factors were assessed in a study by Findler et al.[32] 191 mothers of children with developmental disabilities were given questionnaires to assess happiness, general stress, specific stress, attachment, guilt, and social support. The results indicate that lower levels of attachment avoidance, perceived stress, and guilt coupled with high levels of perceived social support contributed to mother’s happiness levels increasing. This happiness was not dependent on severity of the child’s disability [32]. These findings are consistent with other foundational works on contribution of factors to maternal happiness, including those of the Disability-Stress-Coping Model [33].

A study by Pruitt et al. sought to evaluate mother’s self-report of family and child well-being along with maternal characteristics on maternal well-being.[34] Mothers of children with autism spectrum disorder (ASD) were surveyed for mental health, child symptom severity, family functioning, daily general affect, and parenting interactions; these measures were assessed as well as assessed for correlations to determine any connection to certain demographic factors. The results indicated that child and family characteristics did indeed affect maternal affect as well as parenting interactions. Increased family rigidity as well as increased reported depression was correlated to greater number of frustrating parenting interactions [34]. Although these results may not be generalizable to mothers of children with other kinds of disabilities, they do present important implications on maternal health effects on the family. With mothers being the primary caregivers, as described previously, it is inevitable that their mental health will affect how they care for the family, and the child with the disability. Therefore, to optimize care, research must be done to provide mothers with resources and better outcomes. In addition to the mental or emotional stress, financial stress is also particularly difficult for mothers. When mothers cannot obtain or retain full-time employment, the family experiences diminished income. The diminished income, coupled with the three-fold increase in healthcare costs associated with having a child with a disability, can add pressure and create feelings of guilt for the unemployed mother [30].

Parental stress among groups of parents of children with different disabilities were assessed in a Portuguese study by Felizardo et al.[35] Parents of children with intellectual disability, motor disabilities, or autism spectrum disorder were given Parental Stress Index (PSI), the Social Support Questionnaire (SSQ6), and a generalized parental questionnaire developed by the researchers in order to assess child’s characteristics that might contribute to parental stress, social support dimensions, and sociodemographic data. Majority of parents surveyed were female, between the ages of 20 and 60, married or cohabitating, and in the medium level of socioeconomic status. Results indicated that parents of children with intellectual disability had higher stress levels than the other two groups. Through further analysis, researchers were able to conclude that overall stress could have been higher in this group because of behavioral issues with the child and not meeting overall parent expectation. To contrast, parents of children with motor disabilities experienced stress in the areas of role restriction, which indicates difficulty for parents in determining daily routine care roles in overall family functioning. However, parents of children with autism spectrum disorder scored higher than other parents in the category of adaptability, meaning that they possess the ability to adapt to their child's changing circumstances at a lower perceived stress level. Overall parental stress was negatively correlated with availability of social support [35]. This research presents key implications for interventions designed to reduce parental stress. Type of disability being dealt with in the home is key to designing any form of intervention for reduction of parental stress, particularly associated with characteristics of the child. This finding creates questions of individuality in programs, resources, and therapies designed for parents of children with disabilities. Future research should focus on creating customizable therapies, interventions, and programs for families with children with disabilities.

Relational aspects of raising a child with intellectual disabilities are still unclear, according to the review. Some studies have found inconclusive results on the effects of having a child with an intellectual disability on marriage [31]. Taiwanese marriages in which a child has a disability could result in divorce, according to another study [36]. It can be certain that more stressors are added when a child does have an intellectual disability, but it also might be that having the child does increase the parents' sense of purpose. In fact, it could be that parents' relationships are strengthened because of the added dependency, emotionally and physically, on one another [30, 37].However, other factors might contribute to strengthening of the marital relationship, such as religious or spiritual beliefs [38]. More conclusive literature is needed on the topic, as well as more research into effects of children's' different disability states on marital relationships.

Single parents, as expected, do face very unique challenges to caring for a child with a disability. For some, the dissolving of a prior relationship could be due to partner's difficulty associated with caring for a child with a disability [30]. In that scenario, it is common for parents to feel lack of support or for children to feel abandoned. The situational difficulty increases if other children are involved with the parent who left [30]. Despite the relational difficulty, single mothers reported that lack of resources and mobility were their major difficulties; that, coupled with lack of support and increased dependency on others can create a situation where single parents feel trapped or alone, with heightened sense of social isolation [30].

In order to address the pressures that a single parent could experience raising a child with a disability, Becerra and Michael-Makri examined the application of Structural Family Therapy and benefit to the single mother.[39] This study was conducted with one family, in which the mother served as the head of the household; this mother worked full-time, had recently obtained a GED, and had no financial support from her former spouse. The mother, Linda (a pseudonym), had four children, one of which did not live in the household, another having mild intellectual disability, and another experiencing emotional episodes and breakdowns. Structural Family Therapy was used to help the family restructure individual relationships within the family but also to strengthen familial relationships as a whole. Particularly, relationships in the family involving the child with intellectual disability were examined, as well as their effect on her mother. Therapists worked with Linda to create boundaries between her children in an effort to reduce her stress. However, this proved to be a difficult task for Linda, which in turn, created more stress surrounding the child with the disability. Linda's neglect for her personal wellness or well-being manifested itself in the form of depression and also inability to retain a job; thus, creating another dynamic of her interactions with her family, and her child with a disability. Through therapy, Linda was able to assess her familial communication style, as well as her behaviors, to create a better environment for her family. [39]. Therapy interventions like this could be used for relief or better understanding for single parents. However, currently, professional services for Structural Family Therapy may not be feasible for single-parents of children with disabilities. Therefore, the research must further examine ways to meet the needs existing for family dynamic in single-parent families with children with disabilities.

Siblings of children with disabilities play an important role in family dynamic. Because of the nature of the sacrifice that comes with having a sibling with a disability, siblings of children with disabilities often find it difficult to express feelings. In fact, aversion to expression of feelings is quite commonly identified as an issue among siblings of children with disabilities because of perception of heightened needs of the disabled child and diminishing of the needs of the sibling [30]. This reluctance to express feelings could be related to other outcomes, such as loss of normality, difficulty in creating peer friendships, lack of social efficacy, or self-perception as being 'disabled by association' [30].

Some siblings of children with disabilities also feel responsibility for the disabled child. This is demonstrated by sibling's eagerness to assist parents with chores, activities of daily living, or tasks associated with caring for the child [30]. Parents are appreciative of the help they receive when it is so offered, and perceive this as an act of maturity or 'disability awareness' [30]. Despite this, some children do express regret or anger at having a sibling with a disability [30]. Whether these feelings come from jealousy, neglect, misunderstanding, or other related concepts is unknown. Parental acknowledgement of the sibling's service is also key to maintenance of the behavior by children, which could affect the feelings with which siblings approach the disabled child [30]. However, it can be expected that a certain level of those concepts will exist in any lopsided caring situation.

Children who have disabilities face a variety of barriers, one of those barriers being environmental, which encompasses social, physical, and emotional environment. Parents in various regions of Spain were asked to complete the Spanish version of the European Child Environment Questionnaire (ECEQ) to assess quality of life for their child with cerebral palsy (CP). In addition, researchers requested that parents also include their child's Gross Motor Function Classification Scale (GMFCS) score in order to best understand the context of the child's disability. GMFCS scores were negatively correlated with physical, social, and peer relations domains; children with higher GMFCS scores had perceived lower levels of quality of life in these areas. Parent's demographic socioeconomic information was shown to have a low association with quality of life. Parent perception of overall quality of life for their child was directly affected by the parental view of barriers that the child faced. Barriers, more specifically, negative attitudes, were shown to affect parental relations with children, home life, social support, child psychological well-being, and familial financial resources [40]. These results could be expected. However, further analysis showed that after controlling for the contribution of reported attitudes, school and home related interactions did have an effect on quality of life for the child. Parents also reported difficulty in finding social support services and difficulty finding adequate social support for their child; this resulted in a lower quality of life perception by the parent for physical well-being and social support domains [40]. Although the results of this study may not be directly applicable to American individuals, it does contain valuable insight into what parents think their children face as barriers, as well as the severity of those barriers. Future research could address how parents think those barriers to improved quality of life should be addressed, as well as creation of programs to address those barriers.

Diagnosis periods are often the most difficult for families. In the case of child diagnosis, parents can be left with a myriad of feelings or emotions. Many parents receive diagnosis before the child reaches the age of two years, with as much as 10% of parents knowing at birth that the child had a disability [30]. Reactions of parents can be affected by knowledge of the condition at hand, age of the child, gender of the child, previous experiences with other children, as well as a variety of other factors, including age of child's diagnosis. As time passes, families also begin to sense difference in their dynamic versus the dynamic of families without children with disabilities. The differences mostly consisted of needing more assistance than families without a child with a disability or increased demand of one child over the other children [30]. Those differences, induced by the demand, can create social as well as emotional strain on family members. A source of alleviation of this strain could be support networks, which families cite as being very helpful through the whole experience of living with a child with disabilities [30].

Family Quality of Life

Family quality of life is an area of research that is often studied in families who have a member with a disability. Some studies seek to make comparisons between families with children who have disabilities and families without children who have disabilities. Parents in one Slavic town were surveyed using the World Health Organization's assessment of quality of life (WHOQOL). This survey assesses physical, psychological, social, environmental, and overall quality of life. Mothers were all given the same survey, and fathers were given a different survey to assess parental differences in quality of life. Results indicated that parents with children who were had disabilities rated their quality of life poorer than parents of children without disabilities. Further, parents of children with disabilities did not rate their personal health as being poorer than parents without children with disabilities, but are also less satisfied with their physical quality of life, pertaining to sleep, mobility, etc. Parents of children with disabilities also scored lower in psychological quality of life as well as social. However, parents of children with disabilities scored significantly lower in environmental quality of life, due to lack of security and lack of economic resources [41]. Although these results may not be translatable to other populations due to cultural and language differences compared to Slavic culture, the implications on families with children who have disabilities could be felt worldwide. Other research has indicated that families with members who have disabilities do experience lack of financial support, as well as lack of financial security. Further research should strive to address these issues in multiple cultures and countries, as well as seek information on what families believe would address these needs.

Families in South Africa with children diagnosed with ASD were surveyed for quality of life measures in a work by Schlebusch et al.[42] Families were defined not only as nuclear family, but also opened to extended family, live-in caregivers, friends, and other members of an individual family’s daily supportive unit. Most of these families were ethnically African, two-parent families with two-children; most of these families also would have qualified as economically disadvantaged despite most being employed full-time, because of their thoughts on financial state. Researchers used the Beach Center Family Quality of Life Scale (FQOL) to survey participants. Although this scale had not been validated in South African populations, the researchers chose this scale because of its validation in the United States. According to scale item results, most families felt satisfied with disability support and overall quality of life.

However, families were least satisfied with their own emotional well-being. Upon further analysis, correlations between gender of the child with ASD, additional disabilities or medical conditions in the child with ASD, and child's level of severity and lower FQOL scores were seen [42]. Although these results may not be translatable due to cultural differences and language differences that exist in South Africa, they present implications that could extend to other families in the world who have children with ASD; familial burden of aiding one with a disability could affect quality of life for all of the family, particularly emotional well-being, which also carries implications for the health status of the individuals in the family. Further research must be done to assess family unit quality of life for those who have children with disabilities, but also for those who have siblings, parents, or extended family with disabilities.

Caregivers

Caregivers are a diverse group of individuals who provide various forms of care to individuals unable to do so. Around 70% of caregivers state that they care for one individual. 61% of caregivers are female, while 39% are male [43]. The majority of caregivers state that they care for individuals who are 50 years or older, while 20% state that they care for individuals between 18 and 44 [4, 43].

Although caregiving in itself is a profession, not all caregivers are professionals. Some caregivers are family members. Around 37% of caregivers surveyed in the year 2004 said that they were the only source of unpaid care for the person they care for, and 34% of those who did have unpaid help said they still provided most of the care.[43] Up to 90% of the long-term care needed by adults is provided by unpaid family caregivers, and in 2009, 65.7 million people in our country claimed the role of unpaid family caregiver.[16] These family members may or may not have received specialized training to better care for their loved one. When circumstances permit, family members seek the aid of a professional caregiver, but do not have that resource at all times. Around 41% of caregivers surveyed in the year 2004 said that their care recipient received paid service [43].

Caregivers, as expected, do spend enormous amounts of time providing care. Up to 20% of caregivers spend more than 40 hours a week, and the average amount of time is 20.5 hours per week [16]. As previously mentioned, some caregivers are professionals, meaning that this role provides income; however, it is imperative to remember that not all caregivers are professionals and are instead family members who do have outside employment. Male caregivers are 60% more likely to be working full-time, while female caregivers are 41% likely; females tend to hold more part-time work (14%) [43]. Particularly, caregivers of younger individuals report having financial hardship due to caregiving [43]. Demographic information of caregivers in the year 2004 revealed that a third of caregivers surveyed did not complete more education than a high school level, which could be a detriment to the income of the individual as well as carries implications for the household.[43] Spending time caregiving could potentially take time away from caregivers' formal employment [16]. An estimate of the cost of informal caregiving is $56,290 per year, per patient [16]. The combination of inability by the family caregiver to maintain employment or attain adequate employment and the incurred cost of caregiving could result in financial stress for the family unit.

Caregivers, depending on the ability level of the individual that they care for, provide many services. Bathing, feeding, and dressing are among the activities of daily living (ADL) that caregivers assist with. However, the extension of their duties goes far beyond ADL's. Around 46% of caregivers surveyed in the year 2012 reported performing "medical" tasks with care recipients [44]. Among the tasks reported were very skilled administrations of medications, monitoring of condition symptoms, careful nutritional planning, wound care, as well as equipment operation [44]. Caregivers surveyed in the year 2004 stated that they "need help keeping the person that I care for safe (30%)" [43]The above stressors in taking care of an individual can result in what is now known as caregiver burden.

A fair definition of caregiver burden, as given by Zarit et al., is "the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning"[45]. Caregiver burden has become a more researched topic in recent years, with a heavy focus on caregiver burden in caring for the elderly or those with dementia. Although those populations do warrant the research, there is not adequate information on caregiver burden for other disability-specific areas, such as cerebral palsy, multiple sclerosis, spinal cord injury, traumatic brain injury, etc.

Family Member Caregivers

Family member caregivers do have unique relationships with the individuals that they care for. Parental caregivers also bring different perspectives to well-being of their child with a disability. In one African study, differences between paternal and maternal thoughts on caregiving for a child with intellectual disability were highlighted. Both parents expressed strong feelings of commitment to caregiving, but particularly strong in mothers. This commitment is very clear in the event that burdens and problems arise in caregiving coordination, sibling interaction, and familial strain. Both parents also expressed concern for the future of care for their child, in the event that they were too aged to take care of the child. Fathers expressed concern for financial and physical protection and provision of the child while mothers expressed concern for physical care. These themes are seen across several other works [46]. However, it is notable that these results cannot be interpreted as translational in this review because of cultural differences between African family dynamics and United States family dynamics.

Spouses face unique challenges in the role of caregiver. For women, caregiving can be a gendered role.[30] Women have been shown to provide more hours of care and higher levels of care than men. In addition, women feel that there is more pressure to fulfill that role.[43] This social dynamic of caregiving could create gaps in the literature that fail to address caregiving from a male perspective.

Male and female spouses of individuals with Alzheimer's disease were studied for caregiver burden and stress differences in a study by Croog et al.[47] A sample of 199 caregivers, 119 women and 80 men, were given Zarit Burden Interviews, General Well Being adjustment Scales, and an adapted scale from Zarit and Zarit to assess patient problem behavior. Both gender groups reported 'worry about the future' as a paramount concern, with 'feeling the need to do more', 'anger', and 'limitation of social life' following. However, further analysis of these variables showed significant differences based on gender of the respondent. Males seemed to express a higher level of 'feeling of need to do more' for the spouse, while females expressed a higher level of 'anger or resentment' towards the spouse. Despite the higher report of 'anger or resentment' in females, patient problem behavior was only predictive in male spouse 'anger or resentment.' Male spouses also had higher reported depression scores than female caregivers, while female spouses had higher reported anxiety scores.[47] It could be hypothesized that these illustrated differences in male and female spouse-caregivers could be based off of normative, societal beliefs; as previously mentioned, women are more likely to feel pressure in fulfilling the role of caregiver, which could lead to resentment or anger. Further research is needed to examine the differences between male and female spouse caregivers in the context of mental and emotional health as well as attitude derivation.

Comparisons between family-caregivers based off of familial role has been addressed. Ennis et al. examined differences in anxiety and depression in parent versus spouse caregivers in a review of the literature.[48] Of an initial search of 249 abstracts on traumatic brain injury (TBI) and caregiving, 24 articles were reviewed for this work. These 24 fit the design and research quality standards set by the researchers; designs among these 24 articles include parent and spouse caregiver data with no comparison or comparison of parent and spouse caregivers with respect to anxiety or depression with reporting of either no difference among groups or differences among groups. Overall, the results of the articles that compared the two caregiver groups revealed that there were no statistically significant differences between parent and spouse with respect to anxiety and depression. However, the results also indicated that both groups do report high levels of anxiety and depression [48]. These results indicate that despite the differences in role, there is still a high level of depression and anxiety among spouse and parent caregivers. This could be because of the high level of involvement that these individuals have with a patient, if indeed they do fulfill the traditional roles that parents and spouses have. More research is needed to delineate between spouse and parent caregiver experiences in this population group. Assessment of risk for anxiety and depression in both groups is also needed to best evaluate current treatments or therapies designed to serve parents or spouses more specifically.

Child caregivers face challenges around caring for a parent with a disability. Among those challenges are relational disturbances. Stubbornness in aging parents with increasing disability was reported by child caregivers. Stubbornness, in this context, is defined by “insisting, resisting, or persisting in their ways or opinions” as opposed to accepting advice from others [49]. Stubbornness was assessed by parents as well as children, and discrepancies between the fundamental ideas of what constitutes stubbornness were found. Typically, parents did not self-report levels of stubbornness that were equal to child's report of parental stubbornness. Also, greater child perception of stubbornness was correlated with higher level of disability in the parent [49]. Although stubbornness, as defined above, is most certainly an attribute of individual personality, this study serves to show the relational struggle between child caregivers and aging, disabled parents on the topic of autonomy. Resources for improvement or change in this aspect of quality of life for caregivers, of all family relationship types, and care-recipients is lacking. Research is needed to examine existing programs for caregivers and care recipients for indications that these programs could affect that dimension of the caregiving dynamic.

Middle-aged children spoke to challenges in supporting parents with increasing disability in a work by Kyungmin et al.[50] Children were tracked and surveyed over the course of 5 years, with researchers looking for changes in relationship between the parent and the child, increase of disability level in the parent, and changes in level of outside help or assistance in care. As parental disability increased, middle-aged child caregivers reported less positive relationship quality. Over the 5 year course, increased level of parental disability did prompt the acquisition of outside help, whether paid or unpaid, by the middle-aged child or by the parents themselves. Increased level of help or assistance in caring for the parent seemed to alleviate some of the negative relationship dynamic. However, the middle-aged child's response to the increase in disability was not affected by the outside help or assistance [50]. This information is fairly consistent with other caregiver literature in the expression of change in relationship due to disability. Family caregivers, in any form, typically do experience change in relationship because of the close proximity of the individual to themselves in terms of need and need frequency.

As sibling caregivers state in a work by Tozer and Atkin, there is an idea of past relationship mediating current relationship that creates caring relationship that narrates a rich and unique dynamic. Siblings recounted other themes seen throughout caregiving literature, of feeling “torn between their other relationships and commitments” in providing care for adult siblings with autism.[51] Furthermore, sibling caregivers expressed that service providers did not seem to understand or engage with the sibling in the caregiving capacity; siblings often felt excluded from discussions on their brother or sister’s health, as well as ignored in giving advice or suggestions.[51]

Resources for Caregivers

Resources available for family member caregivers are not very clear. Because of their non-professional status, many caregivers feel that they are not well prepared to assume the caregiver role [16]. A study focusing on female spouse caregivers concluded that the need for caregiver support is paramount, despite any ‘downplaying’ of the situation on the part of the caregiver [52]. Sibling caregivers spoke to the need for support, such as care for the future, burnout, or other familial issues [51]. Male spouse caregivers discussed the loss of autonomy that results from caretaking, as well as the need for consistent support in order to achieve some level of autonomy [53]. 24% of caregivers surveyed in the year 2012 believed that “more training and preparation would ease their burden” [44]. Wittenburg and Prosser suggest that better care is possible if the health care system changes to address the patient as well as the family.[15] Creating treatment plans involving the family of the patient could help optimize outcomes for both the patient and the family, including more complex outcomes such as psychological well-being [15]. In recognizing this suggestion, this review implies that the treatment plan itself could be a resource for caregivers, but is currently not recognized as such.

Some resources available for caregivers via internet have been researched. An internet-based workshop program was developed for use in caregivers who care for adults with intellectual disabilities. This workshop sought to enhance caregiving skills. For 6 weeks, 20-30 caregivers would log on 3 times a week for activities such as reading lessons, interactive components such as discussion centers, Webinars, or logging. The lessons and Webinars would present topics pertinent for caregiving, and that were disease-specific. Caregivers also self-reported baseline values for exercise and use of cognitive symptom management techniques. These baseline values were compared to 3 month outcome measures, looking for change in the values that could correlate with use or nonuse of the internet-based workshop. Almost all of the health indicators improved at a statistically significant measurement [54]. This implies that the social networking environment as well as the informational component of the workshop could create more positive health outcomes for caregivers of adults with intellectual disabilities. However, this study did not have the sample size to support such an implication [54].

A proposed study by Young et al. outlines the potential effects of a care-management program on caregivers of those who have multiple sclerosis (MS)[55]. The program is called the Multiple Sclerosis At Home Access (MAHA). This program's goal in the proposed study was to address the problems and gaps in inadequate care for patients with MS. To combat these gaps, the program provides many medical and social services to MS patients as well as caregivers in a home-access setting. This intervention is unique because of the focus that it has on the family members of the patient as well as the patient themselves. The implications of the findings of this study will assist providers in designing and using the specific patient-centered model outlined, as well as introduce new at home caregiving methodologies. The study was approved, and the results are pending the beginning of the study [55].

A study by Wilhite et al. sought to address the gap in resources for caregivers by creating a fitness intervention for individuals with developmental disabilities as well as their respective caregivers.[56] The intervention was 12 weeks long. The results of physiological measures indicated improvements in the 25 participants' total cholesterol and resting diastolic blood pressure; fitness measures that improved were muscular strength, cardiovascular fitness, as well as flexibility. Caregivers evaluated the program as part of the results, and spoke to the idea that they could help themselves while also being near their adult care recipient. As indicated by the author, there is a need for more programs such as this.[56] This sentiment was echoed by caregivers surveyed in the year of 2004. Among those caregivers that already took advantage of outside services, 79% said that they still felt the need for help with managing emotional stress, finding time for themselves, and balancing work and life responsibilities [43]. An environment modeled in the study by Wilhite et al. would provide caregivers with some of the resources that they need along with an outlet to improve health, especially considering the literature points to health risks associated with caregiving.[56]

Exercise as a positive activity for caregivers to do with care-recipients was also seen in a study by Menne et al.[57] This study replicated a program called *Reducing Disability in Alzheimer's Disease* (RDAD), that was initially developed by the University of Washington. The replication took place in the state of Ohio as a collaboration between several state organizations and the original developer, Linda Terri, PhD. Caregivers and respective care-recipients were recruited through the state organizations, and self-report survey data was collected from caregivers at baseline, after 12 educational, exercise, and/or behavioral management sessions, and 3 months post-baseline. The self-report data included caregiver strain divided into different dimensions of strain (i.e.- relationship, health, emotional, etc.). Caregivers cited exercise sessions as related to reduced relationship strain as well as health strain, and used that management technique most during the duration of the program. Although exercise did contribute greatly to caregivers, behavioral management sessions also were associated with a decrease in unmet needs of the caregivers [57]. This study shows that multidimensional programs serve as resources for caregivers, allowing them to meet their needs and reduce burden in a variety of ways.

Since publication of the above works on physical activity and caregiving, a systematic review of the caregiving literature was performed to describe the efficacy of physical activity interventions for caregivers on their own as well as their care recipients' physical activity levels, physical health, and psychosocial outcomes. Fourteen articles were selected for review. These fourteen articles represented a variety of exercise modalities, training periods, and exercise mediums (i.e.- group fitness, tele-exercise, etc.). The results of the review indicate that physical activity for caregivers could increase caregiver quality of life and overall well-being, as well as reduce distress. Although not significant, some evidence for reduction in caregiver burden was observed in the review. Group-based yoga interventions were also reported to be effective in enhancing physical and psychosocial outcomes for caregivers, although the literature is inconclusive if that is because of the exercise modality or the group environment. Care recipient outcomes were not adequately discussed in the context of the review, seeing as only two articles addressed those in conjunction with caregiver outcomes[58]. The results of this review support the hypothesis that physical activity could benefit physical and psychosocial caregiver outcomes, much like the two aforementioned studies. However, the review is limited to smaller sample sizes, as is common in population-focused training studies[58]. Further research should focus on larger groups of caregivers in order to clearly define benefits of physical activity for caregivers.

Built social networks can also serve as resources for caregivers. The social networks of caregivers who care for individuals with dementia were examined in a work by Cheng et al.[59] Chinese caregivers were surveyed and data from the surveys were examined for positive or negative levels of support within the social network, perceived amount of support from the social network, and correlation between positive or negative level support and positive or negative caregiver outcomes. Overall, caregivers reported small social networks, which could be expected with the limited time that caregiving leaves open. Satisfaction with emotional support was high, and instrumental support by social networks was not as often reported. As expected, negative level of support was correlated with negative caregiver outcomes [59]. It is important to note that these results may not be translatable across all caregiver populations in other countries, since it was a Chinese study done in the native language and in the context of native culture. However, this study does present implications that built support networks may provide emotional support for caregivers, but not the physical or instrumental support needed to alleviate burden.

Caregiver Health and Implications

Past research has shown that caregivers who experience mental or emotional strain are more likely to die than non-caregiving controls [60]. Present research expands on those findings, delving into specific mortality risk. According to a present-day study, caregiver burden can increase caregiver mortality up to 63% risk [16]. Outcomes of caregiver burden include poor self-care, sleep deprivation, weight loss, depression, anxiety, perceived social isolation, decreased social activity, decreased use of positive coping strategies, and suicide [16]. As demonstrated in the present literature, caregiving has an effect on the caregiver's cardiovascular function. It has been shown that caregiving can predict cardiovascular disease incidence in a caregiving population, with long-term caregiving associated with double the cardiovascular risk [61]. Caregiver health and well-being has also been shown be directly affected by the individual who is being cared for. Caregivers of individuals who have conditions that result in disruption of emotional relationship are extremely vulnerable to negative health outcomes.[15] Severity of dementia in the care-recipient was shown to be linearly related to endothelial dysfunction in the caregiving individual [62]. The more dependent the care-recipient, the greater the effects on caregiver quality of life [44].

The quality of care that the individual in need receives is also dependent on caregiver health and well-being. Long term effects of caregiving, some of which listed above, can change the caregiver's role from caregiver to care-recipient; entering the health care system themselves could mean that they are less able or completely unable to care for the individual in need [15]. Also, some literature suggests that caregivers can help model healthy behaviors for the care-recipients, serving as a stimulant to adopt those healthy behaviors [56].

Practitioner-Caregiver Relations

Gaps between practitioner and caregiver are very clear. 20-22% of caregivers surveyed in the year 2004 stated that they "need help talking with doctors and other healthcare professionals" and "making end of life decisions" [43]. Although some caregivers do have positive interactions with practitioners, feelings of "being invisible" as well as being "unrecognized" still exist [51] [16]. This might be because of the practice of 'downplaying' the severity of the caregiving situation, as discussed by Erikkson et al.[52] Striving for patient-centered care, in which the caregiver participates in every level of care planning, could close this gap [63]. Practitioners also, however, express feelings towards caregivers, stating in a work by Tozer and Atkin that some caregivers can be seen as "unreliable", which leads them to become defensive of the patient in question (2015). Practitioners' perceived pressure is high in dealing with families or family caregivers of patients; some practitioners believe it is because of the family caregiver's perception of their role in care facilitation [51]. Gaps also exist in the acknowledgement of caregivers as recipients of care. Caregiver burden is often neglected by practitioners as a source of viable illness [16].

Parent caregivers in Australia were interviewed on their experiences with care organizations in a study by Petriwskyj et al.[64] These experiences were used as snapshots into the power relationships that exist between parent caregivers and care providers in long-term care situations. Parents expressed that the power relationships were varied and different according to the organization being worked with (nonprofit versus profit), as well as dependent on the parent's initiative to take power. Parents often felt that governmental organizations were more difficult to communicate with, particularly disability services for the aging child. Parents also felt that their input at times was not valued by the systems that they were attempting to work with, thus altering the power dynamic in favor of other parties [64]. As illustrated in the previous paragraph, there are issues that exist between caregivers and service providers; the results of this study indicate, in addition to the research needed for caregiver interaction with physicians, a need for research into interactions between caregivers and service providers in long-term care settings.

Conclusions

What this review seeks to uncover is a unique gap in the caregiving literature. Specific family member caregiver relationships have been studied, as well as some of the intricacies that exist within family functioning when a member has a disability. Resources for caregivers have also been studied, and time has been invested in developing interventions for caregivers. However, there is not any literature that addresses collateral benefit of programs designed for care recipients. It is not yet known if caregivers perceive benefit from programs for their care recipients, and what kind of benefits could exist. Results from such a study could be used to create better interactions between caregivers and practitioners, and could enlighten practitioners to the home environments of individuals that they treat. Therefore, this review serves as the basis of knowledge for an investigation into the effects of a wellness program for people with disabilities on the family members or caregivers of those who participate.

Impact of a Student-Led Wellness Program for Individuals with Disabilities on Caregivers and Family Members

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Disability and Rehabilitation

ABSTRACT

Few studies have addressed impact of participation in wellness classes on caregivers or family members of individuals with disabilities. This is an important aspect of program evaluation that is neglected**.** **PURPOSE:** To evaluate effects of the wellness program on family members of caregivers of participants. **METHODS:** Eight program participants and nine respective family members or caregivers were selected for interviews. Interviews were then transcribed and analyzed into codes, categories, and themes. **RESULTS**: Five themes emerged from interview data: benefit of class to self, positive feelings about participation, relationship dynamic, importance of classroom interaction, and burden of class. Zarit Burden Interview scores indicated overall moderate burden in this sample of caregivers. **CONCLUSION**: This study demonstrated the effect of a unique program on the overall wellness of participants with disabilities and their respective caregivers or family members. Caregivers or family members do acknowledge benefits of the program to themselves. However, the program does not reduce caregiver burden significantly.

CHAPTER 3

RESULTS

Introduction

Approximately 12.6% of the population in the United States of America identifies as having a disability, as defined by American Community Survey (ACS) standards of an affirmative response to any of 6 questions on the topics of hearing loss or impairment, vision difficulty or impairment, mental and emotional functioning, physical functioning, and ability to complete activities of daily living.[65] Individuals with disabilities face many challenges with maintaining positive health outcomes over the lifespan. Notably, comorbidities such as type 2 diabetes, obesity, and hypertension are prevalent in this group.[14] Physical inactivity is a known contributor to these adverse health conditions, making regular exercise important in optimizing health for people with disabilities. Wellness programs that involve exercise have been developed specifically for people with disabilties.[13, 14, 66, 67] These programs have been shown to be beneficial and to be associated with positive health indicators. However, all wellness programs face the challenge of sustainability [68]. Individuals with disabilities have additional barriers with sustainability associated with reduced transportation options, greater financial challenges and the need for specific infrastructure[69-71].

There are an estimated 44 million adult caregivers in the United States of America.[15] These caregivers provide care to individuals of varying disease conditions and physical abilities, some of which include individuals with disabilities. Up to 90% of long-term care needed by adults is provided by unpaid family caregivers.[16] Caregiving can take large amounts of time, and can involve physically and emotionally strenuous tasks.[16, 44] A key aspect of being a caregiver is providing transportation. A lack of accessible or affordable transportation options for people with disabilities means that caregivers are often responsible for transportation. Caregivers also report financial hardship due to full-time caregiving, along with lower rates of employment due to lack of time to commit to employment.[16, 43]

Caregiver burden has been defined as "the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning."[45] This burden has implications on the mental and physical health of caregivers. Extreme burden can increase caregiver mortality up to 63% risk, as well as predict incidence of cardiovascular disease risk.[16, 61] Psychological and psychosocial outcomes of caregiver burden include poor self-care, sleep deprivation, weight loss, depression, anxiety, perceived social isolation, decreased social activity, decreased use of positive coping strategies, and suicide.[16] The implications of caregiver burden extend to the quality of care the care recipient receives. Some literature suggests that caregiver adoption of healthy behaviors may in fact stimulate care recipients to adopt healthy behaviors as well, thereby increasing outcomes for both individuals.[56] Resources that provide relief for caregivers are not clear. Although it has been an area of study in several academic fields, consensus on ways to relieve caregivers has not been established. Pharmaceutical and psychological means of providing interventions for caregivers have been explored, with significant but small effects on relief of caregiver burden.[16] Other means of providing relief have been explored, including physical activity, with more positive but also not conclusive results.[57, 58]

At the University of Georgia, practicum course credit is offered to students in exchange for service to individuals in the community with disabilities.[14] The participants in the class with disabilities come to the campus to receive supervised exercise training from undergraduate students, most of whom are pre- physical therapy, occupational therapy, or physician's assistant tracks. These students are paired with an individual or more than one individual and work with them over the course of the semester. Students and community member pairs or teams are supervised by the instructor of record, program creator, and returning students; three levels of supervision is enacted in order to better serve both the participants and the students. [14] An area of current literature not yet addressed is the idea that improving outcomes for the care recipient might collaterally impact outcomes of the caregiver. This study is the first to understand and evaluate effects of this, or any, student-led wellness class on caregivers or family members. The aims of this study are to identify potential effects of the wellness class on caregivers or family members and to gauge the strength of these effects.

Methods

Study Design

This study uses an interpretive approach to address the study aim. Interpretive traditions state that human interpretation is the beginning of developing knowledge.[17] This study also used narrative inquiry to interview individuals on the experiences and stories of being a caregiver or family member to someone with a disability, as well as someone who participates in the student-led wellness class. In narrative inquiry stories construct and shape experiences, as well as provides a way for researchers to understand how individuals understand and create an actionable reality. In this way, knowledge is co-created by the participant and the researcher, both working in conjunction to create an image of reality that pertains to the participant.[72]

Participant Recruitment

Participants were recruited from the wellness class for individuals with disabilities[14]. Inclusion criteria included at least one semester of experience in the course and the ability to understand and comprehensively discuss interview topics. One semester of experience was chosen as criteria in order to ensure that participants had enough experience with the course to speak to the effects of the course. From those who qualified for the study, caregivers or family members were selected for interviews. Inclusion criteria for caregivers included familiarity with the wellness class and primary responsibility of the individual in the course. This study was approved by the Institutional Review Board of the University of Georgia, and informed consent was obtained from all caregivers and participants in this study.

Data Collection

Interview guides were written by the researcher and received review from co-authors before interviewing commenced, following standard qualitative practice.[73, 74] Respective caregivers or family members of participants in the wellness class were interviewed using a different interview guide than that of the participants. The topics of the interviews with caregivers or family members included, but were not limited to: acquisition of loved one's disability, daily life interactions with participant before and after beginning the class, caregiving burden, changes in relationship with loved one since participation in the class, specifics of role as caregiver, etc. Participants in the wellness class were interviewed using a specific guide. The topics of interviews with participants in the wellness class included, but were not limited to: acquisition of disability, duration of participation in the wellness class, perspectives on participation in the wellness class, changes in self due to wellness class, daily life interactions with caregiver or family member before and after beginning of class, and changes in caregiver relationship since beginning participation in the wellness class. Interview questions were phrased in a way that elicited recollection of certain events, or requests for anecdotal examples, followed by probing questions. Once again, interview questions were phrased to elicit recollection of distinctive memories as well as answer in anecdotal examples, followed by probing questions. Interviews lasted approximately a half hour per participant and an hour per caregiver or family member.

Interviews were scheduled by the researcher and the participants and family members or caregivers. Location for the interviews was determined prior to the meeting. Two participants and respective caregivers or family members were interviewed in their homes due to transportation difficulties. All other participants and their respective caregivers or family members were interviewed on campus in a neutral, intimate area. Interviews were conducted one-on-one, with the exception of one caregiver and class participant, with participants interviewing alone and respective caregivers or family members alone, and caregivers were administered the Zarit Burden Interview short form questionnaire without the care recipient present[75]. This was done for the sake of collecting authentic data without bias or without social pressure to answer in a manner deemed appropriate by other parties present.

Data were pulled from the audio recordings and transcripts of the interviews. Interviews were recorded and immediately transcribed by one of the researchers (MW). Upon transcription, all caregivers or family members and participants in the course were given a pseudonym. Other identifiable persons mentioned in the interview were given pseudonyms or simple titles (i.e.- “doctor”). Other identifiable data were given simple titles, such as cities, hospitals, or schools. In addition, the researcher took observational notes of the participant’s demeanor, interview environment, and any additional information taken in the context of the researcher’s observations during the interview. Historical notes of the researcher's prior knowledge of the participants were also taken to provide context to potential topics covered in the interview.[73]

Zarit Burden Interview short form questionnaire data was taken prior to the face-to-face interviews with caregivers or family members.[45] Caregivers or family members completed and returned the paper questionnaires to the researcher. Scores for individual items as well as global scores were entered by the researcher into an Excel document for later review in conjunction with interview responses.

Data Analysis

Data analysis was conducted after each interview was transcribed. Transcripts were analyzed for reoccurring themes. This was done by first coding interviews, using verbatim quotes from the transcripts, as per standard protocol in qualitative data analysis.[73] Each interview was coded separately. Similar codes were then placed into categories. Categories spanned across interviews and caregivers. Categories were then grouped by similarity of concept into themes, which also spanned interviews and caregivers. These common themes were used to analyze overall perspectives of caregivers or family members, as per standard protocol in thematic analysis.[73] All analysis and transcription was completed by the primary researcher (MW) without the use of analyzation software. External advisement from co-authors was sought at different stages of the analysis, as suggested in the form of peer review.[74] The outside consultation was used as a consensus report, as well as a sensitivity and validity check of the primary researcher's conclusions.

Zarit Burden Interview questionnaire scores were calculated for each caregiver or family member. Those scores were kept for the respective members, as well as averaged across the whole sample of caregivers or family members. Scores were used as supplementary data to the interview responses.

Results

Demographic Information

A total of 8 participants, from the wellness class of 24 participants, were selected for interviews. These 8 participants were selected for various reasons, some of which being definite presence of a caregiver, duration of class participation, consent to participate, etc. From these participants, 9 caregivers or family members were selected for interviews and distribution of Zarit Burden Interview questionnaires. Overall, the group was representative of individuals with multiple disability types, ages, races, and genders as well as family structures. Different forms of family member caregivers were also represented in this group. Heterogeneity of the group was a primary goal, in order to find a sample that represented the class participants as best as possible. Table 1 summarizes the available demographic data for the sample.

Interview Data

Five themes emerged from the interview transcriptions (Figure 1). These were: benefit to self from class, burden of class, positive feelings about participation in the class, relationship dynamic, and importance of classroom interaction.

Benefit of class to self

Interview responses suggested that caregivers or family members experienced moderate benefit from their care recipient's participation in the student-led wellness program (Figure 2). This perceived benefit could be separated into physical and emotional or mental domains. Caregivers or family members did see the program as valuable to themselves and a benefit in those respects. Emotional or mental benefit of the class seemed to commonly be expressed in the form of hope or relief of burden. Physical benefit to the caregiver or family member was partially determined by the disability that the care recipient had. The wives and sister in this sample discussed benefits of the class to themselves more than the husband or the mothers in the sample.

Positive Feelings about Participation in the Class

Caregivers or family members were positive regarding their care recipient's participation in the wellness class (Figure 3). It was often noted in interviews that the class did provide physiological and psychological benefit to class participants, which could have led to the caregivers' positive feelings surrounding participation. The feelings could be further separated moderate and strong positive feelings, based off of the researcher's assessment of vocal cues of emotion in the audio recordings of the interviews. Stronger statements of happiness around participation were made by some caregivers or family members. It was clear the class participation was valued from the caregiver or family member perspective.

Relationship Dynamic

Interview data with caregivers or family members indicated the class positively impacted relational dynamics between participants and themselves (Figure 4). The impact could be felt in additions to the relational dynamic, as well as overall enhancement. Caregivers expressed that their care recipient's participation in the class resulted in a change in their relationship. For some caregivers, it was a change in fundamental role. Others expressed that the change was more in day-to-day interactions. Participant interview data corroborated the caregiver interview data. Participants were able to note changes in relationship with caregivers after commencement of participation in the wellness class. Although participants were able to identify a positive change, few of the participants elaborated on the specificity of the change. Where caregivers were able to see changes in role or changes in interaction, participants only identified change.

When analyzed for differences among groups, mothers did not express change in relationship due to care recipient participation or effect on relationship due to care recipient participation as often as other caregivers or family members.

Importance of Classroom Interaction

Caregivers or family members noted that the interaction seen in the class is different than that of other therapies or activities that their care recipients take part in (Figure 5). They cited the student interactions as being the reason for the difference in overall atmosphere of the class when compared to atmosphere of other therapies. This interaction was spoken by caregivers to be of high importance to the program participants. The caregivers' estimation of importance of the interaction was corroborated by participant interview data. Participants all spoke of interaction with student trainers as being a motivating factor, a source of encouragement, a source of community, as well as a pleasurable entity to the course itself. The interaction was also important to the caregivers or family members; this was in terms of perceived participant benefit from the interaction, as well as own personal benefit from interaction. Overall, caregivers spoke of a moderate but positive connection that they made with the students, despite the fact that they themselves were not participating in the wellness program.

Burden of Class

Caregivers and family members perceived strong burden from their care recipient's participation in the class (Figure 6). The burden was related to transportation, which is a very pertinent issue to this population group. 5 of the 8 participants in our study required consistent transportation assistance from a caregiver to attend the wellness program. Despite the burden that the class caused, caregivers or family members stated the class was too beneficial for their care recipients to not come.

In this sample, wives did discuss burden more than other caregivers or family members. Two wives extensively discussed burden, while only one mother in the sample discussed burden.

Zarit Burden Interview

Overall, the Zarit Burden Interview short form global score average showed moderate burden across caregivers or family members (13.44). There were a range of scores, with two caregivers reporting lower caregiver burden and one caregiver reporting high caregiver burden. Higher scores were associated with more frequent occurrences of statements relating to burden in the interviews. This was to be expected, since the Zarit Burden Interview serves as a measure of overall caregiver burden. However, other themes gathered from the interview data were not related to Zarit Burden Interview scores; caregivers were able to identify with positive themes independently from Zarit Burden Interview score.

Discussion

The purpose of this study was to evaluate potential benefits to caregivers or family members from their care recipient's participation in the student-led wellness class. The purpose of this study is unique; therefore, at present, not much evidence exists in the literature to compare these results to. Overall, caregivers or family members expressed positive feelings towards their care recipient's participation. However, this participation did not come without a cost to the caregiver or family member, indicated by burden. Despite the burden, caregivers or family members seemed to believe that the wellness class was worthwhile for the care recipient as well as themselves.

Socially, this wellness class seemed to have a great impact on caregivers or family members. This was demonstrated by the emphasis on student involvement and emotional benefit of the course. Social outlets have been demonstrated to be important to the emotional functioning of caregivers or family members, particularly in the dimensions of burden, support satisfaction, and overload.[59] Caregivers or family members expressed that this class was a source of hope and emotional benefit, which could also be a factor in determining its social value. This finding is consistent with other data pertaining to social support networks of caregivers, which plays a vital role in their health and wellbeing.[76] If caregivers feel more connected and more invested, involvement in the class could increase on their part; this was demonstrated by some caregivers or family members when discussing the role of the students in the course.

Although primary interaction with the student fell on the participant, caregivers or family members still caught residual benefit of this interaction. Some felt so inclined to compare students to family members, or to angels. Some caregivers identified residual benefit as being related to interactions with their care recipient, stating that the presence of the students in the life of the care recipient could have resulted in a change in the care recipient's behavior and mood. This perception was corroborated by interview data from participants; participants did state that interaction with the students was something socially and emotionally valuable. These emotional benefits for the participant carried over into interactions outside of the class; the implications that this presents are imperative to a cost-benefit analysis of any wellness program. The fact that caregivers or family members could indicate changes in their care recipient's mood or behavior indicates that wellness programs have the potential to affect more individuals even outside of the construct of the program. These changes were perceived as strong and positive by caregivers or family members, and some of them cited this as a reason why interactions with care recipients have gotten better. The social interaction or residual interaction is concluded to be important to the value of the class from the estimation of the caregiver or family member, because it does seem to supplement the emotional benefit that caregivers or family members perceive from the course.

Although in this study the benefit of caregiver interaction with students was considered to be indirect, other work suggests that caregivers of individuals with disabilities respond well to working with students.[56] Further, some research does suggest that caregivers perceive significant social support from healthcare professionals, because of their proximity to the patient, to the caregiver, and to the overall situation.[76] Although the students from this course do not have credentials to match those of healthcare professionals, they serve a role comparable to pseudo-healthcare professionals in terms of the proximity of the relationship. This information, while important, contributes to a larger literature that focuses on gaps in communication between caregivers and healthcare professionals.[16, 51, 52, 63] The role students specifically could play in this interaction, based from the above data from the current study and correlating studies, warrants further investigation.

Physical benefit on the part of the caregivers or family members in this sample was attributed to increased fitness of the care recipient. This dimension of perceived benefit was not as strong as perceived emotional or mental benefit; there are multiple reasons why that could have been the case for this sample. Because of the nature of some of the care-recipient’s disability and progression, physical improvement may not be as viable of an outcome as it is for others. Therefore, some care-recipients could increase functional mobility or even health outcomes whereas others were working toward maintenance of existing function. The caregivers of care-recipients who were able to make functional gains acknowledged those gains in interviews. By making those functional gains, care-recipients became more independent and lessened some of the burden of certain tasks, like transfers, on the part of the caregiver or family member. For those caregivers or family members, physical improvement of their care-recipient was important to acknowledge in the interview. Also, physical intimacy in the setting of the wellness class is important to address; for some of the care recipients, the physical touch of assistance in movement is something that is not often received. This could create another area of emotional benefit for class participants, that could have carryover effects for the caregivers. Physical improvement in care-recipients was associated with increased emotional or mental benefit; particularly, emotional benefit because of witness of physical gains. Caregivers who were able to see physical improvements cited those improvements as being agents for increasing morale or even hope. Thus, physical benefit did not exist without also emotional benefit in this sample of caregivers or family members. What this data shows is the ability for care-recipient improvement to impact caregivers in multiple dimensions; by improving patient outcomes, it could also be that practitioners also improve outcomes for the caregiver or family member related to mental health, physical health, and emotional stability. This was seen in a study by Wilhite et al. that examined outcomes for caregivers and care-recipients after an exercise intervention; however, the intervention was catering to both caregivers and care-recipients, so inferences made from the results of this study are not directly comparable to any inferences made from the results of the current study.[56] Better patient care in the home could be a residual benefit to empowering caregivers or family members, which is the outcome that all health practitioners aim to improve.[77] Therefore, this data demonstrates a possible effect of wellness programs on overall healthcare and outcomes related to both the care-recipient and the caregiver or family member.

Burden in the context of this class was discussed in relation to transportation. Transportation issues are commonly cited as a barrier to exercise or wellness program participation in this population group, so these results were to be expected.[70] Although public transportation does exist in this geographical location, it is particularly difficult for individuals with disabilities to access. Because the duty of providing transportation lies primarily on caregivers or family members in this sample, it is logical that this class provides yet another duty on top of what could already exist in terms of healthcare alone. Burden could have been perceived as being great in this sample because of the age of the sample. As one caregiver stated, the individuals in this sample are older adults with increasing health needs of their own. Adding items to the schedule of a care recipient seemed to be a point of contention between care recipients and caregivers in this sample, with hesitation lying in the fact that caregivers would be without any kind of break. However, in the case of this class, caregivers or family members stated that the burden was outweighed by the benefit. Therefore, this class might not have contributed quite as heavily to overall caregiver burden because of the ability the class had to impact or benefit caregivers or family members.

The realization of the differentiation between caregiver burden associated with the class and overall caregiver burden is significant, especially in cases of caregivers or family members with higher levels of caregiver burden. The Zarit Burden Interview short form data indicated that there was one caregiver or family member who felt a higher level of overall caregiver burden than the other caregivers or family members in this sample. The Zarit Burden Interview short form global score was corroborated with interview data for that particular caregiver or family member, who expressed on multiple occasions a sense of feeling overwhelmed with the duties of caring for the care recipient as well as the implications of the duties on physical and mental health. Similar patterns were identified in interview data for other caregivers or family members, with Zarit Burden Interview short form global scores supporting the level of caregiver burden discussed in the interview. However, all caregivers in this sample, including the one who expressed a higher level of caregiver burden, expressed in the interview that the value of the class outweighed the burden it also presented. In fact, the caregiver who had the higher level of caregiver burden explicitly stated that the benefit far outweighed concerns of the program. This link between the qualitative data and the quantitative data in this study provides validation for both sets of data, but it also validates the idea that the wellness class was seen to be a separate entity than other activities that contributed to burden on the part of the caregiver or family member. This could be because of the perceived benefit that was discussed previously; for those caregivers or family members with higher levels of caregiver burden, programs that provide benefits could be extremely important in aiding an environment conducive for production of positive mental and physical health outcomes.

Some limitations exist in terms of generalizability of this data. Because this sample is specific to this wellness class, it cannot be concluded that caregivers or family members associated with other wellness programs would express the same thoughts and feelings that the caregivers or family members in this sample did. In addition, this sample is from a geographically-specific area in the state of Georgia. This environment and social or cultural climate could have affected the opinions of individuals interviewed for this study. This sample is not balanced in terms of family member relationship; there was only one husband in this sample with the majority of caregivers or family members being female (wives, mothers, etc.). This does not represent an evenly distributed sample of males versus females, which could also be attributed to the gendered nature of caregiving.[30] In addition, the heterogeneity of the sample in terms of socioeconomic status, education level, or cultural background could make this data less generalizable. For these reasons, the interview data and opinions or thoughts of caregivers or family members in this sample may not be generalizable.

While not a formally designed cost-benefit study, this study has provided important cost-benefit analysis information for the student-led wellness program. It has been discovered that caregivers or family members see themselves as beneficiaries to their care-recipient's participation in the program; therefore, this study is the first to our knowledge to identify indirect benefit of wellness programs for individuals with disabilities. These benefits exist in a physical and emotional or mental realm, with emotional or mental benefit being strongest. Special consideration must be given to the circumstances in which this class exists; because of the role of the students in this wellness class, the benefits of social interaction are also felt by caregivers or family members. Together, these benefits outweigh the burden presented by transportation in this sample of caregivers or family members. This study has brought evidence to the literature that indirect benefit exists, which warrants further research. Examining the area of indirect benefit of wellness programs on social circles, extended families, and workplaces is a future direction and possible extension of this study.

Table 1. Demographic information for sample.

Caregiver Pseudonym	**Relationship to Participant**	**Sex**	**Age Range Approximation**	**Educational Level**	**Participant Disability**
Sabrina	Sister	Female	Mid-life		TBI (traumatic brain injury)
Pearl	Mother	Female	Later-life		TBI (traumatic brain injury)
Sally	Wife	Female	Mid-life		Stroke
Marie	Wife	Female	Later-life	Graduate studies	SCI (spinal cord injury)
Janice	Wife	Female	Mid-life	Graduate studies	Parkinson's Disease
Rebecca	Mother	Female	Later-life	Graduate studies	Intellectual Disability
Leah	Mother	Female	Later-life		Cerebral Palsy

Hannah	Wife	Female	Later-life		Blindness
Harry	Husband	Male	Later-life	Graduate studies	Cerebral Palsy

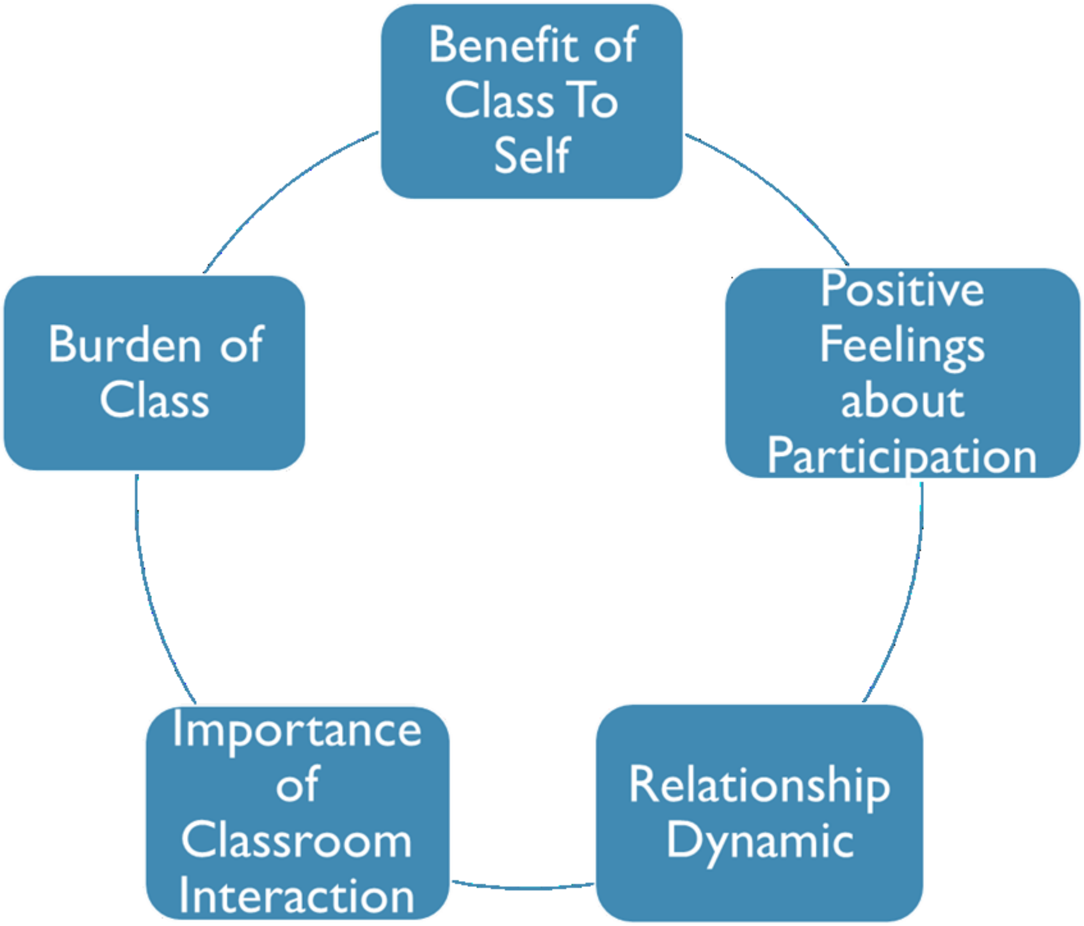


Figure 1. Themes and relationships from interview data.

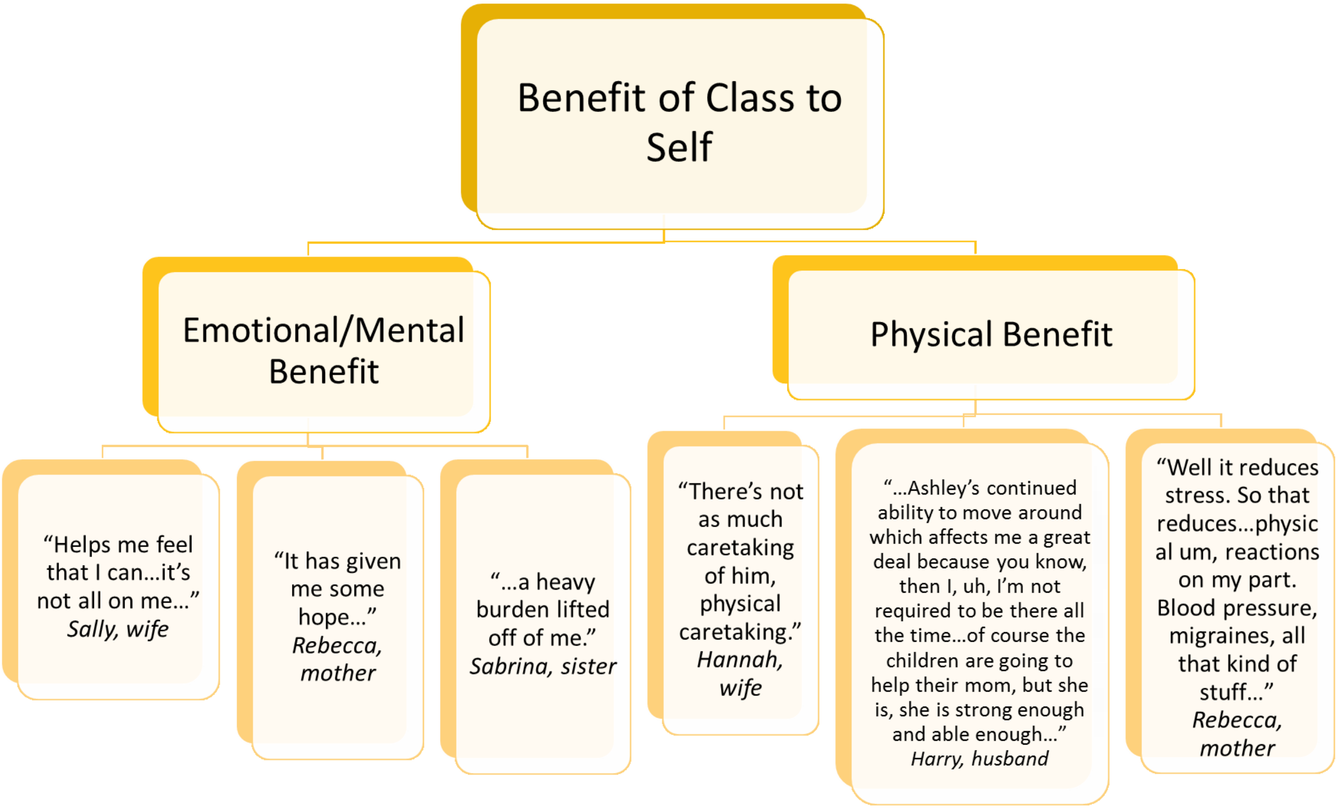


Figure 2. Benefit of class to self interview data summary.

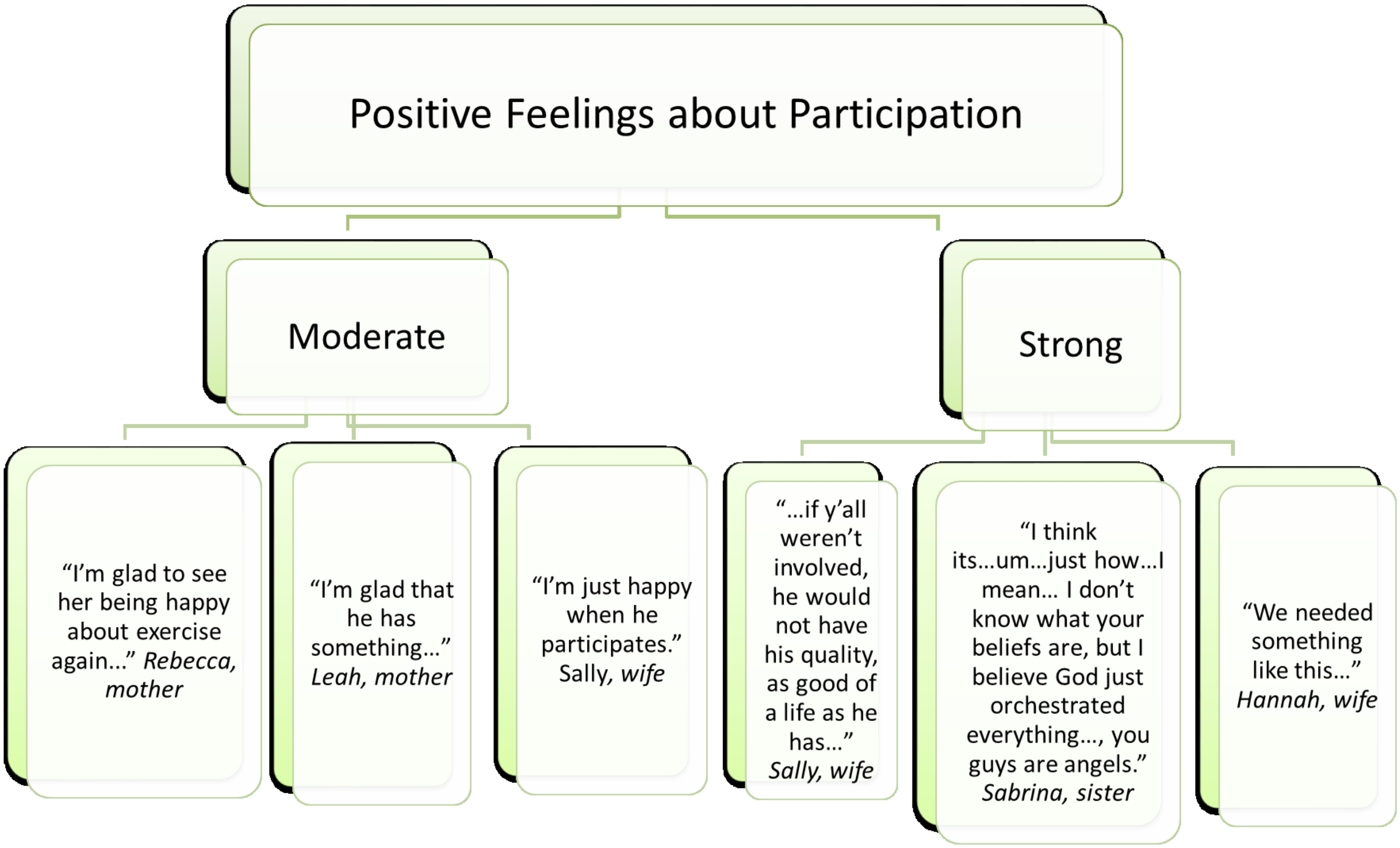
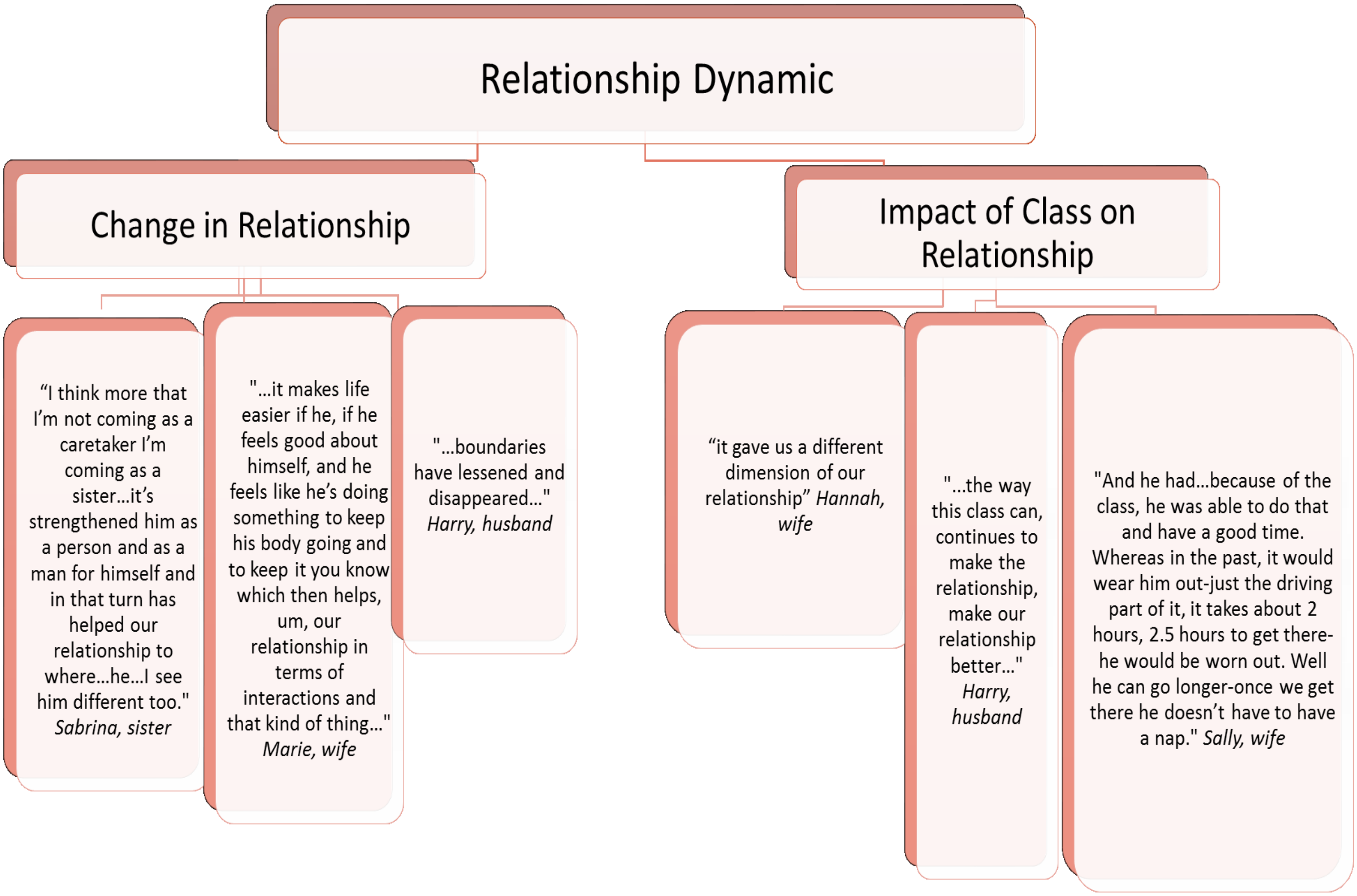


Figure 3. Positive feelings about participation interview data summary.



"I think more that I'm not coming as a caretaker I'm coming as a sister…it's strengthened him as a person and as a man for himself and in that turn has helped our relationship to where…he…I see him different too." *Sabrina, sister*

"…it makes life easier if he, if he feels good about himself, and he feels like he's doing something to keep his body going and to keep it you know which then helps, um, our relationship in terms of interactions and that kind of thing…" *Marie, wife*

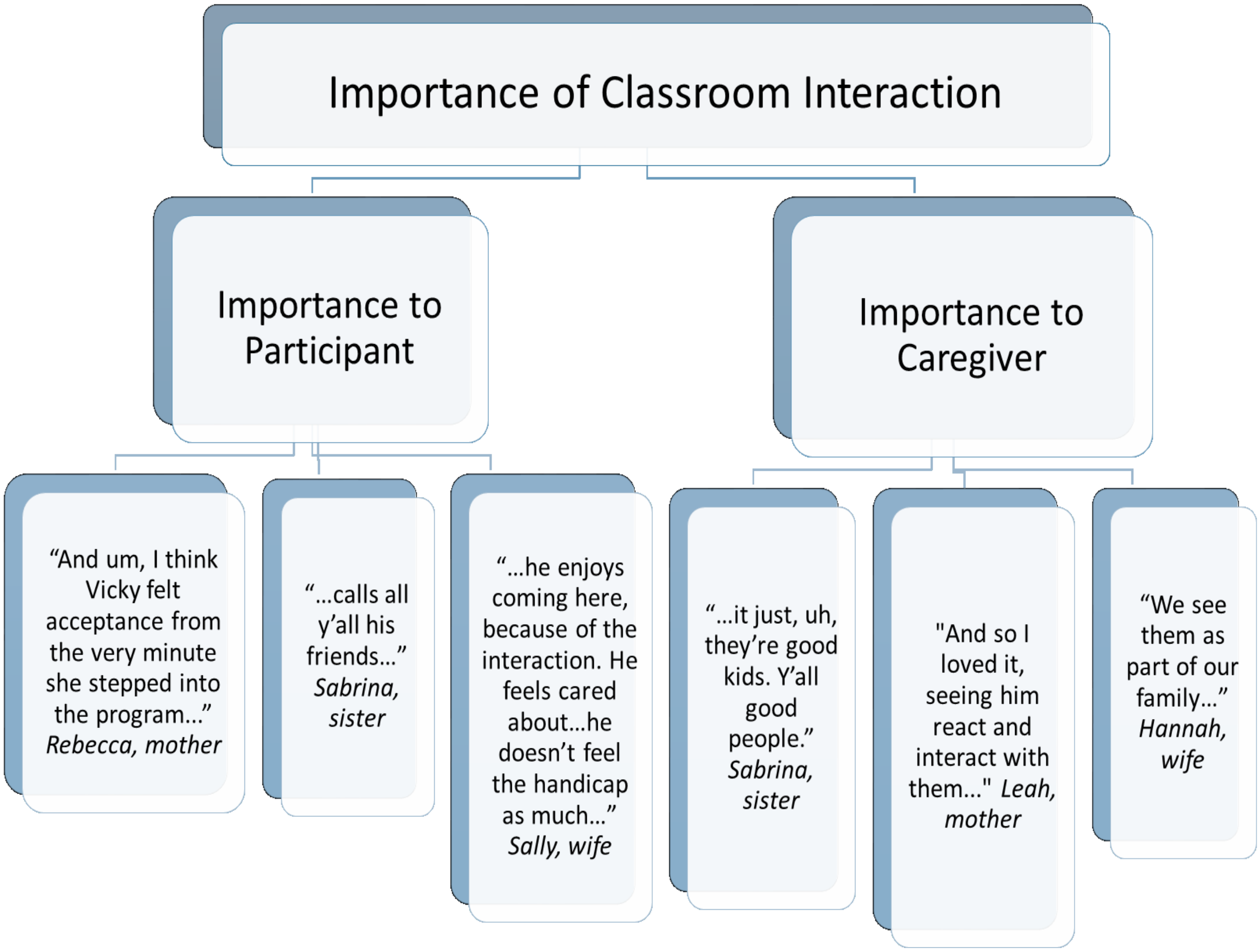
"…boundaries have lessened and disappeared…" *Harry, husband*

"it gave us a different dimension of our relationship" *Hannah, wife*

"…the way this class can, continues to make the relationship, make our relationship better…" *Harry, husband*

"And he had…because of the class, he was able to do that and have a good time. Whereas in the past, it would wear him out-just the driving part of it, it takes about 2 hours, 2.5 hours to get there-he would be worn out. Well he can go longer-once we get there he doesn't have to have a nap." *Sally, wife*

Figure 4. Relationship dynamic interview data summary.



"And um, I think Vicky felt acceptance from the very minute she stepped into the program..." *Rebecca, mother*

"...calls all y'all his friends..." *Sabrina, sister*

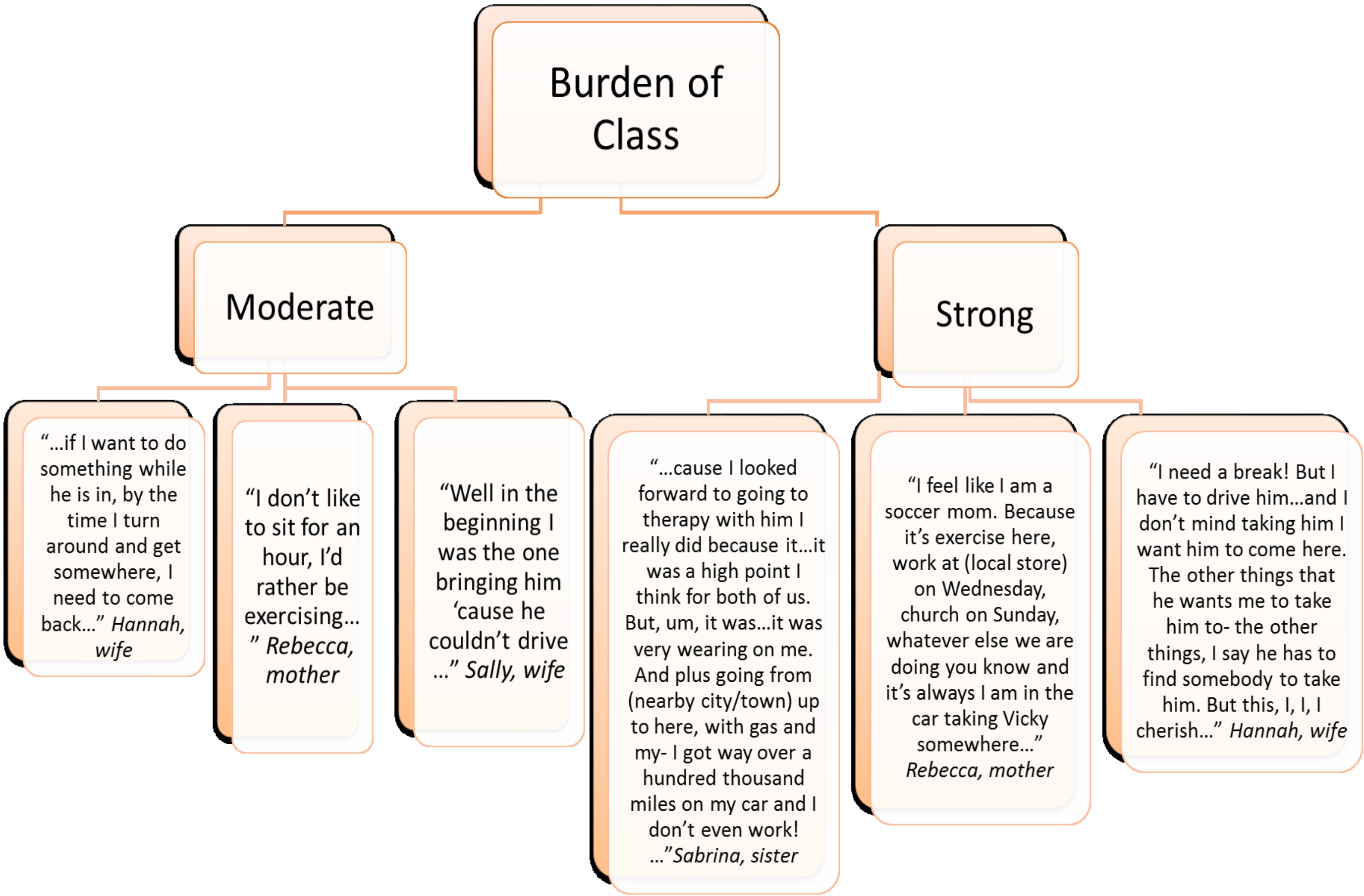
"...he enjoys coming here, because of the interaction. He feels cared about...he doesn't feel the handicap as much..." *Sally, wife*

"...it just, uh, they're good kids. Y'all good people." *Sabrina, sister*

"And so I loved it, seeing him react and interact with them..." *Leah, mother*

"We see them as part of our family..." *Hannah, wife*

Figure 5. Importance of classroom interaction interview data summary.



"…if I want to do something while he is in, by the time I turn around and get somewhere, I need to come back…" *Hannah, wife*

"I don't like to sit for an hour, I'd rather be exercising…" *Rebecca, mother*

"Well in the beginning I was the one bringing him 'cause he couldn't drive …" *Sally, wife*

"…cause I looked forward to going to therapy with him I really did because it…it was a high point I think for both of us. But, um, it was…it was very wearing on me. And plus going from (nearby city/town) up to here, with gas and my- I got way over a hundred thousand miles on my car and I don't even work! …"*Sabrina, sister*

"I feel like I am a soccer mom. Because it's exercise here, work at (local store) on Wednesday, church on Sunday, whatever else we are doing you know and it's always I am in the car taking Vicky somewhere…" *Rebecca, mother*

"I need a break! But I have to drive him…and I don't mind taking him I want him to come here. The other things that he wants me to take him to- the other things, I say he has to find somebody to take him. But this, I, I, I cherish…" *Hannah, wife*

Figure 6. Burden of class interview data summary.

CHAPTER 4

DISCUSSION

First and foremost, I believe it is of importance to note the context in which this study took place. This is the first qualitative study from the Exercise Muscle Physiology Lab in the Kinesiology department. Neither my advisor nor I had prior experience performing formal qualitative research or assessment; this presented challenges for us moving forward with the idea of the project. Fortunately, the assistance and mentorship of a faculty member with extensive experience in qualitative research was obtained and generously offered. That mentorship, in addition to acquired coursework and extensive reading, served as my training in qualitative methodology and framework. For individuals in the future who would like to do perform qualitative research outside of field, it is highly recommended that you have mentorship from an expert faculty; without such mentorship, this project would not have been possible. Any coursework on the foundations of qualitative frameworks, qualitative traditions, or methodology would be highly recommended.

In terms of the existing literature, to my knowledge, this is the first study to examine collateral benefit of a wellness program for individuals with disabilities. Current caregiving literature has examined benefits of interventions directed towards caregiver health outcomes, as well as comparisons of modalities of interventions for caregiver health outcomes. In the context of wellness programs for individuals with disabilities, current literature places caregivers or family members in the role of evaluator of a program’s effectiveness, agenda, and weaknesses, among other variables. Therefore, this study places caregivers or family members in unexplored context- beneficiaries of programs that their care recipients participate in.

The qualitative approach was chosen because of our belief that this would be the most effective approach to address the research question. Although survey data could have been exclusively used to collect responses on the topics discussed in interviews, survey data would have been lacking crucial detail. The heterogeneity of the sample, while very important to the research design and purpose, created different contexts and individual differences in circumstance that would have been amiss to try to generalize by distribution of a survey. In addition, because of the smaller sample size, in-depth interviews were possible to conduct without misuse of resources or added strain. Contextually rich data was imperative to address the research question and surrounding circumstances that would influence perceptions or attitudes related to the research question; in-depth interviews gave us that quality of data. The Zarit Burden Interview short form questionnaires were given as a way to supplement the interview data. It could serve as a validation tool, but also could serve to provide more context to each caregiver or family member's perception of how burdened they were. While this was a diverse sample, the conclusions from this sample were quite uniform. This presents important implications for future studies on this subject; effects of programs like this might be uniform despite differences in personal and physical circumstance.

The findings from this study contribute to an important part of program evaluation, which is cost-benefit analysis. Although the findings are not attributed to direct cost-benefit, it is extremely important to remember indirect cost-benefit as part of the larger 'whole' of any program. The data from this study did reveal that there are indirect costs as well as benefits, as outlined by caregivers or family members of those who participate in the class. To our knowledge, this is the first study in which caregivers or family members have identified indirect benefits for the sake of program evaluation and impact. The results of this study have indicated that there are areas to address for the sake of program development and improvement for caregivers or family members of those who participate. The results have given us, as program coordinators and directors, actionable items for improvement of our wellness class; for example, inclusion of participants' caregivers or family members in exercise so that caregivers or family members do not feel as if they are not getting direct benefit from transporting the participant to the class.

Caregivers or family members were able to perceive benefit from the care recipient's participation in the course. Although that seems to be a small realization, it is rather significant. This realization brings fresh motivation. The wellness class for individuals with disabilities has now been shown to affect more than just those who participate, giving academia the ability to positively influence the surrounding community. As professionals in academia, it can be difficult to find ways to serve those in the community around us within our capacity; however, this study has demonstrated that it is possible within this context. For students, this study can demonstrate the effects of what they perceive as 'every day' and the meaning of the interactions that they have with participants' families and caregivers. It is the hope that students can carry the meanings of the interactions that they have with participants, families, and caregivers on into their next stage in life, and this study could help solidify those meanings to students who take the course.

Some caregivers or family members in this sample spoke of physical benefits to themselves because of their respective care recipient's participation in the wellness program. This was not a consensus-confirmed benefit; because of the nature of the irreversibility of some of the disability states represented by this sample, some care-recipients did not change as much as others in terms of physical improvement. For those who did report perceived physical benefit, it mostly pertained to tasks of daily living, like transfers, that became less taxing for the caregiver because of physical gains made by the care-recipient. A large portion of caregiving burden can be attributed to physical tasks such as these. As demonstrated in this sample of care recipients and caregivers, improving health outcomes of care recipients can also improve outcomes for caregivers. Physically, symptoms of caregiver burden such as exhaustion, migraines, or weakness can be affected by indirect action; this is contrary to much of the current research focus, which is upon interventions directly upon caregivers to improve outcomes. Studying other programs for effectiveness of physical activity on health outcomes of participants could lead to examination of the quality of life or caregiver burden levels of caregivers of the participants.

Physical benefit to the caregiver was also associated with emotional or mental benefit. The caregivers who reported physical benefit also reported feeling relieved or as if less pressure was on them to fulfill physical duties in caregiving. It was apparent that the two coexisted, and physical benefit was not present without also emotional benefit. However, emotional benefit could stand alone. In fact, all caregivers reported emotional or mental benefit, whereas not all could report physical benefit, as described above. This demonstrates the importance of the class to caregivers or family members in terms of morale or emotional support. Current literature has highlighted the importance of support networks in improving both mental and physical caregiver outcomes; through support networks, caregivers or family members can achieve morale and support through community and shared experiences. When one looks at the mental or emotional benefits that caregivers expressed in this sample, it does mimic the effects of recognized and perceived camaraderie (i.e.- not feeling alone, feeling as if someone understands, feeling as if their opinion is valued, etc.). The implication of this finding might be that caregivers or family members find this class to provide community. This is supported by some of the caregivers or family members finding relationships with students to be valuable, and even discussing opening their homes to students who have worked with care-recipients after the semester is over. Because the class does not directly impact the caregivers or family members, this finding is unexpected. It seems to speak to the shared experience of interaction with the care-recipient as being a community-builder rather than actual communication. Knowledge of this phenomenon can certainly change the perspectives of students who take this course, as well as future instructors of the course.

Providing caregivers or family members with opportunities to see their loved ones making physical or emotional improvements could be imperative to attenuation of caregiver burden. However, this does not negate the presence of the burden. For this sample of caregivers or family members, burden was part of the care-recipient's participation in the class; caregivers or family members expressed burdens of the class in interviews. Burden was mostly centered around transportation. Transportation is one of the major barriers to exercise that individuals with disabilities face. Although some individuals are able to drive, it is quite expensive to obtain an accessible vehicle, which many individuals cannot afford. Public transportation is also an option for some individuals, depending on their geographic location. However, once again, issues of accessibility can hinder individuals with disabilities from using public transportation. Therefore, the burden of transportation often falls on caregivers or family members, who also have tasks at hand and needs of their own. In order for caregivers or family members to transport an individual with a disability to a location, it usually means that the caregiver or family member would need to sacrifice a task or more than one task on their agenda, and also to be available at the time that the care-recipient would need them to retrieve him or her. This burden can interfere with career, school, or personal aspirations of the caregiver or family member. Because caregivers or family members had to be available to transport care-recipients to and from the wellness class, they did perceive burden because of the things they could have been doing otherwise. However, caregivers or family members were able to see past the burden in the case of the wellness class, which differed from other activities the care-recipients participated in. Caregivers or family members in this sample did state that the benefit of the class outweighed the burden the class caused them. This could mean that when presented with emotional or mental benefit, caregivers or family members might feel less burdened. Although this may seem like a small discovery, I do believe that it warrants further pursuit for the sake of caregivers or family members who have opportunities to enroll care-recipients in programs like this or community programs in general.

Student-participant interaction was discussed as being highly influential for satisfaction with the wellness program. This interaction, although primarily between participant and student or students, also was shown to have residual effects on the caregivers or family members in this sample. The interaction with students seemed to affect caregiver or family member morale in multiple facets. Caregivers felt relief in seeing their care recipient’s working with the students as well as encouragement in seeing the acceptance that care recipients found in the program. It was also stated by multiple caregivers or family members that the students were able to bring something unique to interactions that was notably different than other healthcare professionals that they had interacted with. It is not known why caregivers or family members perceived interactions with students differently than with other healthcare professionals; however, it was apparently clear that caregivers or family members thought that the interaction with students was positive, and could have been more influential than interactions with other healthcare professionals. Current literature does support a communication gap between patients and practitioners as well as practitioners and caregivers or family members. According to current literature, the gap could be caused by perceptions of caregiver knowledge of conditions, lack of time for intensive interactions on the part of the practitioner, caregiver perceptions of the practitioner, etc. If these causes are indeed founded, this presents interesting implications on the findings of this study. It is not known if students have preconceived notions about caregivers of participants in the class; however, it could be hypothesized that interactions with students could have made caregivers or family members in this sample feel less evaluated or judged than interactions with practitioners. It could also be the informal nature of the care that allows for more of a friendship-like relationship between caregivers and students. Future research could investigate the qualities of the interactions between students and caregivers or family members. A further understanding of these interactions could help address what kinds of communications that caregivers desire from healthcare professionals, and continuing signs and indications of satisfaction could be used as determining criteria for what kind of programs are examined.

Because of the status of caregivers in this sample, the benefits that were discussed in interviews could not be classified as direct; the intervention, or the wellness class, was not geared towards or acting directly upon the caregivers or family members of participants. For this reason, any perceived benefit on the part of the caregiver or family member was determined to be indirect. Despite this, caregivers or family members did seem to perceive benefits as being close to themselves. All of the caregivers or family members from this sample were able to identify how the class had affected them in some way, which could be hypothesized to be abnormal since the wellness class was not serving them directly. Although this phenomenon could be specific to this sample of caregivers or family members, it does present interesting implications for healthcare professionals. By serving patients, and serving them well, healthcare professionals do have the opportunity to greatly impact many more individuals on a personal level.

This research raises important questions for future endeavors. Within the context of this class, this research has raised the question of why participants choose to come to the wellness class, despite the burden it has been shown to cause caregivers. Although, based on caregiver interview data, it could be hypothesized that the interaction and benefit are key, pursuit of direct data from participants is necessary to answer this question. This study has also inspired other work to be done on the course, including a study on the perspectives of students who take the course for university credit. That study is in the process of being carried out, pending recruitment. In pursuing these other research questions, what would result is a complete analysis of the workings of the wellness class for individuals with disabilities. A comprehensive cost-benefit analysis of the course would allow for future instructors and students in the course to understand what happens within the context of the class. This understanding could lead to outreach to other universities in order to create mutually-benefitting courses like this in other areas. Attempts to do so have already occurred, and were not as successful as anticipated. This research could help change that.

Globally, this research raises questions about other wellness programs for people with disabilities. Programs do exist that serve this population group, and those programs do have different systems of operation and sustainability than the one highlighted in this study. In order to truly understand cost-benefit of these programs, I believe that similar research must be done on those programs. Furthermore, I believe that more research should be conducted on caregivers and family members of individuals with disabilities. Understanding their perspectives, struggles, and daily lives might inform interventions catered to those that they care for. There could be information shared that makes interventions for people with disabilities more accessible, and also more beneficial to caregivers or family members.

REFERENCES:

1. Erickson W, Lee, C., von Schrader, S. 2012 Disability Status Report: United States. 2014.

2. U.S. Department of Justice Civil Rights Division Disability Rights Devision. A Guide to Disability Rights Laws. 2009;2016.

3. Centers for Disease Control and Prevention. Disability and Health. 2014.

4. Georgia Medicaid. 2016.

5. World Health Organization Media Centre. Disability and Health Fact Sheet. 2016;2016.

6. National Council on Disability. *The Current State of Health Care for People with Disabilities*. Washington, D.C.; 2009.

7. Barte JC, Veldwijk J, Teixeira PJ, Sacks FM and Bemelmans WJ. Differences in weight loss across different BMI classes: a meta-analysis of the effects of interventions with diet and exercise. *Int J Behav Med*. 2014;21:784-93.

8. Janssen V, De Gucht V, Dusseldorp E and Maes S. Lifestyle modification programmes for patients with coronary heart disease: a systematic review and meta-analysis of randomized controlled trials. *Eur J Prev Cardiol*. 2013;20:620-40.

9. Aguiar EJ, Morgan PJ, Collins CE, Plotnikoff RC and Callister R. Efficacy of interventions that include diet, aerobic and resistance training components for type 2 diabetes prevention: a systematic review with meta-analysis. *Int J Behav Nutr Phys Act*. 2014;11:2.

10. Puetz TW and Herring MP. Differential effects of exercise on cancer-related fatigue during and following treatment: a meta-analysis. *Am J Prev Med*. 2012;43:e1-24.

11. Wegner M, Helmich I, Machado S, Nardi AE, Arias-Carrion O and Budde H. Effects of exercise on anxiety and depression disorders: review of meta- analyses and neurobiological mechanisms. *CNS Neurol Disord Drug Targets*. 2014;13:1002-14.

12. Ploughman M, Shears J, Harris C, Hogan SH, Drodge O, Squires S and McCarthy J. Effectiveness of a novel community exercise transition program for people with moderate to severe neurological disabilities. *NeuroRehabilitation*. 2014;35:105-12.

13. Froehlich-Grobe K, Lee J, Aaronson L, Nary DE, Washburn RA and Little TD. Exercise for everyone: a randomized controlled trial of project workout on wheels in promoting exercise among wheelchair users. *Arch Phys Med Rehabil*. 2014;95:20-8.

14. Young HJ, Erickson ML, Johnson KB, Johnson MA and McCully KK. A wellness program for individuals with disabilities: Using a student wellness coach approach. *Disabil Health J*. 2015;8:345-52.

15. Wittenberg E and Prosser LA. Health as a Family Affair. *N Engl J Med*. 2016;374:1804-6.

16. Adelman RD, Tmanova LL, Delgado D, Dion S and Lachs MS. Caregiver burden: a clinical review. *JAMA*. 2014;311:1052-60.

17. Prasad P. *Crafting qualitative research : working in the postpositivist traditions*: Armonk, N.Y. : M.E. Sharpe, ©2005.; 2005.

18. Björnsdóttir K, Stefánsdóttir Á and Stefánsdóttir GV. People with Intellectual Disabilities Negotiate Autonomy, Gender and Sexuality. *Sexuality and Disability*. 2017;35:295-311.

19. Eastgate G, Scheermeyer E, van Driel ML and Lennox N. Intellectual disability, sexuality and sexual abuse prevention - a study of family members and support workers. *Australian Family Physician*. 2012;41:135-139.

20. Eastgate G. Sex, consent and intellectual disability. *Australian Family Physician*. 2005;34:163-166.

21. Alexander N and Taylor Gomez M. Pleasure, sex, prohibition, intellectual disability, and dangerous ideas. *Reproductive Health Matters*. 2017;25:114-120.

22. Eastgate G. Sexual health for people with intellectual disability. *Salud Publica De Mexico*. 2008;50 Suppl 2:s255-s259.

23. Karellou I. "It Is Only Natural….": Attitudes of Young People with Intellectual Disabilities toward Sexuality in Greece. *Journal of Mental Health Research in Intellectual Disabilities*. 2017;10:217-236.

24. Ditchman N, Easton A, Batchos E, Rafajko S and Shah N. The Impact of Culture on Attitudes Toward the Sexuality of People with Intellectual Disabilities. *Sexuality & Disability*. 2017;35:245-260.

25. Sultana N. The sexual and marital relationships of people with a learning disability. 2016.

26. Retznik L, Wienholz S, Seidel A, Pantenburg B, Conrad I, Michel M and Riedel-Heller SG. Relationship Status: Single? Young Adults with Visual, Hearing, or Physical Disability and Their Experiences with Partnership and Sexuality. *Sexuality and Disability*. 2017.

27. Boland P, Levack WMM, Hudson S and Bell EM. Coping with multiple sclerosis as a couple: 'peaks and troughs' - an interpretative phenomenological exploration. *Disability & Rehabilitation*. 2012;34:1367-1375.

28. Knox L, Douglas JM and Bigby C. 'The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI. *Brain Injury*. 2015;29:745-757.

29. Carr D, Cornman JC and Freedman VA. Disability and Activity-related Emotion in Later Life: Are Effects Buffered by Intimate Relationship Support and Strain? *Journal of Health & Social Behavior*. 2017;58:387-403.

30. Burke P. *Disability and impairment : working with children and families*: Philadelphia : Jessica Kingsley Publishers, 2008.1st American paperback ed.; 2008.

31. Davys D, Mitchell D and Martin R. Fathers of people with intellectual disability: A review of the literature. *Journal of Intellectual Disabilities*. 2017;21:175-196.

32. Findler L, Klein Jacoby A and Gabis L. Subjective happiness among mothers of children with disabilities: The role of stress, attachment, guilt and social support. *Research in Developmental Disabilities*. 2016;55:44-54.

33. Wallander JL, Varni JW, Babani L, Banis HT and Wilcox KT. Family resources as resistance factors for psychological maladjustment in chronically ill and handicapped children. *Journal of Pediatric Psychology*. 1989;14:157-173.

34. Pruitt MM, Willis K, Timmons L and Ekas NV. The Impact of Maternal, Child, and Family Characteristics on the Daily Well-Being and Parenting Experiences of Mothers of Children with Autism Spectrum Disorder. *Autism: The International Journal of Research and Practice*. 2016;20:973-985.

35. Felizardo S, Ribeiro E and Amante MJ. Parental Adjustment to Disability, Stress Indicators and the Influence of Social Support. *Procedia - Social and Behavioral Sciences*. 2016;217:830-837.

36. Ying-Ting H, Joseph O and Tsu-Hsuan H. Impact on Marital and Sibling Relationships of Taiwanese Families Who Have a Child with a Disability. *Journal of Comparative Family Studies*. 2011:213.

37. Taanila A, Kokkonen J and Järvelin M-R. The long-term effects of children's early-onset disability on marital relationships. *Developmental Medicine & Child Neurology*. 1996;38:567-577.

38. Parker JA, Mandleco B, Roper SO, Freeborn D and Dyches TT. *Religiosity, Spirituality, and Marital Relationships of Parents Raising a Typically Developing Child or a Child With a Disability*.

39. Applying Structural Family Therapy with a Mexican-American Family with Children with Disabilities: A Case Study of a Single-Parent Mother. 2012;43:17-24.

40. Badia M, Begoña Orgaz M, Gómez-Vela M, Verdugo MA, Ullán AM and Longo E. Do environmental barriers affect the parent-reported quality of life of children and adolescents with cerebral palsy? *Research in Developmental Disabilities*. 2016;49-50:312-321.

41. Juhásová A. Comparison of Quality of Life of Families with Children with Disability and Families with Children without Disability. *Procedia - Social and Behavioral Sciences*. 2015;174:3378-3384.

42. Schlebusch L, Dada S and Samuels A. Family Quality of Life of South African Families Raising Children with Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders*. 2017;47:1966-1977.

43. AARP NAfCa. Caregiving in the U.S. 2004.

44. Feinberg L. RSC, Houser A., Choula R.; AARP Public Policy Institute. Valuing the Invaluable: The Growing Contributions and Costs of Family Caregiving. 2012.

45. Zarit SH, Todd PA and Zarit JM. Subjective Burden of Husbands and Wives as Caregivers: A Longitudinal Study1. *The Gerontologist*. 1986;26:260-266.

46. McKenzie J and McConkey R. Caring for Adults with Intellectual Disability: The Perspectives of Family Carers in South Africa. *Journal of Applied Research in Intellectual Disabilities*. 2016;29:531-541.

47. Croog SH, Burleson JA, Sudilovsky A and Baume RM. Spouse caregivers of Alzheimer patients: problem responses to caregiver burden. *Aging and Mental Health*. 2006;10:87-100.

48. Ennis N, Rosenbloom BN, Canzian S and Topolovec-Vranic J. Depression and anxiety in parent versus spouse caregivers of adult patients with traumatic brain injury: A systematic review. *Neuropsychological Rehabilitation*. 2013;23:1-18.

49. Heid AR, Zarit SH and Fingerman KL. "My Parent is so Stubborn!"--Perceptions of Aging Parents' Persistence, Insistence, and Resistance. *Journals of Gerontology Series B: Psychological Sciences & Social Sciences*. 2016;71:602-612.

50. Kyungmin K, Bangerter LR, Yin L, Polenick CA, Zarit SH and Fingerman KL. Middle-Aged Offspring's Support to Aging Parents With Emerging Disability. *Gerontologist*. 2017;57:441-450.

51. Tozer R and Atkin K. 'Recognized, Valued and Supported'? The Experiences of Adult Siblings of People with Autism Plus Learning Disability. *J Appl Res Intellect Disabil*. 2015;28:341-51.

52. Eriksson H, Sandberg J and Hellström I. Experiences of long-term home care as an informal caregiver to a spouse: gendered meanings in everyday life for female carers. *International Journal of Older People Nursing*. 2013;8:159-165.

53. Rollero C. The Experience of Men Caring for a Partner With Multiple Sclerosis. *J Nurs Scholarsh*. 2016;48:482-9.

54. Lorig K, Thompson-Gallagher D, Traylor L, Ritter PL, Laurent DD, Plant K, Thompson LW and Hahn TJ. Building Better Caregivers: A Pilot Online Support Workshop for Family Caregivers of Cognitively Impaired Adults. *Journal of Applied Gerontology*. 2012;31:423-437.

55. Young L, Healey K, Charlton M, Schmid K, Zabad R and Wester R. A home-based comprehensive care model in patients with Multiple Sclerosis: A study pre-protocol. *F1000Res*. 2015;4:872.

56. Wilhite B, Biren G and Spencer L. Fitness Intervention for Adults with Developmental Disabilities and their Caregivers. *Therapeutic Recreation Journal*. 2012;46:245-267.

57. Menne HL, Bass DM, Johnson JD, Primetica B, Kearney KR, Bollin S, Molea MJ and Teri L. Statewide Implementation of "Reducing Disability in Alzheimer's Disease": Impact on Family Caregiver Outcomes. *Journal of Gerontological Social Work*. 2014;57:626-639.

58. Lambert SD, Duncan LR, Kapellas S, Bruson AM, Myrand M, Santa Mina D, Culos-Reed N and Lambrou A. A Descriptive Systematic Review of Physical Activity Interventions for Caregivers: Effects on Caregivers' and Care Recipients' Psychosocial Outcomes, Physical Activity Levels, and Physical Health. *Ann Behav Med*. 2016;50:907-919.

59. Cheng S-T, Lam LCW, Kwok T, Ng NSS and Fung AWT. The Social Networks of Hong Kong Chinese Family Caregivers of Alzheimer's Disease: Correlates With Positive Gains and Burden. *Gerontologist*. 2013;53:998-1008.

60. Schulz R and Beach SR. Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA*. 1999;282:2215-2219.

61. Capistrant BD, Moon JR, Berkman LF and Glymour MM. Current and Long-Term Spousal Caregiving and Onset of Cardiovascular Disease. *Journal of epidemiology and community health*. 2012;66:10.1136/jech-2011-200040.

62. Mausbach BT, Roepke SK, Ziegler MG, Milic M, von Känel R, Dimsdale JE, Mills PJ, Patterson TL, Allison MA, Ancoli-Israel S and Grant I. Association Between Chronic Caregiving Stress and Impaired Endothelial Function in the Elderly. *Journal of the American College of Cardiology*. 2010;55:2599-2606.

63. Gillick MR. The critical role of caregivers in achieving patient-centered care. *JAMA*. 2013;310:575-6.

64. Petriwskyj A, Franz J and Adkins B. Parents, services and system: an exploration of power dynamics in future planning among parent carers for people with disability. *Disability & Society*. 2016;31:1081-1097.

65. Krauss L. 2016 Disability Statistics Annual Report. 2017.

66. Young HJ, Herman CL and Rimmer JH. Movement-to-music (m2m) As An Alternative Form Of Exercise Rehabilitation For An Individual With Multiple Sclerosis: 1568 Board #221 June 2, 8: 00 AM - 9: 30 AM. *Med Sci Sports Exerc*. 2016;48:430.

67. Learmonth YC and Motl RW. Physical activity and exercise training in multiple sclerosis: a review and content analysis of qualitative research identifying perceived determinants and consequences. *Disability & Rehabilitation*. 2016;38:1227.

68. Graves BS, McCully KK and Whitehurst M. Successful Active Aging Programs. *Florida Atlantic University*. 2000:1-32.

69. Bezyak JL, Sabella SA and Gattis RH. Public Transportation: An Investigation of Barriers for People With Disabilities. *Journal of Disability Policy Studies*. 2017;28:52-60.

70. Newitt R, Barnett F and Crowe M. Understanding factors that influence participation in physical activity among people with a neuromusculoskeletal condition: a review of qualitative studies. *Disabil Rehabil*. 2016;38:1-10.

71. Architectural and Transportation Barriers Compliance Board WDC. *Americans with Disabilities Act: Accessibility Guidelines for Buildings and Facilities, Transportation Facilities, Transportation Vehicles*; 1994.

72. Tracy SJ. *Qualitative research methods : collecting evidence, crafting analysis, communicating impact*: Chichester, West Sussex, UK : Wiley-Blackwell, 2013.; 2013.

73. Roulston K. Considering quality in qualitative interviewing. *Qualitative Research*. 2010;10:199-228.

74. Roulston K, deMarrais K and Lewis JB. Learning to Interview in the Social Sciences. *Qualitative Inquiry*. 2003;9:643.

75. Bédard M, Molloy DW, Squire L, Dubois S, Lever JA and O'Donnell M. The Zarit Burden InterviewA New Short Version and Screening Version. *The Gerontologist*. 2001;41:652-657.

76. Balfe M, Keohane K, O'Brien K and Sharp L. Social networks, social support and social negativity: A qualitative study of head and neck cancer caregivers' experiences. *European Journal of Cancer Care*. 2017;26:n/a-n/a.

77. Lufei Y, Kathleen H, Mary C, Kendra S, Rana Z and Rebecca W. A home-based comprehensive care model in patients with Multiple Sclerosis: A study pre-protocol [version 1; referees: 2 approved]. *F1000Research, Vol 4 (2015)*. 2015.