

An Examination of 'Choice' on Mental Health among Informal Caregivers  
to Persons with Intellectual Developmental Disabilities

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Submitted in partial fulfillment  
of the requirements for the degree of

Master of Arts

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## **Abstract**

**Introduction:** To examine the effects of ‘choice’ on the mental health outcomes of informal intellectual developmental disability (IDD) caregivers, which has been examined in previous literature in alternate caregiving contexts. **Background:** Stressors of the caregiving role have been shown to negatively affect the mental health of informal caregivers in multiple contexts, where stressors can include a specific task or number of tasks, time spent caregiving or perceived stress levels. However, research has also shown that whether the caregiver identifies as having a choice in taking on their role may also have an affect on their mental health status, where lack of choice may cause psychological impairments, and decreased life satisfaction. **Methodology:** Using the General Social Survey – Cycle 26 – Caregiving and Care Receiving, linear regression and multinomial logistic regression analyses were analyzed to determine how choice in the caregiving role affects the caregivers mental health in relation to numerous caregiving stressors. **Results:** The results show that those who have higher levels of stress experience worse mental health outcomes, alongside those who have more tasks, and more time allotted to their duties. Choice approaches significance in relation to mental health, however, does not have a significant relationship with the development of mental health outcomes in these caregivers when the burdens of the caregiving role are considered. **Conclusion:** Overall, this research shows the complexities in which the informal caregiving role has on the development of mental health concerns within this population, where the burdens of the role play a more significant role on their mental health than their perception of choice.

**Key words:** Intellectual Developmental Disability (IDD), Informal, Caregiver, Mental Health, Choice

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**Abbreviations**

**IDD** – Intellectual Developmental Disability

**IADL** – Instrumental Activities of Daily Living

**ADL** – Activities of Daily Living

**GSS** – General Social Survey

**OR** – Odds Ratio

**CI** – Confidence Interval

## **Chapter One: Introduction**

### **Rationale and Implications**

The purpose of this thesis is to examine the effects of ‘Choice’ and ‘Lack of Choice’ on the development of mental health concerns within Intellectual Developmental Disability (IDD) caregivers. Lack of choice has been examined within other caregivers such as old age, dementia and cancer, in which it is common for the children of the care receivers to feel as though they lacked a choice in the decision to care for their parents, while those who are not immediate family members often described having a choice in their caregiving duties (Bouldin et al., 2010). However, this caregiving aspect has not been extensively researched in the population of IDD. In the context of informal IDD caregivers, parents are often unaware of their child possessing an IDD until after birth, or until they begin to show signs of developmental delays. Therefore, it is important to examine whether this ‘lack of choice’ in being an informal IDD caregiver effects the mental health of the care providers.

This research could have implications within clinical, research, and political realms. Clinically, this research may aid clinicians in becoming more aware of reasons why families may be experiencing mental health concerns. They may be able to assist families in becoming more cohesive in solving their problems surrounding where they may be lacking choice in their role(s) and help them cope with the challenges faced by caring for an individual with an IDD by providing them with multiple care options to choose from.

With respect to the political realm, policy makers across numerous organizations and health systems could use the results of this research to develop policies to increase

the availability of having multiple choices surrounding financial supports and program assistance, alongside support groups to aid with the additional stressors that are faced within the informal caregiving community. Giving parents or guardians choice regarding the supports they need and the needs for their care recipient may reduce the likelihood of developing mental health concerns within their role.

Finally, in terms of research, my thesis has implications towards a new body of knowledge in the population of IDD caregivers, allowing for further examination and replications on the idea of choice in this population. With further examinations, we may be able to help determine what aspects of the role IDD caregivers feel they lack choice in, alongside determining which ones have the greatest impact on their mental health.

To my knowledge, this is the first study to examine choice in the IDD caregiver population specifically, and how it affects their mental health. Although this concept has been examined in other caregiver types, this population is unique due to the obligations that parents may feel regarding having to informally care for their child with an IDD. In this population, the concept of choice may present itself differently compared to other caregivers.

## Chapter Two: Review of the Literature

As reported by Statistics Canada, nearly 46% of Canadians will care for someone without pay at some point in their lifetime, leading to around 13 million people who are 15 years of age and older who will informally care for someone with a chronic or life-long condition (Sinha et al., 2014). This includes but is not limited to caring for an individual who has been diagnosed with an IDD.

IDD is a condition that is present at birth or develops before the age of 18 where the individual experiences difficulties in social, conceptual, and practical realms (American Psychiatric Association, 2013), alongside facing deficits in their behaviour, language, and learning development (CDC, 2018). Occurring on a spectrum, those diagnosed with an IDD can have difficulties that range from mild to severe in any one or more of these domains. Those with mild or moderate forms of IDD often experience challenges in their instrumental activities of daily living (IADL), negatively affecting their capability to shop independently, manage their finances and/or medications, meal preparation, etcetera (American Psychiatric Association, 2013; Kernisan, n.d.; Kernisan & Scott, n.d.). However, those with more profound levels of disability may also face challenges in their activities of daily living (ADL), having an impact on self-grooming, toileting, feeding and even mobility (Kernisan, n.d.; Kernisan & Scott, n.d.). These deficiencies in IADLs and ADLs often require support from others – usually family members – to facilitate independence (*What Is A Developmental Disability? - Developmental Services Ontario*, n.d.), resulting in a lifetime of required support.

To give some perspective on the scope of this issue, 160,500 individuals in Canada over the age of fifteen were diagnosed with an IDD in 2012 and were still living

within their family household (Government of Canada, 2015). Yet, in 2015 there were 12,900 adults with IDD that were waitlisted for supports through community residential services for permanent living placements (Canadian Union of Public Employees, 2015). Unfortunately, these individuals often do not make it off of the waitlist (Canadian Union of Public Employees, 2015), resulting in their family members having to provide care for their child with IDD, even after they mature into adulthood (Ben-Zur et al., 2005). These family members then become the informal caregivers, as they are unpaid for their caregiving duties (Gressmann, 2014).

### **Snapshot of IDD Care Providers**

The literature has portrayed IDD caregivers as primarily the parents of the individual (Turcotte, 2013), with studies reporting between 68% to 93% (Burton-Smith et al., 2009a, 2009b; Caldwell, 2008; Dawson et al., 2016; Grey et al., 2017; Chou, Fu, et al., 2011; Chou, Chiao, et al., 2011) being the mother of the individual, and 4% (Dawson et al., 2016), 7% (Burton-Smith et al., 2009a, 2009b), and 14% (Grey et al., 2017), reporting the father being the primary caregiver. However, some research found that 1.1% (Burton-Smith et al., 2009a, 2009b), 3.1% (Caldwell, 2008), 4.5% (Grey et al., 2017), and 8% (Dawson et al., 2016) had siblings, and 1.3% (Burton-Smith et al., 2009a, 2009b) had a grandparent, as their primary caregiver.

These caregivers are faced with varying caring hours, depending on their relationship to the individual and the severity of the care receivers' disability. Moreover, one study found that that weekly caregiving hours are higher when the care provider is the parent or the spouse of the care receiver, with those caring for someone with an IDD experiencing the greatest number of hours (Sinha et al., 2014). It has been reported that

51% of IDD caregivers care for at least 10 hours a week, with most cases being their children (Sinha et al., 2014), and 13% care for 100 hours or more (The Change Foundation, 2016).

### **Caregiving Stress**

Having to care for an individual who may require support within multiple aspects of their daily lives can create burden and stress in the lives of the informal caregivers. Research has found that informally caring for someone includes all aspects of “a chronic stress experience including: physical and psychological strain experienced over extended periods of time, high levels of unpredictability, alongside the potential of stress development in other life domains...” (Schulz & Sherwood, 2008, pg.23). In general, this apparent increase in stress has been shown to jeopardize the mental health of informal caregivers compared to non-carers, as research has shown that about 17.5% of informal caregivers are above clinical cut-offs for mental illness compared to only around 3.6% of the general population (Grey et al., 2017). Extensive amounts of research have been completed to examine the factors that play a role in the development of higher stress and burden levels in IDD caregivers. It has been found that caring for an individual with a lower level of ADL and IADL functioning (Chou et al., 2010; Chou, Fu, et al., 2011; Jones et al., 2013; Plant & Sanders, 2007; Schulz & Sherwood, 2008; White & Hastings, 2004), caregiving load/demand or intensity (Llewellyn et al., 2010; Plant & Sanders, 2007; Turcotte, 2013), number of hours caregiving (Plant & Sanders, 2007; Schulz & Sherwood, 2008; Totsika et al., 2017), reduced social activities and networks (Burton-Smith et al., 2009a; Edwards et al., 2007; Yoong & Koritsas, 2012), and behaviour issues of the care receiver (Jones et al., 2013; Plant & Sanders, 2007; Samadi et al., 2014;

Schulz & Sherwood, 2008; White & Hastings, 2004), all contribute to the burdensome and stressful experiences of informal caregivers.

Previous studies have explored the effects that the level of functioning of the individual with IDD has on the caregivers, discovering that caring for an individual with low IADL and ADL functioning can lead to increased stress levels (Dawson et al., 2016; Plant & Sanders, 2007; White & Hastings, 2004), depression (Chou et al., 2010), and general mental health concerns in the caregiver (Schulz & Sherwood, 2008). This was also found in regards to anxiety, but was found to be due to higher IADL functioning (Jones et al., 2013). It was thought that the increased independence of the care receiver may provoke feelings of anxiety in the caregiver when they no longer require strict support from them (Jones et al., 2013). In addition, the functioning level of the care receiver was also found to be associated with the level of perceived burden of the caregiver (Chou et al., 2010), where lower levels of IADL were found to affect their objective burden, but had no effect on their subjective burden (Chou, Fu, et al., 2011). This higher objective level of burden is particularly associated with the additional tasks a caregiver must complete when their care receiver is at a lower functioning level, especially those who require additional support with ADLs such as toiletry and mobility.

When caring for a low IADL and/or ADL functioning individual with IDD, caregivers can experience increased levels of care demands, load, and/or intensity due to the additional responsibilities that are placed on them as their functioning level moves down the spectrum. Research has found that approximately 31% of the variance that is seen in caregivers' mental health scores can be accounted for by their level of caregiving demands (Llewellyn et al., 2010). Those who described their caregiving responsibilities

as difficult were found to have higher levels of stress (Plant & Sanders, 2007), with those having more demanding roles experiencing higher levels of anxiety, guilt and feelings of stigma (Chou, Fu, et al., 2011). Due to the potential of having more demanding responsibilities when caring for someone with low functioning, this can also lead to increased or prolonged hours supporting the care receiver.

The number of caregiving hours that a carer experiences can vary greatly depending on the level of functioning of the individual, and how demanding their role is. Generally, the time involved in completing the various tasks was found to be positively associated with the stress levels described by the caregivers (Plant & Sanders, 2007). Those who described having long caring hours were at an increased risk of stating that caregiving has had a negative impact on their health by about 82% (Totsika et al., 2017). These extended hours taking on extra responsibilities to care can create burden due to the decreased amount of time left to participate in other activities.

The literature has shown that informal caregivers often face limitations when it comes to social activities due to the time it takes to complete their caregiving duties (Burton-Smith et al., 2009a). Caregivers have described having restricted friendships to mostly only other caregivers, while also not being able to participate in preferred leisure activities with their typical peers since it often needs to be scheduled around varying programme hours (Yoong & Koritsas, 2012), usually between 0900 and 1500 hours. These negative effects have also been found within their social networks (Burton-Smith et al., 2009a), where 18.3% of caregivers describe only seeing their friends and family once or twice every three months – while only 10.2% of the general population experience this low level of social contact (Edwards et al., 2007). This limited quality

time makes it difficult for informal caregivers to create healthy relationships with family and friends (Yoong & Koritsas, 2012), which can lead to feelings of depression and isolation within the caregiver population.

Lastly, if the care receiver also participates in challenging behaviours, this can accentuate the issues mentioned above. Behavioural problems among individuals with IDD are quite common (American Psychiatric Association, 2013), and depending on their level of disability and the supports provided, the severity can fluctuate. Research has documented that these difficult behaviours from the care recipient are associated with the stress levels expressed by the caregivers (Jones et al., 2013; Plant & Sanders, 2007; White & Hastings, 2004), with greater mental health concerns being expressed in those caring for an individual with more challenging behavioural issues, including greater levels of anxiety (Jones et al., 2013; White & Hastings, 2004), and lower levels of emotional health (Samadi et al., 2014).

### **Theories Surrounding Choice Making**

While there is a large body of literature examining the relationship between the burden of care and mental health outcomes among caregivers, there is little literature that examines the choice, or lack thereof to provide care among caregivers of IDD persons, on the mental health and stress levels of informal caregivers. Having a choice in any scenario has been described as having the ability to choose between multiple options (Schulz et al., 2012), explaining that when people are given a choice, they are being given the opportunity to “express a preference and [are able] to assert the self” (Leotti et al., 2010, pg.457). When they get to use this expression, no matter how small it is, they are given the perception of both control and self-efficacy (Leotti et al., 2010). But when it

comes to becoming an informal caregiver – the choices are often complicated (Bouldin et al., 2010). Within the IDD caregiver context, choices can include whether they want to take on the caregiving role or not, which caregiving duties the caregiver wants to take, and which ones they would like to pass onto others, as well as how they would like to spend their free time when it becomes available (Larkin & Mitchell, 2016). However, research surrounding the effects of choice on the mental health of the population are varied, as choice has been described as being good for the psychological wellbeing of individuals, but has also been found to be detrimental.

Self-determination theory is one theory surrounding choice making, which explains that the need to ‘rule the self’, or being autonomous, is considered to be a psychological need (Ryan & Deci, 2006). Being able to have a choice has been found to be “intrinsically positive, and a good thing” on people’s independence and mental wellbeing (Larkin & Mitchell, 2016, pg.190), where researchers have found that when there is no reinforcement from either choice, people still prefer to have a choice over not having one at all (Leotti et al., 2010). The opposite relationship has also been described, where controlling environments, or those that lack choice, have negative effects on individual wellness (Ryan & Deci, 2006).

However, there is also literature that mentions that having choices can be harmful to peoples’ mental health. It is believed that having choices can “lead to anxiety, stress and regret”, where people may actually begin to avoid having to make choices due to the possibility of having a negative consequence (Larkin & Mitchell, 2016, pg.190). When people begin to feel as though they are not being an effective agent in their lives, and feel as though they are unable to produce desired results from their choices, they may begin to

experience hopelessness and depression (Leotti et al., 2010). But perhaps it is the number of choices they are being given that affects their mental health. One study proposed that if someone is given too many options to choose from, they may feel overwhelmed as opposed to feeling autonomous, but one may also only be given one choice, and still feel autonomous if “they truly endorse” the given option (Ryan & Deci, 2006, pg.1577).

### **Caregiver Choice**

Caregiver choice has been described in the literature as when “the individual believes they had freedom to choose to take up the responsibility of care” (Pertl et al., 2019, pg.1801). Yet, this may not be the case for all IDD caregivers, since, as previously mentioned, the caregivers are often the parents of the care receiver. However, there are multiple ways in which the caregivers may perceive that they lack choice in their role. Perceived lack of choice could be due to personal values (Larkin & Mitchell, 2016; Pertl et al., 2019), societal norms including reciprocity and responsibility (Pertl et al., 2019), caregiver emotions such as altruism and obligation (Larkin & Mitchell, 2016), lack of tangible assistance (Pertl et al., 2019), financial constraints (Longacre et al., 2014; Pertl et al., 2019), and inadequate available support services (Longacre et al., 2014; Pertl et al., 2019).

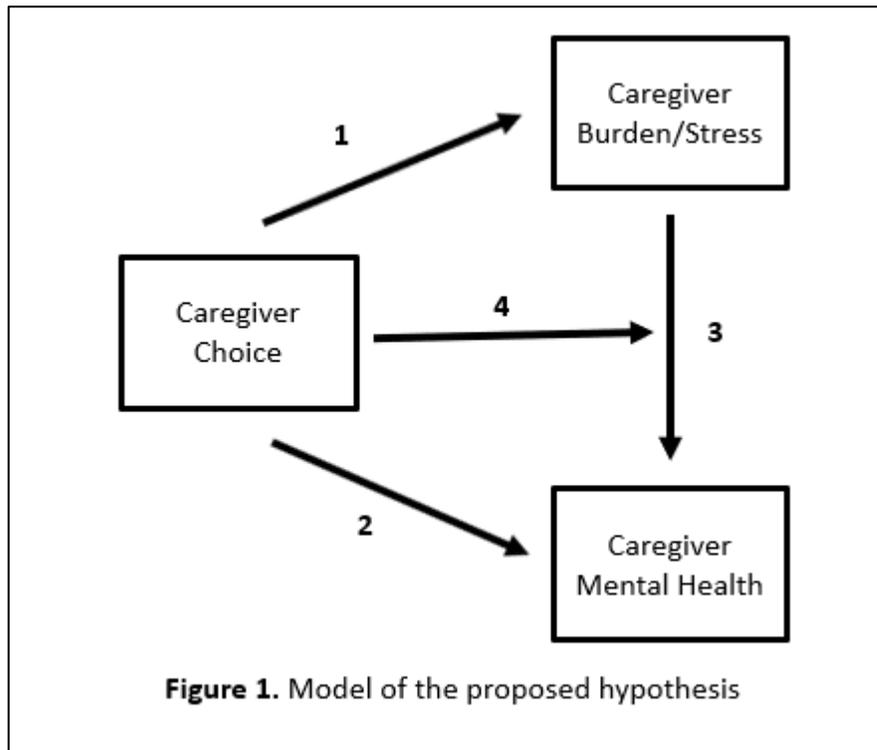
With this in mind, it is important to note that when people are not given a choice, this can cause reluctance in completing the role, which can include learning new skills and becoming effective caregivers (Bouldin et al., 2010). When these skills and tasks are not self-motivated, it can result in greater impaired psychological wellbeing for the individual who is completing them (Schulz et al., 2012). However, when there are choices available, they are found to be more enjoyable and often lead to improved

performance (Leotti et al., 2010). This has been found in alternate caregiving contexts, where lack of choice for those caregiving in old age (Bouldin et al., 2010; Schulz et al., 2012), cancer (Longacre et al., 2014), and dementia (Pertl et al., 2019) affected the caregivers' emotional wellbeing and performance skills. Lack of choice was shown to be a significant predictor of poorer outcomes on life satisfaction, happiness, quality of life and emotional stress (Pertl et al., 2019). Those who described feeling like they had little choice experienced more stress and more difficulties adjusting to their caregiving roles, and those experiencing more choice described having higher levels of life satisfaction and emotional wellbeing (Larkin & Mitchell, 2016; Longacre et al., 2014).

However, parenting requires constant coping and adjustment to the varying caregiving challenges presented, especially with the greater caregiving demands of those caring for a child with an IDD (Woodman & Hauser-Cram, 2013). As previously discussed, the numerous stressors that parents of children with IDD face place them at an increased risk for poor mental health outcomes (Ward et al., 2014; Woodman & Hauser-Cram, 2013). But research has found that most families actually tend to adapt to their new family dynamic (Woodman & Hauser-Cram, 2013). Entire family units may become resilient, which increases family hardiness, or the "ability to work together and be cohesive when combating stressors and finding solutions to their problems" (Woodson et al., 2015, pg.58).

This leads to the purpose of this research, where the examination of lack of choice is explored within the informal IDD caregiver population. Specifically the two research questions that will guide this analysis are (1) within the informal IDD caregiver population, if those who believe they lack choice in becoming a caregiver are more

burdened than those who believe they do have a choice, and (2) is the relationship between caregiver burden and mental health stronger among those who perceive a lack of choice in becoming an IDD carer, compared to those who feel they do have a choice.



From these two research questions, a series of hypotheses are derived (see Figure 1):

1. Those who believe they have a choice will report less completed caregiving tasks, less time allotted in their caregiving role, and experience lower levels of stress.
2. Those who believe they have a choice in becoming a caregiver will have less mental health concerns compared to those who believe they do not have a choice;

3. Those who identify a higher caregiving burden will experience greater mental health concerns compared to those who identify a lower caregiving burden;
4. A higher caregiving burden will have a stronger effect on mental health concerns among those who perceive a lack of choice in becoming an IDD caregiver compared to those caregivers who believe that they had a choice.

## **Chapter Three: Methodology**

Within this chapter, the methodology for research will be discussed outlining the use and purpose of the General Social Survey, the measures considered for examination, and the methods for data analysis, which include the use of descriptive statistical measures and regression models.

### **General Social Survey Data Collection**

The 2012 General Social Survey – Cycle 26 (GSS) on caregiving and care receiving conducted by Statistics Canada was used to conduct this research.(Statistics Canada, 2012a, 2012b). The GSS has conducted research on the topic of care a total of six times, in 1985, 1990, 1996, 2002, and 2007, with cycle 26 in 2012 being the most recent collection of this data. This cycle was selected because it focused specifically on caregiving and receiving and asked a question regarding choice of caregiving.

The GSS – Cycle 26 was completed in 2012 using random digit dialing to interview individuals aged 15 and over who lived in private households in each of Canada’s provinces, excluding the Northwest Territories, Yukon and Nunavut, along with anyone permanently living in institutions (Statistics Canada, 2012b). Households without landlines were also excluded. The GSS used a method called ‘rejective sampling’ to “reject a certain proportion with a given probability to give more time finding the population of interest” (Statistics Canada, 2012b, pg.7) due to the low prevalence of caregivers and care receivers in the population. This means that there was a pre-set number of interviews in which after an initial set of questions, if the interviewee was identified as a non-caregiver and non-care receiver, their interview was not done to

completion. To determine if the respondent was a caregiver, the GSS asked whether they had provided care to anyone such as family, friends or neighbours within the past 12 months; this included “indoor and outdoor chores, driving for errands or appointments, financial aid, care coordinating, medication and/or personal care” (Statistics Canada, 2012b). If the interviewee answered yes, they were directed through a series of questions to determine the types of care provided, the number of hours caring, the type of ailment cared for, current education level and job status, alongside perceived mental health statuses (Statistics Canada, 2012b). There were 10,771 ‘terminated’ cases which were still considered respondents but were not used in estimates, yet they were used in the weighing process.

Within the GSS, there were multiple sample weight adjustments that “depended on the province, caregiving/receiving status, stratum, age and sex of the respondent” (Statistics Canada, 2012b, pg.12) to make it representative of the population. Throughout the five waves completed in 2012, the GSS weighed each wave separately so that the estimates would be in proportion to the Canadian population at the time of each specific wave (Statistics Canada, 2012b). For cycle 26, elimination of non-working banks sampling was completed, so that each telephone number within a particular stratum would have equal chances of being selected to participate. Each stratum had the first seven digits of their number the same, with the last two digits varying between 00-99. Following this, there was a basic weight calculation, two-stage adjustment, household weight calculation, person weight calculation, adjustment of person weights for rejective sampling, adjustment of person weights to external totals, stratum – wave adjustment, province – age – sex adjustment, ranking ratio adjustments, and final person sample

weight calculation. Due to the probability sample being used, estimation was meant for each participant to represent other individuals within the population that are not included in the sample. For the purposes of this study, there were 178 participants who provided a response to whether or not they felt they had a choice in providing care to someone with an IDD, representing a total of 160,185 people within the Canadian population.

### **Ethical Considerations**

For the purposes of this study, ethical consent was provided by the Research Ethics Board at Brock University on November 14<sup>th</sup>, 2019 for the use of secondary data (See Appendix A). The dataset was obtained through Ontario Data Documentation, Extraction Service and Infrastructure Initiative (ODESI) for the examination of the previously described relationships.

### **Measures**

**Choice.** To determine whether the caregivers felt as though they did or did not have a choice in taking on their informal caregiving role, they were asked “Do you feel you had a choice in taking on your caregiving responsibilities during the past 12 months?” in which they were able to give a yes, no, or don’t know response. For the purposes of this paper, these responses were coded as (0) no, and (1) yes. An attrition analysis was conducted on the choice variable as there were multiple missing cases, to identify if there is a significant difference between those who did not provide a response to this question, and those who did. Those who did not provide a response were due to reporting that they did not provide more than 2 hours a week providing care, responded “I

don't know", or were a proxy to the participant (i.e., someone answered the questionnaire on behalf of the caregiver).

### **Caregiver Burden**

Caregiver burden was examined by three differing measures. It includes one variable of perceived caregiving stress, a series of objective measures of the actual tasks performed, and a measure of the amount of time spent providing care. These three measures of burden (see below for specific details for each measure) were examined both individually and collectively.

**Self-Rated Caregiving Stress.** The informal caregivers were asked "How stressful have your caregiving responsibilities been during the past 12 months?" in which they were able to respond with very stressful, stressful, somewhat stressful or not at all stressful. For the purposes of this paper, the stress variable was coded to reflect higher scores with higher levels of stress. Therefore, they were coded (1) not at all stressful, (2) somewhat stressful, (3) stressful, and (4) very stressful, to identify the levels of perceived stress reported by the participants.

**Caregiving Task Burden.** For the purposes of this study, objective caregiver burden will be determined through the addition of multiple responsibilities in which the caregiver has stated they require to complete within their role. The caregivers were asked a series of seven questions including "During the past 12 months, have you helped your primary care receiver with transportation to do shopping or errands, or to get to medical appointments, or social events?"; "During the past 12 months, have you helped [the care receiver] with meal preparation, meal clean-up, house cleaning, laundry or sewing?";

“During the past 12 months, have you helped [the care receiver] with house maintenance or outdoor work?”; “During the past 12 months, have you helped [the care receiver] with personal care?”; “During the past 12 months, have you helped [the care receiver] with medical treatments or procedures?”; “During the past 12 months, have you helped [the care receiver] with scheduling or coordinating care-related tasks, such as making appointments or hiring professional help?”; and “During the past 12 months, have you helped [the care receiver] with banking, bill paying or managing finances?”. Respondents were able to answer yes or no to this series of questions to determine their participation in these variety of tasks. These were examined both individually and summed in the analyses. To create the summed variable, yes was coded as (1), and no was coded as (0) to determine the total number of tasks each participant assisted their care recipient with. The individual item analysis allowed for dichotomous comparison across each task while the summed variable was treated as a continuous measure to assess the effect of a higher number of overall tasks.

**Caregiving Time Burden.** Caregivers were asked, “In an average week, how many hours of care or help did you provide with [the caregiving activities]?” where participants were able to provide a numerical value between 0 and 168 hours. This variable is treated as a continuous measure in all analyses.

## **Mental Health**

**Self-Rated Mental Health.** To determine the mental health of the interviewees, they were asked “In general, would you say your mental health is excellent, very good, good, fair or poor?”. For this paper, mental health was coded to reflect higher or better

mental health, with higher scores. Therefore, they were coded as (1) poor, (2) fair, (3) good, (4) very good, and (5) excellent.

### **Covariates**

**Age.** Respondents were asked “What is your age?” by the interviewer, to which they were able to provide a numerical value. This variable was treated as a continuous variable for all analyses.

**Sex.** To determine the sex of the informal caregivers, interviewees were asked “Is [respondents] sex (1) male or (2) female?”

Due to the low power analysis of this research, additional information regarding marital status (See Appendix A) and relationship of the care receiver to the caregiver (See Appendix B) were included in the appendix for reference. This additional information assists in providing a clearer picture of the participants and whom they are assisting with care.

### **Data Analysis**

The data analysis was completed in four steps. First, an attrition analysis was conducted to identify the number of missing cases within the choice variable and whether these participants differed from those who responded to this question which could introduce a bias within the sample. Following these results, it was determined that an imputation strategy would not be necessary as there was no significant difference across the main dependent variable and few differences across other variables.

Next, descriptive statistics and a bivariate correlation analysis were completed to examine the differences between those who stated that they identify as having choice in taking on their caregiving role, compared to those who felt they did not have a choice, and to determine if there are any correlations between the proposed variables. The descriptive statistics and correlations were analyzed for each of the caregiving tasks, the summed tasks, the self-rated stress levels, mean self-rated stress, each of the mental health levels, mean self-rated mental health, time allotted to caregiving duties, average time used in the caregiving role(s), along with the age and sex of the participant.

Third, a linear regression analysis was completed looking at caregiver choice, self-rated stress levels, time allotted to the caregiving role and the caregiving tasks completed on the self-rated mental health outcomes of the IDD caregivers, while adjusting for their age and sex. This was completed across several regression models, first looking at the sole effect of choice then including self-rated-stress and time allotted to caregiving on mental health. The next few models examined how the effect of choice changed when in consideration of the different caregiving burdens. This analysis was also completed with the summed tasks variable replacing the individual tasks to examine how the number of tasks one helps their care receiver with affects the caregiver's mental health status. Finally, a regression analysis was completed to examine the interaction effects between choice and stress, choice and time allotted to caregiving tasks, along with choice and the summed tasks variable to determine how these variables interact with choice in relation to how they affect the caregivers' mental health.

Lastly, a series of adjusted multinomial logistic regression analyses of caregiver choice on the mental health of the informal caregivers was completed to assess whether

there is a linear or a curvilinear relationship between choice and the caregivers' mental health. A multinomial logistic regression analysis adjusted for age and sex was assessed to examine the odds ratios (OR) of individuals who mentioned they did have a choice on their odds of describing the differing levels of mental health in reference to excellent mental health level. Next, a fully adjusted multinomial logistic regression was completed to examine the ORs regarding individuals who mentioned having a choice on their odds of describing their mental health level in reference to excellent mental health, when all of the burden aspects of the caregiving role are being considered.

## Chapter Four: Results

### Attrition Analysis

This analysis compared those who provided a valid response to the “choice” variable versus those who were missing on this variable. Those who had a missing response to the “choice” variable were people who reported that they provided less than 2 hours a week providing care (N=18), responded “I don’t know” (N=2), or were a proxy to the participant (i.e., someone answered the questionnaire on behalf of the caregiver; N=14). For self-rated caregiver stress, proxy responders were not asked this question, so no comparisons were made (Table 1). However, there were a few tasks that had some significant differences. Specifically, 38.2%, 60.1% and 44.9% of people who provided a valid choice response mentioned that they participated in house maintenance, personal care and banking respectively compared to 20.6%, 38.2% and 23.5% ( $p<0.05$ ) who did not answer. Meal preparation/house cleaning/laundry/sewing had the largest significant difference ( $p<0.001$ ), where 72.5% of those who gave a valid choice response stated they participated in this task compared to 38.2% of those who had a missing choice response. There was also a significant difference for the overall sum of tasks where those who provided a valid response to the question regarding choice did a mean of 4 tasks, compared to a mean of only 2.7 tasks ( $p<0.01$ ) for those who did not provide a response to the choice question. Finally, the time allotted to caregiving was significant ( $p<0.001$ ) where those who provided a valid response provided a mean of 27.4 hours of care, compared to 2.4 hours of care provided by those who did not provide a response. These differences can be seen in table 1. It is understandable that they would differ across time spent providing care and the caregiving tasks as many were selected out answering the

“choice” variable based on providing < 2 hours of care as they were a conceptually a different group that provided little caregiving. And as they did not differ across the key outcome variable of mental health nor the perceived stress variable, no strategies were employed to retain them in the final sample for further analysis.

Table 1: Attrition analysis comparing participants with valid versus missing responses regarding their perception of choice in taking on their informal caregiving role.

	N	Valid Response (N=178)		Missing Response (N=34)	
		Yes	No	Yes	No
<b>Caregiving Tasks (Yes/No)</b>	(N=212)				
Transportation (%)		81.5	18.5	76.5	23.5
Meal Preparation/House Cleaning/Laundry/Sewing (%)		72.5***	27.5***	38.2***	61.8***
House Maintenance (%)		38.2*	61.8*	20.6*	79.4*
Personal Care (%)		60.1*	39.9*	38.2*	61.8*
Medical Treatments (%)		46.1	53.9	32.4	67.6
Scheduling Care tasks (%)		61.2^	38.8^	44.1^	55.9^
Banking (%)		44.9*	55.1*	23.5*	76.5*
<b>Combined Tasks (<math>\bar{x}</math>; <i>SD</i>)</b>	(N=212)	4.0(1.90)**		2.7(2.0)**	
<b>Self-Rated Stress</b>	(N=180)				
(4)Very Stressful (%)	24	13.5		-	
(3)Stressful (%)	39	21.9		-	
(2)Somewhat Stressful (%)	74	40.4		-	
(1)Not at all Stressful (%)	43	24.2		-	
<b>Self-Rated Stress (<math>\bar{x}</math>; <i>SD</i>)</b>	212	2.24(0.97)		-	
<b>Hours Caregiving (<math>\bar{x}</math>; <i>SD</i>)</b>	(N=200)	27.4(31.9)***		2.4(7.35)***	
<b>Mental Health</b>	(N=212)				
(5)Excellent (%)	50	21.9		32.4	
(4)Very Good (%)	57	26.4		29.4	
(3)Good (%)	82	39.9		32.4	
(2)Fair (%)	18	9.6		2.9	
(1)Poor (%)	5	2.2		2.9	
<b>Mental Health (<math>\bar{x}</math>; <i>SD</i>)</b>	212	3.6(1.01)		3.9(1.02)	
<b>Sex (%)</b>	(N=212)				
(1)Male	80	36.5		44.1	
(2)Female	132	63.5		55.9	
<b>Age (<math>\bar{x}</math>; <i>SD</i>)</b>	(N=212)	49.1(15.31)		47.6(17.04)	

Note: Missing responses for the Choice variable are due to caring for <2 hours, responses being answered by a proxy or responding with "I don't know". Missing responses for the Self-Rated Stress variable are due to caring for <2 hours and responses being answered by proxies. Missing responses for Time are due to participants responding with "I don't know"; \*\*\* $p < 0.001$ ; \*\* $p < 0.01$ ; \* $p < 0.05$ ; ^ $p = 0.063$

## **Descriptive Statistics**

In Table 2, of those who provided a valid response regarding their choice in becoming an informal IDD caregiver (N=178), 80 caregivers reported that they did have a choice in becoming an informal IDD caregiver compared to 98 who reported that they did not have a choice. There were significant differences between those who report having a choice and those who reported not having a choice for the tasks of transportation, personal care, and scheduling ( $p<0.01$ ), with 72.5%, 48.8%, and 48.8% respectively for those who perceive they have a choice, compared to 88.8%, 69.4%, and 71.4% respectively, who report that they did not have a choice in becoming an IDD caregiver. There was also a significant difference for medical treatments ( $p<0.05$ ), where 37.5% of those who identify as having a choice report helping with medical treatments, compared to 53.1% of those who do not believe that they had a choice in becoming an IDD caregiver. In regard to the summed tasks, there was a significant difference ( $p<0.01$ ) between those who perceive they have a choice and those who perceive they have no choice, with a mean of 3.5 tasks and 4.5 tasks respectively.

For self-rated stress, those who report having a choice in taking on their caregiving role tend to report lower levels of stress compared to those who report having no choice in taking on their role. There was a significant difference found ( $p<0.01$ ), as there was a mean of 1.9 (between not at all stressful and somewhat stressful) for those who perceive a choice in taking on their role, compared to a mean of 2.5 (between somewhat stressful and stressful) for those who perceive not having a choice.

Finally, there were significant differences between those who report having a choice compared to those who report not having a choice for both the time allotted to

caregiving, and the age of the caregiver. On average, those who identify as having a choice reported caregiving for approximately 22.6 hours a week, compared to 31.4 hours a week for those who felt that they did not have a choice ( $p < 0.05$ ); with the caregivers who have a choice reporting a mean age of 50.3, and those who report not having a choice having a mean age of 48 ( $p < 0.01$ ).

Finally, with respect to mental health levels, there were no significant differences between the two groups. However, it appears as though there is a slight upward trend, where those who find that they did have a choice in becoming an informal IDD caregiver report slightly better levels of mental health compared to those who perceive no choice in taking on their role.

Table 2: Descriptive statistics comparing perceptions of choice regarding various caregiving aspects for Informal Intellectual Disability Caregivers.

	Total (N)	Choice (1) (N=80)		No Choice (0) (N=98)	
<b>Caregiving Tasks (Yes/No)</b>	(N=178)	Yes(1)	No(0)	Yes(1)	No(0)
Transportation (%)		72.5**	27.5**	88.8**	11.2**
Meal Preparation/ House Cleaning/ Laundry/Sewing (%)		66.3	33.8	77.6	22.4
House Maintenance (%)		38.8	61.3	37.8	62.2
Personal Care (%)		48.8**	51.2**	69.4**	30.6**
Medical Treatments (%)		37.5*	62.5*	53.1*	46.9*
Scheduling Care Related Tasks (%)		48.8**	51.2**	71.4**	28.6**
Banking (%)		37.5	62.5	51.0	49.0
<b>Combined Tasks (<math>\bar{x}</math>; <i>SD</i>)</b>		3.5(1.97)**		4.5(1.72)**	
<b>Self-Rated Stress</b>	(N=178)				
(4)Very Stressful (%)	24	3.8***		21.4***	
(3)Stressful (%)	39	16.3***		26.5***	
(2)Somewhat Stressful (%)	72	50.0***		32.7***	
(1)Not at all Stressful (%)	43	30.0***		19.4***	
<b>Self-Rated Stress (<math>\bar{x}</math>; <i>SD</i>)</b>	(N=178)	1.9(0.79)***		2.5(1.04)***	
<b>Hours Caregiving (<math>\bar{x}</math>; <i>SD</i>)</b>	(N=178)	22.6(29.64)*		31.4(33.25)*	
<b>Mental Health</b>	(N=178)				
(5)Excellent (%)	39	30.0		15.3	
(4)Very Good (%)	47	23.8		28.6	
(3)Good (%)	71	35.0		43.9	
(2)Fair (%)	17	8.8		10.2	
(1)Poor (%)	4	2.5		2.0	
<b>Mental Health (<math>\bar{x}</math>; <i>SD</i>)</b>	(N=178)	3.7(1.07)		3.4(0.94)	
<b>Sex (%)</b>	(N=178)				
(1)Male	65	35.0		37.8	
(2)Female	113	65.0		62.2	
<b>Age (<math>\bar{x}</math>; <i>SD</i>)</b>	(N=178)	50.3(16.60)**		48.0(14.17)**	

Note: \*\*\* $p < 0.001$ ; \*\* $p < 0.01$ ; \* $p < 0.05$ ;

## **Bivariate Correlations**

The correlations in table 3 suggest that there are multiple significant correlations between the variables presented. It was found that sex significantly correlated with meal preparations and medical treatments ( $p < 0.05$ ), personal care and combined tasks ( $p < 0.01$ ), and time allotted to caregiving duties ( $p < 0.001$ ). Sex was also trending towards significance with self-rated stress ( $p = 0.052$ ). Regarding age of the caregiver, it was only significant in the caregiver assisting the care receiver with their banking needs ( $p < 0.001$ ). The time allotted to caregiving tasks was significantly correlated with banking needs ( $p < 0.05$ ), as well as meal preparation, personal care, medical treatments, and scheduling tasks ( $p < 0.001$ ). The self-rated stress of the caregivers significantly correlated with meal preparation, personal care, banking and the time allotted to their caregiving duties ( $p < 0.01$ ), alongside helping with transportation, medical treatments and assisting with scheduling of care recipient related items ( $p < 0.001$ ). The combined number of tasks that a caregiver assists with correlated significantly age, and meal preparation ( $p < 0.01$ ), along with all other caregiving tasks, time allotted to caregiving, self-rated stress and caregiver choice ( $p < 0.001$ ). Mental health is approaching significance in its correlation with personal care ( $p = 0.055$ ), while being significantly correlated with meal preparation and helping with the care receiver's banking needs ( $p < 0.05$ ). However, mental health is also correlated with medical treatments ( $p < 0.01$ ), self-rated stress levels and the number of tasks that the caregiver completes ( $p < 0.001$ ). Finally, caregiver perception of choice in taking on their role was found to be correlated with medical treatments ( $p < 0.05$ ), transportation, personal care, scheduling ( $p < 0.01$ ), self-rated caregiver stress, and combined tasks ( $p < 0.001$ ).

Table 3: Bivariate Correlation examining sex, age, multiple tasks, caregiving hours, self-rated stress, combined tasks, caregiver choice, and self-rated mental health.

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>	<b>11</b>	<b>12</b>	<b>13</b>	<b>14</b>
<b>1</b>	--	0.05	0.01	0.14*	-0.01	0.20**	0.14*	0.17*	0.06	0.08***	0.15^	0.18**	0.03	-0.99
<b>2</b>		--	0.09	-0.03	-0.08	0.002	-0.08	0.03	0.31***	0.04	-0.04	0.05	0.08	-0.02
<b>3</b>			--	0.22**	0.14*	0.10	0.23**	0.36***	0.24***	0.07	0.31***	0.52***	-0.21**	-0.17
<b>4</b>				--	0.29**	0.26***	0.28***	0.33***	0.18**	0.33***	0.22**	0.62**	-0.13	-0.17*
<b>5</b>					--	0.05	0.20**	0.22**	0.22**	0.08	0.07	0.51***	0.01	-0.07
<b>6</b>						--	0.41***	0.40***	0.10	0.43***	0.25**	0.57***	-0.21**	-0.13^^
<b>7</b>							--	0.38***	0.12	0.34***	0.26***	0.64***	-0.16*	-0.23**
<b>8</b>								--	0.32***	0.36***	0.31***	0.73***	-0.23**	-1.12
<b>9</b>									--	0.14*	0.25**	0.53***	-0.14	-0.17*
<b>10</b>										--	0.21**	0.43***	-0.14	-0.11
<b>11</b>											--	0.41***	-0.29***	-0.32***
<b>12</b>												--	-0.26***	-0.25***
<b>13</b>													--	0.12
<b>14</b>														--

Note: 1- Caregiver Sex; 2- Caregiver Age; 3- Transportation; 4- Meal Preparation; 5- House Maintenance; 6- Personal Care; 7- Medical Treatments; 8- Scheduling; 9- Banking; 10- Time Allotted; 11- Self-Rated Stress; 12-Combined Tasks; 13- Caregiver Choice; 14- Mental Health;

\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.0001$ ; ^ $p = 0.052$ ; ^^ $p = 0.055$

## Linear Regressions

To begin, table 4 shows the regression analysis examining how having a choice in the caregiving role effects the amount of burden in which the caregiver experiences. The results indicate that those who identify as having a choice in taking on their caregiving role are significantly more likely to report lower levels of caregiving stress, a lower number of caregiving tasks ( $p < 0.001$ ), and also less time allotted to their caregiving duties ( $p < 0.05$ ). In regard to individual tasks, those with a choice are less likely to report helping their care recipient with transportation ( $p < 0.01$ ), personal care ( $p < 0.01$ ), scheduling ( $p < 0.01$ ), medical treatments ( $p < 0.05$ ), and banking ( $p < 0.05$ ). It is also important to note that the sex of the caregiver appears to be significant in the amount of stress, time and tasks that the caregiver experiences. It is shown that female caregivers experience more stress ( $p < 0.05$ ), more time caregiving ( $p < 0.001$ ), more total tasks ( $p < 0.05$ ), and are also more likely to be assisting with meal preparation ( $p < 0.05$ ), personal care ( $p < 0.01$ ), and scheduling ( $p < 0.05$ ).

Table 4: Linear regression analysis of caregiver choice, age and sex on the caregiving burdens of self-rated stress, time and combined assisted tasks for informal IDD caregivers. (N=178)

	<i>b</i>							
<b>Self-Rated Stress</b>								
Choice	-0.57***							
Age	-0.002							
Sex	0.32*							
<b>Time</b>								
Choice	-9.35*							
Age	0.004							
Sex	18.52***							
<b>Combined Tasks</b>								
Choice	-1.02***							
Age	0.003							
Sex	0.65*							
<b>Individual Tasks</b>								
	1	2	3	4	5	6	7	
Choice	-0.17**	-0.11	0.02	-0.21**	-0.15*	-0.23**	-0.16*	
Age	0.003^	-0.002	-0.004	-0.001	-0.003	0.00	0.01***	
Sex	-0.03	0.14*	0.11	0.21**	0.14	0.15*	0.04	

*Note: 1- Transportation; 2- Meal Preparation etc.; 3- House Maintenance; 4- Personal Care; 5- Medical Treatments; 6- Scheduling; 7- Banking;*

*\*\*\*p<0.001; \*\*p<0.01; \*p<0.05; ^p=0.067*

Tables 5 and 5a presents the linear regression models of the perception of choice, perceived caregiver stress and time, and the various caregiving burdens on the mental health of the informal IDD caregivers. In table 5, model 1, the perception of choice was shown to be trending toward significance ( $p=0.08$ ), where those who had a choice are shown to be more likely to report better mental health. Model 2 shows that those who report higher levels of caregiving stress, are more likely to report lower levels of mental health ( $p<0.001$ ). Model 3 showed that those who report having more caregiving hours are more likely to report lower levels of mental health, however this was not shown to be significant. In model 4, the tasks were analyzed to examine their individual effects in consideration of one another, in which only medical treatments was shown to be significant ( $p<0.05$ ), where those who help their recipient with medical treatments report having worse mental health. Models 5, 6 and 7 assessed these models in a hierarchical fashion assessing the adjusted effects of choice, stress, time and caregiving burdens. In model 5, the effect of stress remained significant ( $p<.001$ ) while the effect of choice was greatly reduced. In model 6, with the inclusion of time, the results remained consistent with time not being a significant factor. Finally, in model 7 with the inclusion of all variables, caregiver stress remained the only significant predictor ( $p<0.01$ ), while medical treatments were no longer significant at the  $p<0.05$  level ( $p=0.08$ ).

Table 5a presents the regression analysis in which the individual tasks are replaced with the summed tasks variable to determine the effects of the number of tasks being completed on the mental health of the caregiver. In addition, it examines the possible interactions between choice with caregiver stress, time, and the number of caregiving burdens. Model 4a shows that those who provide more caregiving tasks are more likely to report worse mental health, which is shown to be significant ( $p<0.001$ ). However, in model 7a with the inclusion of choice, stress and

time, there is no longer a significant result for the combined tasks ( $p=0.09$ ). But the effect of caregiving stress on mental health remains significant ( $p<0.01$ ). In models 8, 9 and 10 testing the interaction effects, none of the interactions between choice and any of the other variables were shown to be significant.

Table 5: Linear regression analysis of caregiver choice, stress, caregiving time and tasks on mental health outcomes of Informal Intellectual Developmental Disability Caregivers. (N=178)

	<b>Model 1</b>	<b>Model 2</b>	<b>Model 3</b>	<b>Model 4</b>	<b>Model 5</b>	<b>Model 6</b>	<b>Model 7</b>
	<i>b</i>	<i>b</i>	<i>b</i>	<i>b</i>	<i>b</i>	<i>b</i>	<i>b</i>
<b>Choice</b>	0.27 <sup>^^</sup>				0.09	0.08	0.05
<b>Self-Rated Stress</b>		-0.33 <sup>***</sup>			-0.32 <sup>***</sup>	-0.31 <sup>***</sup>	-0.25 <sup>**</sup>
<b>Hours Caregiving (<math>\bar{x}</math>)</b>			-0.003			0.00	0.001
<b>Tasks</b>							
Transportation				-0.27			-0.09
Meal Preparation/ House Cleaning/ Laundry/Sew				-0.20			-0.21
House Maintenance				0.05			0.06
Personal Care				-0.06			-0.08
Medical Treatments				-0.36 <sup>*</sup>			-0.33 <sup>^</sup>
Scheduling of Care Tasks				0.17			0.20
Banking				-0.26			-0.17
Sex	-0.12	0.01	-0.08	-0.12	-0.02	-0.01	0.003
Age	-0.01	-0.01	-0.002	0.001	-0.01	-0.01	-0.01
<b>R<sup>2</sup></b>	0.03	0.11	0.02	0.10	0.11	0.11	0.15

Note: *b* – unstandardized coefficient; Choice variable is coded as having a choice; Task variables are coded as assisting with the task.

\*\*\* $p < 0.001$ ; \*\* $p < 0.01$ ; \* $p < 0.05$ ; <sup>^</sup> $p < 0.055$ ; <sup>^^</sup> $p = 0.08$

Table 5a: Linear regression analysis of caregiver choice, stress, caregiving time, combined tasks and interactions on mental health outcomes of Informal Intellectual Developmental Disability Caregivers. (N=178)

	<b>Model 4a</b>	<b>Model 7a</b>	<b>Model 8</b>	<b>Model 9</b>	<b>Model 10</b>
	<i>b</i>	<i>b</i>	<i>b</i>	<i>b</i>	<i>b</i>
<b>Choice</b>		0.05	0.41	0.8	0.50
<b>Self-Rated Stress</b>		-0.27**	-0.27**	-0.27**	-0.27**
<b>Hours Caregiving</b>		0.001	0.001	0.001	0.001
<b>Combined Tasks</b>	-0.125***	-0.08^	-0.78^	-0.08	-0.02
<b>Choice x Stress</b>			-0.01		
<b>Choice x Hours Caregiving</b>				-0.001	
<b>Choice x Tasks</b>					-0.11
<b>Sex</b>	-0.12	-0.002	0.01	-0.001	-0.03
<b>Age</b>	0.00	-0.01	-0.01	-0.01	-0.01
<b>R<sup>2</sup></b>	0.07	0.12	0.13	0.12	0.13

Note: Choice variable is coded as having a choice.

\*\*\* $p < 0.001$ ; \*\* $p < 0.01$ ; \* $p < 0.05$ ; ^ $p = 0.09$ ; ^ $p = 0.058$

## Multinomial Logistic Regressions

In addition to the linear regression reported above, there was concern that the relationship between choice and mental health was not linear, so a multinomial analysis was conducted to examine this relationship more closely. Table 6, alongside figure 2, shows the multinomial logistic regressions of caregiver choice on the mental health of the informal IDD caregivers adjusted for caregiver age and sex. The odds of a respondent who feels as though they did not have a choice in taking on their caregiving role were significantly more likely to report their mental health as good compared to excellent, compared to those who believe they do have a choice (OR = 2.74, 95% CI 1.20-6.25,  $p < 0.05$ ). The odds of a caregiver who feels as though they did not have a choice in taking on their caregiving role describing their mental health as very good compared to being excellent is 2.50 times higher than those who do believe they had a choice (OR= 2.50, 95% CI 1.04-6.03,  $p < 0.05$ ). This suggests a curvilinear relationship between the perceived choice of the caregiver and their mental health status where those who believe they do not have a choice are considerably more likely to report having good (or very good) mental health than to report having excellent mental health, compared to those who do report having a choice.

Table 7 alongside figure 3 presents the multinomial logistic regression adjusting for various caregiving burdens to assess the effect of perceived choice of the caregiver on their mental health. After adjusting for these additional variables, there were no significant results regarding the perception of choice on the mental health of the caregiver. However, when the other variables are considered, the relationship between caregiver choice and mental health becomes more linear. Regarding self-rated stress levels, the relationship appears to be quite

linear with increasingly higher odds of reporting lower levels of mental health but only one category was statistically significant. Those who report higher levels of stress are 3.26 times more likely to report a fair mental health status over excellent mental health, compared to those with lower stress levels (OR = 3.26, 95% CI 1.43-7.47,  $p < 0.01$ ). As well, among the tasks analyzed to examine their individual effects, only medical treatments was shown to be significant, with those involved in this task being 4.46 times more likely to report having good mental health rather than excellent mental health (OR = 4.46, 90% CI 1.53-13.05,  $p < 0.01$ ).

Table 7a shows the multinomial logistic regression analysis examining the effects the combined tasks variable, time allotted to caregiving, and the perception of caregiver choice on the self-rated mental health of the caregiver, with the exclusion of self-rated stress to help determine how the inclusion of the subjective stress burden may effect the more objective stressors within the caregiving role. The results show that there is only a significant result where those who have more completed combined tasks are 1.57 times more likely to report good mental health over excellent mental health (95% CI 1.21-2.03,  $p < 0.01$ ). However, there are three results that are approaching significance, with those who are older being 1.03 times more likely to report good mental health (95% CI 0.99-1.06,  $p = 0.06$ ), more completed tasks being 1.39 times more likely to report fair mental health (95% CI 0.97-1.98,  $p = 0.073$ ), and those who lack choice in beginning their role being 2.29 times more likely to report very good rather than excellent mental health (95% CI 0.91-5.78,  $p = 0.079$ ).

Finally, table 7b and figure 3a examines the multinomial logistic regression analysis using the combined tasks variable, alongside all the other burdens in relation to the effect of perceived choice on the mental health of the informal IDD caregiver. There were no significant results for the perceived choice on the mental health of the caregivers. However, it was found

that higher levels of stress resulted in consistently lower levels of mental health suggesting a linear effect. Specifically, those who report having higher stress levels are 4.15 (95% CI 1.04-16.59,  $p<0.05$ ), 2.93 (95% CI 1.36-6.32,  $p<0.01$ ), and 1.62 (95% CI 0.94, 2.79,  $p=0.08$ ) times more likely to report having poor, fair, or good mental health respectively rather than excellent compared to those with lower levels of stress. Finally, those who report taking part in more caregiving tasks are 1.45 times more likely to state they are in good mental health rather than excellent mental health, compared to those who report fewer caregiving tasks (OR=1.45, 95% CI 1.11-1.91,  $p<0.01$ ).

Table 6: Multinomial logistic regression analysis adjusted for age and sex of caregiver choice on the mental health of Informal Intellectual Developmental Disability Caregivers. (N=178)

Mental Health	Very Good		Good		Fair		Poor	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
No Choice	2.50*	[1.04,6.03]	2.74*	[1.20,6.25]	2.32	[0.72,7.46]	1.67	[0.21,13.42]
Sex	1.13	[0.47,2.73]	1.91	[0.82,4.43]	1.15	[0.35,3.71]	0.75	[0.10,6.00]
Age	1.02	[0.99,1.05]	1.03^	[1.00,1.06]	1.00	[0.97,1.04]	1.02	[0.95,1.09]

Note: Reference category for Mental Health is 'Excellent'; Reference category for choice variable is 'having a choice'; CI – Confidence Interval; OR – Odds Ratio;

\* $p < 0.05$ ; ^ $p = 0.054$

Table 7: Adjusted multinomial logistic regression analysis examining caregiver choice, stress and caregiving tasks on the mental health of Informal Intellectual Developmental Disability Caregivers. (N=178)

Mental Health	Very Good		Good		Fair		Poor	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
<b>No Choice</b>	2.12	[0.80, 5.64]	1.62	[0.63, 4.20]	1.35	[0.37, 5.38]	0.53	[0.03, 9.24]
<b>Self-Rated Stress</b>	1.28	[0.70, 2.33]	1.63	[0.92, 2.87]	3.26**	[1.43, 7.47]	7.21	[0.62, 84.09]
<b>Hours Caregiving</b>	0.99	[0.98, 1.01]	0.99	[0.98, 1.01]	0.99	[0.97, 1.02]	0.98	[0.92, 1.04]
<b>Tasks</b>								
Transportation	1.05	[0.31, 3.5]	1.29	[0.37, 4.48]	1.10	[0.16, 7.78]	0.64	[0.02, 25.35]
Meal Preparation	1.18	[0.42, 3.39]	1.30	[0.45, 3.78]	1.06	[0.23, 4.89]	8951715 25.7	[895171 525.7, 8951715 25.7]
House Maintenance	0.85	[0.29, 2.43]	0.84	[0.30, 2.36]	1.96	[0.49, 7.90]	1.061E-9	[0,0]
Personal Care	1.80	[0.61, 5.29]	1.55	[0.54, 4.46]	1.16	[0.23, 5.88]	2.31	[0.16, 33.98]
Medical Treatments	2.50	[0.81, 7.71]	4.46**	[1.53, 13.05]	3.16	[0.70, 14.23]	0.18	[0.002, 18.091]
Scheduling of Care related tasks	0.39	[0.13, 1.24]	0.96	[0.31, 2.94]	0.34	[0.07, 1.74]	0.30^^	[0.001, 1.42]
Banking	1.99	[0.65, 6.08]	1.63	[0.57, 4.76]	0.97	[0.22, 4.31]	19.07	[0.58, 628.58]
<b>Sex</b>	1.04	[0.39, 2.79]	1.42	[0.54, 3.73]	0.78	[0.21, 2.94]	0.49	[0.02, 13.16]
<b>Age</b>	1.01	[0.98, 1.05]	1.03^	[0.10, 1.07]	1.00	[0.96, 1.06]	1.05	[0.93, 1.19]

Note: Mental Health reference category is 'Excellent'; Reference category for the choice variable is 'having a choice'; CI- Confidence Interval; OR- Odds Ratio

\* $p < 0.05$ ; \*\* $p < 0.01$ ; ^ $p = 0.055$ ; ^^ $p = 0.075$

Table 7a: Adjusted multinomial logistic regression analysis examining caregiver choice, and combined caregiving tasks on the mental health of Informal Intellectual Developmental Disability Caregivers. (N=178)

Mental Health	Very Good		Good		Fair		Poor	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
<b>No Choice</b>	2.29 <sup>^^</sup>	[0.91-5.78]	1.92	[0.79-4.66]	1.78	[0.53-6.02]	1.60	[0.18-14.01]
<b>Hours Caregiving Combined Tasks</b>	0.99	[0.98-1.01]	1.00	[0.98-1.01]	1.00	[0.98-1.02]	0.99	[0.95-1.04]
<b>Sex</b>	1.18	[0.90-1.54]	1.57 <sup>**</sup>	[1.21-2.03]	1.39 <sup>^</sup>	[0.97-1.98]	1.14	[0.61-2.14]
<b>Age</b>	1.19	[0.47-3.02]	1.68	[0.67-4.18]	1.05	[0.30-3.65]	0.82	[0.10-7.17]
	1.02	[0.99-1.04]	1.03 <sup>#</sup>	[0.99-1.06]	1.0	[0.96-1.04]	1.02	[0.95-1.09]

Note: Odds Ratio – OR; Mental Health Reference Category is Excellent; Reference category for the choice variable is having a choice;

\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$ ; <sup>^</sup> $p = 0.073$ ; <sup>^^</sup> $p = 0.079$ ; <sup>#</sup> $p = 0.06$ .

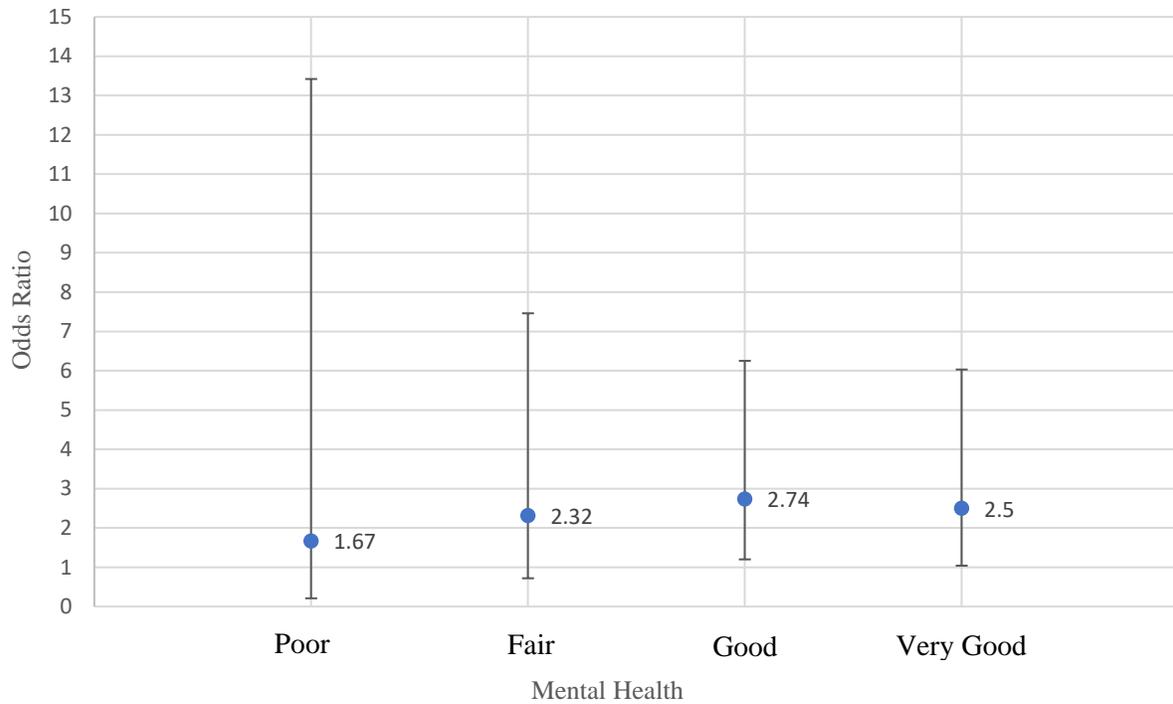
Table 7b: Adjusted multinomial logistic regression analysis examining caregiver choice, stress and combined caregiving tasks on the mental health of Informal Intellectual Developmental Disability Caregivers. (N=178)

Mental Health	Very Good		Good		Fair		Poor	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
<b>No Choice</b>	2.11	[0.82, 5.41]	1.64	[0.66, 4.06]	1.10	[0.30, 4.11]	0.88	[0.83, 9.28]
<b>Self-Rated Stress</b>	1.29	[0.73, 2.27]	1.62 <sup>^</sup>	[0.94, 2.79]	2.93 <sup>**</sup>	[1.36, 6.32]	4.15 <sup>*</sup>	[1.04, 16.59]
<b>Hours Caregiving</b>	0.99	[0.98, 1.01]	1.00	[0.98, 1.01]	1.00	[0.97, 1.02]	0.99	[0.95, 1.04]
<b>Combined Tasks</b>	1.13	[0.86, 1.50]	1.45 <sup>**</sup>	[1.11, 1.91]	1.16	[0.79, 1.71]	0.87	[0.44, 1.79]
<b>Sex</b>	1.15	[0.44, 2.96]	1.53	[0.60, 3.91]	0.84	[0.23, 3.04]	0.60	[0.07, 5.42]
<b>Age</b>	1.02	[0.99, 1.04]	1.03 <sup>^</sup>	[1.00, 1.06]	1.00	[0.96, 1.06]	1.02	[0.94, 1.09]

Note: Odds Ratio – OR; Mental Health Reference Category is Excellent; Reference category for the choice variable is having a choice;

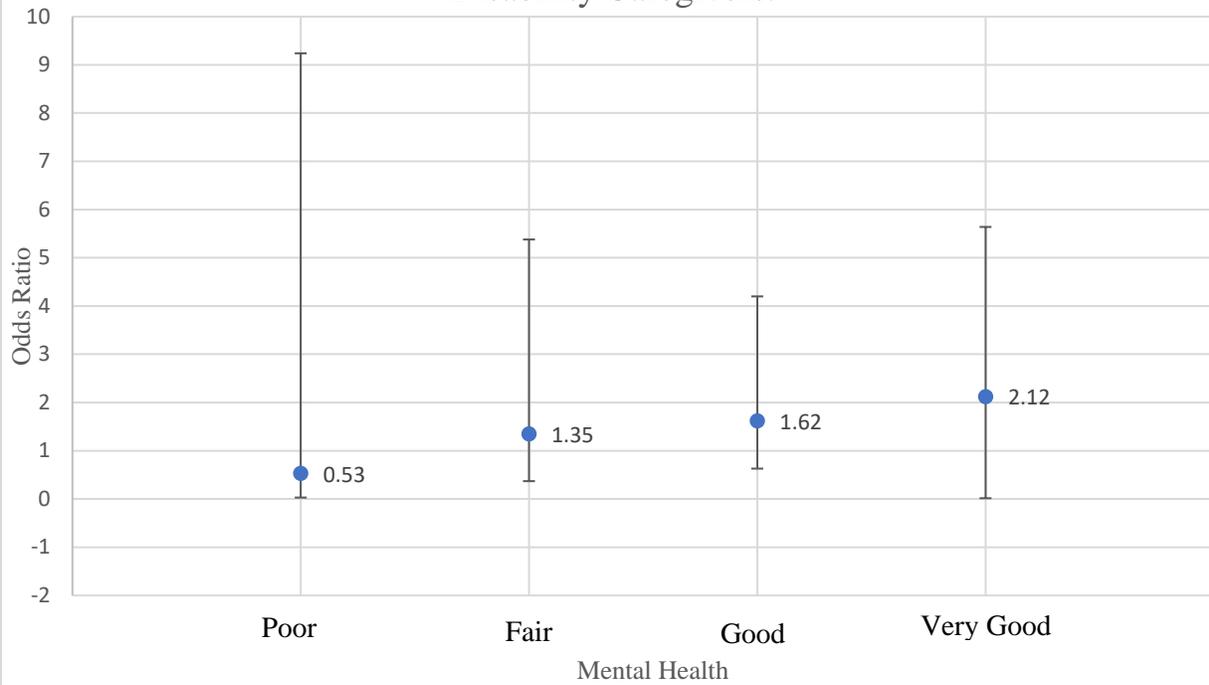
\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$ ; <sup>^</sup> $p = 0.06$ ; <sup>^</sup> $p = 0.08$ .

**Figure 2.** Age and Sex Adjusted Multinomial Logistic Regression of Mental Health on Choice of Informal Intellectual Developmental Disability Caregivers\*



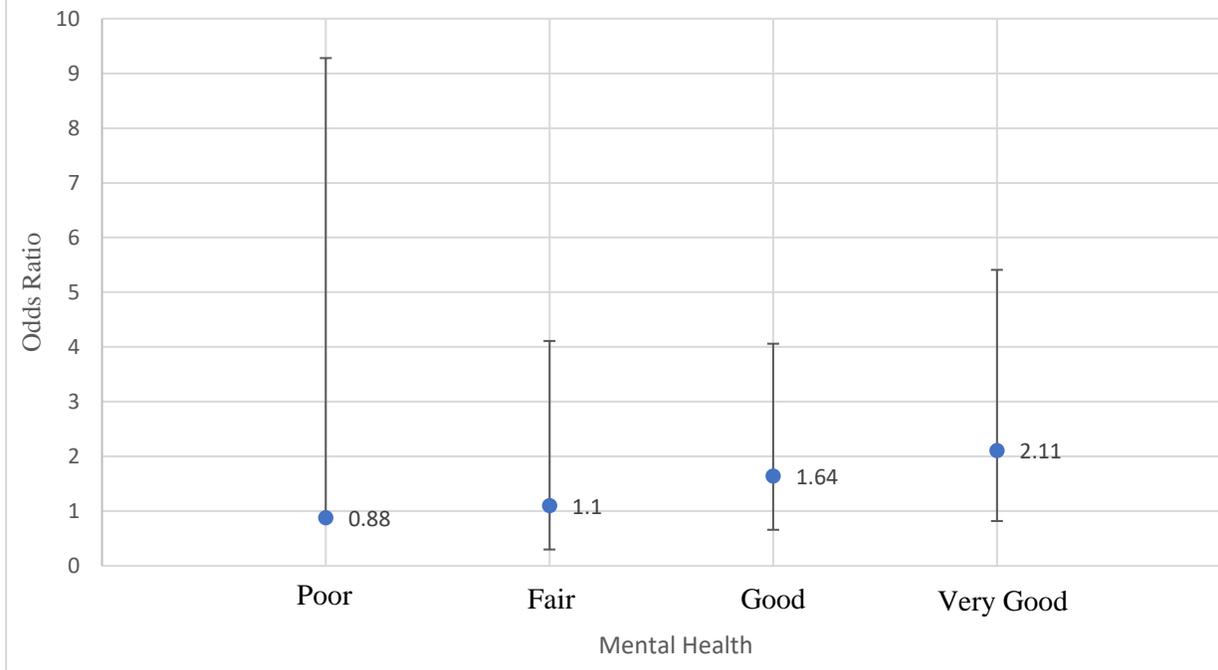
\* Reference category is excellent mental health.

**Figure 3.** Fully Adjusted Multinomial Logistic Regression of Mental Health on Choice of Informal Intellectual Developmental Disability Caregivers.\*



\* Reference category is excellent mental health.

**Figure 3a.** Fully Adjusted Multinomial Logistic Regression of Mental Health on Choice of Informal Intellectual Developmental Disability Caregivers.\*



\*Reference category is excellent mental health.

## Chapter Five: Discussion

The purpose of this research was to examine how the perception of having a choice in becoming an informal IDD caregiver effects the mental health of those caregivers, with consideration to the caregiving burdens that they may be experiencing. The research examined whether (1) within the informal IDD caregiver population, if those who believe they lack choice in becoming a caregiver are more burdened than those who believe they do have a choice, and (2) if the relationship between caregiver burden and mental health is stronger among those who perceive a lack of choice in becoming an IDD carer, compared to those who feel they do have a choice.

To begin, the first proposed hypothesis was supported in that the perception of choice was associated with caregiver burden. This finding is consistent with previous research which has indicated that the perception of choice within the caregiving role is a significant predictor of caregiving burden (Bouldin et al., 2010; Pertl et al., 2019; Schulz et al., 2012). The literature has shown that those who report having little or no choice in taking on their caregiving role, often report higher levels of emotional stress (Larkin & Mitchell, 2016; Longacre et al., 2014), while those with more choice report experiencing higher levels of life satisfaction (Larkin & Mitchell, 2016; Longacre et al., 2014). These experiences may be due to caregivers who report having a choice also reporting that they have less burden within their caregiving roles (Bouldin et al., 2010), as those who report having longer hours and higher levels of care often report having no choice (Schulz et al., 2012). These results are replicated here (see Table 4) where those who identify as having a choice, are significantly more likely to report lower levels of self-rated stress

levels ( $p < 0.001$ ), less time allotted to their caregiving tasks ( $p < 0.05$ ), and assisting their care receiver with less overall tasks ( $p < 0.001$ ) compared to those who lack choice.

Next, when examining the effect of choice on mental health, the linear regression analysis suggested that those who believe they do have a choice in taking on their caregiving role may be more likely to report higher levels of mental health compared to those who believe they do not have a choice, however the relationship did not reach statistical significance ( $p = 0.08$ ). Yet, linear regression assumes that this particular relationship is linear, therefore a multinomial logistic regression was completed for a further analysis to test this assumption. This analysis indicated that the relationship between the choice of the informal IDD caregiver and their mental health may be curvilinear, where those who felt they did not have a choice being significantly more likely to report having good mental health rather than excellent compared to those reporting having a choice. Yet, when these analyses were adjusted for the burdens associated with the caregiving role, this effect adjusted to be more linear – specifically when the self-rated caregiving stress levels were taken into account (Table 7; 7a-b; Figure 2-3a).

The results suggesting that those who perceive having a choice often report having better mental health states compared to those who do not believe they have a choice follows the theory of self-determination, as it mentions that having a choice in their lives is “intrinsically positive, and a good thing” on the individuals’ mental wellbeing (Larkin & Mitchell, 2016, pg. 190). This relationship was also found in alternate contexts, where when those who were caring for loved ones with cancer (Longacre et al., 2014), dementia (Pertl et al., 2019) or old age (Larkin & Mitchell, 2016) had a choice in taking on their caregiving role, they were more likely to report higher levels of emotional wellbeing and life satisfaction (Larkin & Mitchell, 2016; Longacre et al., 2014).

Regarding the stress levels of the informal IDD caregivers, previous research has shown that when informal caregivers describe having high levels of stress, this often harms their mental health (Grey et al., 2017). Higher levels of stress may be a result of differing aspects such as the number of hours caregiving (Plant & Sanders, 2007; Schulz & Sherwood, 2008; Totsika et al., 2017), or the caregiving load/demand (Llewellyn et al., 2010; Plant & Sanders, 2007; Turcotte, 2013). This study found that perceived caregiving stress appears to be a significant predictor of the mental health statuses of the informal IDD caregivers. When age and sex are considered, those who report having higher levels of stress are more likely to report having worse mental health ( $p < 0.001$ ), and this remains significant throughout the models when adjusting for choice and various other caregiving burdens. Moreover, this effect appears to be linear as illustrated in the two multinomial regressions indicating that higher perceived burden of caregiver stress, the lower one's reported mental health. Therefore, those with high self-reported stress levels are far more likely to be reporting increasingly lower levels of mental health compared to those who feel that their role is less stressful.

As discussed above, one of the stress provoking tasks that the caregiver may be participating in are the caregiving tasks themselves. To the author's knowledge, this is the first study to examine the specific tasks in which a caregiver may be participating in and how they affect the mental health of the caregiver. The sole task that appears to have an independent effect on the mental health of informal IDD caregivers in both the linear and multinomial regression analysis is the assistance with medical treatments. It was found that those who help with medical treatments are more likely to report lower levels of mental health ( $p < 0.05$ ). In the multinomial model, those who assist their care receiver with medical treatment procedures are 4.46 time more likely to report having good mental health rather than excellent compared to those who do not

help with the medical treatments of their individual with IDD (OR=4.46, 95%CI 1.53-13.05,  $p<0.01$ ). The nonsignificant findings across the other individual tasks indicate that specific tasks themselves may not have a significant effect on the caregivers' mental health but perhaps the overall number of tasks that care is being provided for.

Regarding the summing of the number of reported tasks, previous research has shown an increased number of tasks is strongly linked with the level of functioning of the IDD person receiving care. That is, those who require assistance with more tasks are generally found to be lower in overall functioning. Others have demonstrated that when the individual is at a lower functioning level (requiring more caregiving tasks), that this can lead to increased stress (Dawson et al., 2016; Plant & Sanders, 2007; White & Hastings, 2004), depression (Chou et al., 2010), and mental health concerns (Schulz et al., 2012) of the caregiver. For the context of this analysis, this aspect is discussed in terms of number of caregiving tasks, which can be interpreted as the caregiving demand/load in which the caregiver experiences. The current study found that the more tasks that a caregiver assisted their care receiver with, the more likely they were to report worse mental health scores ( $p<0.001$ ). However, after self-rated stress levels were adjusted for, this relationship is no longer significant suggesting it may be related to perceived caregiving stress. It was also found that those with higher numbers of reported caregiving tasks are 1.45 times more likely to report their mental health as good rather than excellent (OR=1.45, 95%CI 1.11-1.91,  $p<0.01$ ) after adjusting for self-reported caregiving stress suggesting that the effect is not necessarily linear. This result is similar to previous research as it continues to suggest that a higher caregiving load/intensity (or the lower the functionality of the care recipient) results in lower mental health scores, but perhaps there is a lower bound to how low these scores may go.

Finally, previous literature has demonstrated that the time allotted to caregiving varies greatly depending on the functioning level of the care receiver, and ultimately the number of tasks that are required to be completed by the informal caregiver. Generally, research has shown that the more time that a caregiver takes to complete their tasks, the higher the risk of describing their health as negative (Totsika et al., 2017). However, the results of this study did not find a significant relationship between the time it takes to complete the tasks and the mental health of the caregiver in the linear regression or multinomial regression analyses. Therefore, at least in this sample, time does not appear to have a significant effect in the mental health outcomes of the informal IDD caregivers.

### **Limitations**

With all research comes limitations. First, the study contained a small sample size of 178 valid participants. An *ad hoc* power analysis determined that this study has a power of 47%, and indicates that approximately 400 valid participants would be required to have a statistical power of 80%. With this low statistical power, results should be taken with caution by readers as having low statistical power increases the likelihood of making a type-II error, not being able to identify a true significant effect. As such, the effect of choice on mental health may be greater than this study was able to identify suggesting caution in dismissing this relationship.

Regarding the GSS-Cycle 26, the principle limitation was the use of proxy responders for participant data. The GSS allowed for other individuals to speak on behalf of the caregiving respondent, called proxies. The proxies were granted allowance to respond to some questions within the survey but were excluded from answering others. The questions that the proxies were not allowed to answer included the question regarding caregiver choice as well as the caregiver

self-rated stress level question. However, the proxies were granted permission to answer the self-rated mental health question on behalf of the target participant. The attrition analysis (Table 1) found that there were no significant differences between those who did or did not provide a valid response to the choice in caregiving question for mental health scores, age or sex. There were some significant differences in the responses to a few tasks, the number of combined tasks, and the hours allotted to caregiving. However, the significant difference for the time allotted to caregiving between the two groups is due to the inability to respond to the choice question if the caregiver has not cared for more than 2 hours a week. This assumes that those who provided care for short periods of time perhaps are not caregivers by definition and (assuming they are not) are experiencing less stress within their role. As there were no significant differences between the main variable of interest and the fact that most provided care for less than 2 hours per week, these persons were removed from the analysis.

The utilization of the GSS also leads to some limitations and biases related to the way in which the questionnaire was constructed. First, the survey was constructed based primarily on single item measures to determine their effect. Research has mentioned that single item measures are often open to multiple meanings and interpretations, while also being more vulnerable to biases (Hoepfner et al., 2011). For example, the survey asks whether the participant feels as though they had a choice in taking on their caregiving responsibilities within the last 12 months, which for this particular population may be open for interpretation. Due to ideals of responsibility and values, these participants may not interpret the duties mentioned by the survey as caregiving tasks, but rather their responsibility – in which both choice and lack thereof may be their response. Previous research has described that these emotions and attitudes towards the caregiving role are fluid, and may change multiple times throughout someone's caregiving

journey (Larkin & Mitchell, 2016), as it has been shown 7.4% of those who stated they did not have a choice, and 11.4% of those who stated they did have a choice changed their answer to this question after follow-up (Pertl et al., 2019).

Second, there are a number of biases present when surveys are used, such as recall bias, social desirability bias, and voluntary response bias. These biases are present within the questions of the GSS, as it may be challenging for participants to recall the exact or average number of hours per week they are caregiving, or even if they had assisted their care receiver with some of the aforementioned tasks within the past 12 months. In regard to social desirability, due to the nature of the survey, some may feel obligated to state that they did have a choice as this would be a socially acceptable answer, alongside stating that they do help with the various tasks to avoid judgement for lack of assistance to someone who requires it. Finally, those who completed the lengthy survey volunteered to do so, therefore those who did not complete the entirety of the survey may have drastically different characteristics than those who did complete it – such how much time they spend caregiving, as those who have more caregiving hours may not have the time to complete a phone survey.

### **Future Directions**

Future research should consider examining a multitude of other factors that we were unable to examine in this study such as household income, assistance from paid organizations and/or family and friends, respite availability, government program supports, and receiving tax credits on how they affect the perception of choice within the caregivers' role. As previously discussed, the perception of choice within a caregiving role may be affected by reciprocity and responsibility (Pertl et al., 2019), the emotions of the caregiver (Larkin & Mitchell, 2016), the

lack of any tangible assistance in providing care (Pertl et al., 2019), financial constraints (Longacre et al., 2014; Pertl et al., 2019), and/or inadequate availability of support services for the caregiver (Longacre et al., 2014; Pertl et al., 2019). There are multiple systemic errors that may be present for those supporting individuals with IDD, where the “service gaps often leave ... the families without any real choice, and dependent on a system unresponsive to their needs” (Dube, 2016, pg.1, para.1).

Further, it may be beneficial to examine whether the choices within the caregiving role such as the decision to use respite are made willingly or unwillingly (that is, the services were not made available). These decisions may be affected due to a vacancy in the programs or funding supports, leading to whether the caregiver willingly decided to use services or not, or if their decisions were unwillingly decided based on service gaps or lack of adequate funding. These distinctions are important to make, as those who are experiencing a lack of choices to access services due to systemic service gaps may perceive themselves to have less choice in taking on their caregiving role, but also may be experiencing more subjective stress levels due to the undesired choices that they are having to make.

Finally, the perception of choice may also be different for those who adopt their child. Those who adopt may be previously informed of the disability which may make them more likely to perceive more choice in becoming an informal caregiver as they were previously aware of the future challenges, compared to parents of biological children who may have only discovered the disability after birth.

## **Implications for Practice**

This research has shown the effects of completing multiple caregiving tasks while also considering how their self-rated stress levels affect their mental health. This result could assist health care professionals in developing a relevant questionnaire to give to families who are caring for someone with an IDD, to help with ‘flagging’ families or caregivers who may be at a higher risk of mental health concerns due to the amount of caregiving tasks that they endure, while considering how stressful the caregiver and families feel the role is for them. With this in mind, this questionnaire could also include a portion in which they discuss areas in which the caregiver could use more support, where they are struggling with supporting their individual. This addition would assist many families who are potentially left in the dark due to the lack of knowledge surrounding the available supports to them, and how to access them.

## **Conclusion**

To conclude, among the principle predictors of the burdens of the caregiver, perceived stress levels had the strongest effect on mental health and appeared to completely account for any differences in perception of having a choice in taking on their caregiving role. The perception of choice appears to have a curvilinear relationship with the mental health of the informal IDD caregivers, with those lacking a choice in taking on their caregiving role being more likely to report having good mental health rather than excellent. The stress that the caregivers experience also plays a significant role in their mental health, alongside the number of tasks that the caregiving is required to assist their care receiver with. In comparison to other caregiving populations, it appears as though those caring for an individual with an IDD are having similar experiences. Research has shown that when it comes to the idea of choice within

the caregiving role, results are ambiguous – within this research, 45% of the population felt as though they had a choice, with other research examining multiple disability care types showing 43.8% (Schulz et al., 2012) and 53.6% describing having a choice in taking on their role, while more specific roles such as cancer caregiving having about 69% stating they did have a choice, with dementia caregiving having only 17.9% (Pertl et al., 2019).

However, the variables examined here are just a snapshot of the issues that may be affecting the mental health of this unique group of informal caregivers. Ultimately, this research reflects the challenges that may be experienced within the informal IDD caregiving role and provides insights for future research to examine factors which may be affecting the perception of choice, and the mental health of the informal caregivers.

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## Appendix A

Appendix A: Descriptive statistics for marital status on the perception of choice for IDD caregivers (N=212).

	Choice (80)	No Choice (98)	Missing Choice (34)
Married (%)	45	55.1	59.4
Common-Law (%)	7.5	11.2	3.1
Widowed (%)	10	8.2	6.3
Separated (%)	1.3	4.1	9.4
Divorced (%)	12.5	7.1	3.1
Single, never married (%)	22.5	14.3	18.8
Missing	1.3	--	--

## Appendix B

Appendix B: Descriptive statistics for caregiver relation to care receiver on the perception of choice for IDD caregivers (N=212).

	Choice (80)	No Choice (98)	Missing Choice (34)
Spouse (%)	1.3	--	--
Son (%)	22.5	52	31.3
Daughter (%)	6.3	25.5	15.6
Mother (%)	1.3	1	6.3
Brother (%)	17.5	13.3	21.9
Granddaughter(%)	3.8	--	--
Father-in-law (%)	1.3	--	--
Brother-in-law (%)	3.8	--	--
Sister-in-law (%)	2.5	3.1	--
Nephew/Niece (%)	2.5	--	3.1
Uncle (%)	2.5	--	3.1
Aunt (%)	2.5	--	3.1
Cousin (%)	1.3	--	--
Close friend (%)	17.5	2	3.1
Neighbour (%)	1.3	1	3.1
Other (%)	11.3	--	--
Missing	1.3	1	--