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*Medical Aspects of Disability*

## Caregivers' Perceptions of Family Quality of Life of Individuals with Developmental Disabilities Comorbid with Dementia: A Pilot Study

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### Abstract

**Introduction:** Although individuals with intellectual/ developmental disabilities (I/DD) are living longer than in the past, they also are exposed to age-related changes in health and well-being. They are prone to acquire dementia that often manifests earlier and more frequently than in the general population. However, there is sparse knowledge on the daily challenges that affect the quality of life of the individuals with I/DD and comorbid dementia and their family caregivers.

**Aim:** This pilot study examined strengths and challenges of individuals with dual diagnoses of I/DD and dementia using the family quality of life (FQOL) framework.

**Method:** Cross-sectional data was gathered from a convenience sample of family caregivers using a web-based electronic survey.

**Results:** The variables of interest in this study were the levels of importance and satisfaction attributed to the nine FQOL domains, and overall FQOL. The mean level of importance was higher than the associated ratings of satisfaction in eight of the nine domains, with an overall importance mean of 4.15 and satisfaction mean of 3.28. Analysis of the open-ended comments indicated that the negative impact of social isolation, compound caregiving, and dynamically changing caregiving needs on overall FQOL was balanced by participants' values and beliefs.

**Implications for Practice:** The discrepancies in the FQOL domains pertaining to formal and informal services and social supports elucidate a need to empower families with high caregiving needs through research, practice and policy.

**Conclusions:** Providers should be cognizant of the needs of individuals with I/DD and dementia comorbid, as well as the needs of their family caregivers.

*Key words:* Aging families, Caregiving, Dementia, Developmental Disability, Family quality of life, Intellectual Disability

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## 1. Introduction

People living with intellectual/ developmental disabilities (I/DD) have functional limitations in at least three of the following major life domains of self-care, language, learning, mobility, self-direction, independent living capacity, and economic self-sufficiency, with early onset before the age of 22 years (U.S. Code at 42 USC 15002). As people with I/DD live longer their life expectancy is expected to mirror that of the general population (Coppus, 2013). For example, the life expectancy of individuals with Down syndrome has increased drastically from about 10 years in the 1950s, to 25 years in the 1980s, 35 years in the 1990s, and a current median age of almost 60 years (Bayen et al., 2018; Englund et al., 2013; Hithersay et al., 2019; Yang et al., 2002). However, the increasing life expectancy of people with I/DD poses additional age-related health declines such as dementia (Heller, 2019).

Dementia is a generic term used to describe disease process that cause a progressive deterioration of cognitive functioning needed for functional independence and independent living. The term dementia is still commonly used although it has been replaced in the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) by the terms major and minor neurocognitive disorders, to focus on the person's abilities rather than deficits (American Psychiatric Association, 2013). Individuals with I/DD often experience dementia earlier and at a greater rate than the general population (Strydom et al., 2010). Alzheimer's disease, the most common form of dementia, is the sixth-leading cause of death in the United States (Alzheimer's Association, 2015). Alzheimer's disease is strongly associated with Down syndrome, which is the most identifiable cause of an I/DD (Salehi et al., 2016). More than half of the people with Down syndrome over the age of 60 are estimated to exhibit some form of dementia (Bayen et al., 2018). People living with any I/DD are five times more likely than their neurotypical peers to acquire dementia later in life (Strydom et al., 2013). The challenges associated with dementia for individuals with I/DD, include chronic health issues, delusions and hallucinations, and sleep challenges. Secondary infections, such as

pneumonia, are common contributors to premature death in individuals with dementia (Manabe et al., 2019). People with Down syndrome and dementia can have additional comorbidities such as weight loss, hypothyroidism, as well as hearing and vision impairments (Esbensen, 2010; Prasher et al., 2016).

People with dementia gradually lose their ability to complete activities of daily living and in end stages often cannot recognise their own family members. Such progressive loss of skills affects the capacity of family members, friends, health care workers, and service providers. Family caregivers of individuals with either dementia or I/DD have been the topics of previous research, however, the needs and experiences of caregivers of individuals with dual diagnoses of I/DD and dementia often go unrecognised (Heller et al., 2018; Mahon et al., 2019). Individuals with dual diagnoses and their family members may experience unique realities and needs that differ from individuals with either diagnosis alone. For example, individuals with I/DD tend to experience dementia at a younger age than their same age peers without I/DD (Heller et al., 2018). Detecting early and subtle changes associated with dementia among those with I/DD can be difficult, often complicating the demands of caregiving for these individuals (Krinsky-McHale & Silverman, 2013).

People with both I/DD and dementia can demonstrate learning/memory difficulties, delusions, hallucinations, depression, aggression, and wandering (Cooper & Prasher, 1998; Urv et al., 2010). Individuals living with these dual diagnoses face many day-to-day challenges requiring assistance from family members with nearly every aspect of independent living, including self-care. Additionally, they face physical challenges, such as the heightened risk of falling, which further exacerbates their engagement in everyday activities. The risk of falling is three times higher for the dementia population relative to the general population (Eriksson et al., 2008). For adults with I/DD, the fall rate is estimated to range from 29% to 70% (Hsieh et al., 2014). Therefore, those with dual diagnoses can have a greater risk of falling, which can be a major concern for their family caregivers.

The addition of dementia for an individual with I/DD likely to influence the quality of life (QOL) of other

family members. Behavioural and psychological symptoms of dementia can affect the QOL of both individuals affected by dementia as well as that of the family unit (Feast et al., 2016). Each stage of dementia coupled with the instability of the stages (back and forth nature of stages) can pose unique challenges on the QOL of the entire family unit. Adapting to the new realities associated with the onset and progression of dementia can impose new challenges for the families' QOL (Samuel & DiZazzo-Miller, 2019). However, we know little about the family quality of life (FQOL) of aging families because it is still nascent and much of what we know about FQOL is based on the life experiences of children with I/DD (Jokinen, 2006).

The QOL of an individual with I/DD improves when their basic needs are met and when they have opportunities to accomplish their goals within major life settings (Brown et al., 2016). In transitioning from individual QOL to FQOL, the focus shifts to the family unit as a whole and the extent to which the family and family structure is influenced by the family member with ID (Zuna et al., 2009). FQOL is defined as the existence of conditions in which families are satisfied that their needs are met, enjoy their life together, and have opportunities to do those things of perceived importance (Park et al., 2003).

Isaacs et al., (2007) described FQOL as a multidimensional social construct with nine domains of family life: *Health* of the family, financial well-being (*finances*); *family* relationships; informal support from friends, relatives, neighbours and *others*, excluding service providers; support from disability *services*; influence of personal, spiritual, cultural or religious *values*; *careers* and career preparation; *leisure* and recreation; and *community* interaction. Each domain is evaluated using six QOL dimensions: *importance* of the domain to FQOL; *opportunities* available to family members to engage in domain-related activities; *initiative* or the intrinsic drive that enabled family members to take advantage of the available opportunities; *attainment* or the degree to which the family was able to accomplish the desired things; *stability* referring to the degree to which circumstances within a domain were likely to improve, decline, or stay the same; and *satisfaction* or the overall perception of gratification experienced by the family

(Samuel & DiZazzo-Miller, 2019). Although the international FQOL framework uses six different dimensions to understand the multidimensional nature of each of these nine domains, the scope of this study is limited to only a description of two of these dimensions- Importance and Satisfaction of the nine FQOL domains.

## 2. Aim of the Study

There is a dearth of empirical research on the practical day to day challenges faced by family caregivers of individuals with dual diagnoses of I/DD and dementia. The target population for this study is hidden and difficult to identify because many of these adults with I/DD were born before special education was mandated in the United States in 1975 and so unknown to the service system. Given that 85% of those with I/DD live with mild levels of disability (King et al., 2009), it is expected that many of them were not institutionalised and they will still be living in their family homes. Therefore, we used the internet to reach out to this understudied population of adults aging with dual diagnoses of I/DD and dementia. The term "dual diagnoses" in the rest of the paper will be used to refer to those living with both and I/DD and dementia. The objective of this study was to understand the strengths, challenges, and needs of this population using the FQOL framework.

Specifically, the research questions of interest were

1. What is the level of importance and satisfaction attributed to the FQOL domains?
2. Are the ratings of the importance of the FQOL domains different from the perceived levels of satisfaction with each domain?
3. What is the overall FQOL of this population using qualitative and quantitative data?

## 3. Methods

A descriptive cross-sectional survey web-based research design was used for this study. Surveys were administered through Qualtrics software. Prior to conducting the study, approval was obtained from XXX University Institutional Review Board.

### 3.1. Recruitment Procedures

Organisations and support groups that were likely to interact with families of individuals diagnosed with both I/DD and dementia were contacted to assist with the recruitment process. Specifically, study information was sent to contacts and professionals affiliated with Alzheimer's organisations, Down Syndrome groups, and organisations supporting individuals with I/DD. Information was sent to groups within the United States. Professionals at these organisations agreed to disseminate study information and the survey link to their constituents in various formats that included: flyers, newsletters, social media posts, and word of mouth. Participants also were recruited via snowball sampling.

### 3.2. Description of Sample

To be included in the sample, family caregivers had to meet specific inclusion criteria: be an adult who is providing care for an individual with I/DD who also acquired dementia, and have access to a computer, mobile phone, or tablet to complete the online survey. For the purpose of this study, a family caregiver includes parents, spouses, siblings, or other relatives and friends. Formal paid caregivers were excluded from the study. The online survey was completed by 37 caregivers. Of this number, 9 incomplete surveys were eliminated, and 15 were eliminated because the survey was either completed by a formal paid caregiver ( $n = 7$ ) or if the care-recipient was not reported to have dual diagnoses of I/DD and dementia ( $n = 8$ ). The final sample of interest consisted of 13 family caregivers of people with dual diagnoses of I/DD and dementia.

Table 1 provides a summary of the characteristics of the respondent, the majority of who were parents of the person with I/DD ( $n = 10$ , 76.9%), with a mean age of 65.8 years ( $SD = 8.88$ ). Most were females ( $n = 12$ , 92.3%) and had completed undergraduate and graduate degrees (i.e., bachelor's degrees [ $n = 3$ , 23.1%] or graduate/professional degrees [ $n = 3$ , 23.1%]). The majority of them were married ( $n = 9$ ,

69.2%), with annual self-reported family incomes varying from less than \$20,000 to more than \$100,000. Six (46.1%) of them reported annual family income levels that exceeded \$60,000 annually. Only one (7.7%) reported working full-time, four (30.8%) were employed part-time, and eight (61.5%) were not working, indicating they were either retired, disabled, or stay-at-home family caregivers. More than half of the respondents ( $n = 7$ , 53.84%) were compound caregivers, i.e., they were caring for more than one person with a disability. Most of the study participants ( $n = 8$ ; 61.5%) indicated that they spent more than 20 hours per week caregiving. The majority identified themselves as full-time caregivers who were living with the care-recipient ( $n = 8$ , 61.5%). The individuals with I/DD who were not living in their family homes with their families were living in a nursing home ( $n = 1$ ), supported living ( $n = 2$ ) or other arrangements ( $n = 2$ ).

The ages of the individuals with a dual diagnosis in this study ranged from 16 to 62 years, with a mean age of 45.85 years ( $SD = 12.67$ ). More than half of the participants ( $n = 7$ , 58.8%) reported that they were caring for an individual with severe levels of impairments. The most frequently reported associated problems among the care-recipients were mood/anxiety ( $n = 9$ , 69.2%), speech/language difficulties ( $n = 9$ , 69.2%), and behaviour problems ( $n = 8$ , 61.5%). The communication ability of the individuals with dual diagnoses ranged from "able to communicate needs, wants, and some ideas in a meaningful way" ( $n = 7$ , 53.8%), "able to communicate within a limited range of topics in a meaningful way" ( $n = 3$ , 23.1%), and "very little meaningful communication" ( $n = 3$ , 23.1%). In terms of the level of supports required, the majority indicated that their care-recipients required support for some aspects of life ( $n = 6$ , 46.2%), followed by five (38.4%) who required support for most, but not all aspects of life, and two (15.4%) who required support for almost all aspects of life ( $n = 2$ , 15.4%; See Table 2).

**Table 1**  
*Descriptive Statistics: Family Caregiver Characteristics (N = 13)*

Family Caregiver Characteristics	N	%
Age of Caregiver	<i>M</i> =65.77 ( <i>SD</i> =8.88), Range: 50 to 82 years	
Gender		
Male	1	7.69
Female	12	92.31
Marital Status		
Married or domestic partnership	9	69.23
Not married, divorced, widowed, separated)	1	7.69
Single, never married.	3	23.08
Educational Level		
High school diploma/GED	3	23.08
Some college	4	30.77
Bachelor's degree	3	23.08
Graduate/professional degree	3	23.08
Family Income		
Under \$30,000	2	15.38
\$30,000 to \$59,999	4	30.77
\$60,000 and over	6	46.15
Missing	1	7.69
Employment Status		
Working full-time	1	7.69
Working part-time	4	30.77
Not working (e.g., retired, disability, public assistance, stay-at-home caregiver)	8	61.53
Relationship of caregiver to individual with I/DD and dementia		
Parent	10	76.92
Sibling	2	15.38
Other non-relative (e.g., family friend)	1	7.69
Number of family members with a disability or chronic condition who need care		
One	6	46.15
Two	5	38.5
Three	2	15.5
Caregiving Involvement		
I live with the person, so it is a full-time commitment for me	8	61.5
I don't live with the person, but I am the primary caregiver	2	15.4
I don't live with the person, and I am not the primary caregiver	3	23.1
Hours spent caregiving		
More than 20 hours per week	8	61.5
11 to 20 hours per week	1	7.7
5 to 10 hours per week	4	30.8

**Table 2**  
*Description of care-recipients (N = 13)*

Characteristics of person with I/DD and dementia	N	%
Age of person with I/DD and dementia	M=45.85, SD= 12.67, Range: 15 to 62	
Severity of chronic condition		
Mild	1	7.69
Moderate	5	38.46
Severe	7	53.84
Co-morbidities or associated problems*		
Mood/Anxiety	9	69.23
Speech and language difficulties	9	69.23
Behaviour	8	61.54
General problems with motor control and coordination	6	46.15
Thyroid disease	6	46.15
Seizures	5	38.46
Vitamin deficiency	4	30.77
Gastro-intestinal/digestive/stomach	4	30.77
Severe psychiatric disturbances	3	23.01
Sensory integration impairment	3	23.01
Heart problems	2	15.38
Other	2	15.38
Anemia	1	7.69
Severe depression	1	7.69
Communication level		
Able to communicate within a limited range of topics in a meaningful way	3	23.01
Able to communicate needs, wants, and some ideas in a meaningful way	7	53.84
Very little meaningful communication	3	23.01
Support level		
Requires support for almost all aspects of life	2	15.38
Requires support for most, but not all aspects of life	5	38.46
Requires support for some aspects of life	6	46.15

\*Does not equal 100% due to multiple response categories

### 3.3. Instrument

**Family Quality of Life Survey.** FQOL was measured using a modified electronic version of the second iteration of the short version of the Family Quality of Life Survey (FQOLS-2006) developed for the main family caregivers of people with I/DD (Isaacs et al., 2007; Isaacs et al., 2012; Samuel et al., 2012). The survey included three sections. The first section was a researcher-developed demographic survey that was used to collect data on personal and family variables such as age, gender, ethnicity, marital status, parents' educational level and annual family income. The second section of the survey collected demographic information on the individual with I/DD

and dementia, their relationship with their family caregiver, living arrangements, and about the caregiving context. The third section measured overall and domain-level FQOL using 62-items in nine life domains: *health* of the family, financial well-being (*finances*), *family* relationships, practical and emotional supports from relatives, friends, neighbours or *others*, formal support *services*, influence of *values*, *careers* and preparing for careers, *leisure* and recreation, and *community interaction*.

One of the changes in the modified electronic version of the survey was the addition of six more questions to address the issue of double-barrelled questions in the *others* domain. The questions pertaining to the

practical and emotional supports was separated into two in the stage of data collection and later collapsed together for parsimony during data analysis. Although the original FQOLS-2006 used only 56 psychometrically similar items in section 3 of the survey it still requires longer administration time when compared to the electronic version of the survey. Most items on the survey used a “forced-choice” method to obtain consistent responses across participants. Some items provided a text box that allowed participants to provide additional information.

The participant rated the importance of each life domain using a 5-point Likert scale ranging from 1 for not at all important to 5 for very important. For example, “How important is your family’s health to your family’s quality of life?”. Satisfaction was rated using a 5-point Likert scale ranging from 1 for very dissatisfied to 5 for very satisfied. For example, “All things considered how satisfied are you with the health of your family?”. The Cronbach alpha coefficients of  $\alpha = 0.78$  for importance and  $\alpha = 0.86$  for satisfaction were indicative of adequate internal consistency as a measure of reliability. The alpha values were higher than what has been reported in past research (Importance  $\alpha = 0.55$  and Satisfaction  $\alpha = 0.64$ ) when this survey was used with family caregivers of individuals with only an I/DD (Werner et al., 2009). The alpha coefficient of  $\alpha = 0.81$  for the two-items comprising the global FQOL scale was also similar to past report of the reliability of this scale ( $\alpha = 0.84$ ; Samuel et al., 2016).

#### 4. Data Analysis

The quantitative data were analysed using IBM-SPSS ver. 26.0. The analysis used t-tests for dependent samples to determine if differences between perceived importance and satisfaction with FQOL differed significantly. All decisions on the statistical significance of the findings were made using a criterion alpha level of 0.05.

### 5. Findings

#### 5.1. Description of importance and satisfaction ratings

The ratings of importance of satisfaction and the

**Table 3**

magnitude of their differences are summarised in Table 3. The domain that was perceived to be most important to overall FQOL was services (4.77), followed by health ( $M = 4.54$ ), family ( $M = 4.46$ ), finances ( $M = 4.38$ ), values ( $M = 4.31$ ), others ( $M = 4.19$ ), community ( $M = 4.00$ ), leisure ( $M = 3.69$ ), careers ( $M = 3.00$ ). The participants reported that the seven of the nine domains were either important or very important to their FQOL as indicated by a rating of 4 or higher. However, in terms of satisfaction with the domains, the participants reported that they were not satisfied (rating below 4) with eight of the nine life domains. Satisfaction ratings in descending order were finances ( $M = 4.00$ ), family ( $M = 3.62$ ), health ( $M = 3.46$ ), values ( $M = 3.46$ ), careers ( $M = 3.15$ ), leisure ( $M = 3.15$ ), others ( $M = 3.08$ ), community ( $M = 3.08$ ), services ( $M = 2.77$ ).

#### 5.2. Differences between importance and satisfaction ratings

Results of the t-tests for dependent samples indicated that there was a statistically significant difference between the total scores for family caregivers’ perceptions of the importance of the domains to FQOL and ratings of domain level satisfaction ratings ( $t [12] = 4.57, p = .001$ ). The mean level of importance ratings ( $M = 4.15, SD = 0.53$ ) was significantly higher than the mean level of satisfaction experienced ( $M = 3.28, SD = 0.80$ ). On a domain level, importance ratings were higher than satisfaction in eight of the nine domains, although these differences approached statistical significance only in four of the domains: *services* ( $d = 2.0, SD = 1.00$ ), *others* ( $d = 1.12, SD = 1.24$ ), *health* ( $d = 1.08, SD = 1.26$ ), *family* ( $d = 0.85, SD = 1.35$ ). The greatest discrepancy was noted between importance of *services* to FQOL ( $M = 4.77, SD = 0.44$ ) with the perceived level of satisfaction with *services* ( $M = 2.77, SD = 1.01$ ). The least difference was observed in *careers* ( $d = -0.15, SD = 1.68$ ), and *finances* ( $d = 0.39, SD = 1.04$ ). The negative sign indicates directionality where the participants reported a slightly higher level of satisfaction only in the domain of *careers*.

*Importance and Satisfaction Ratings: Descriptive statistics and results of t-Test for Dependent Samples (N = 13)*

Domain		<i>M</i>	<i>SD</i>	<i>Mean Difference d</i>	<i>SD difference</i>	<i>of t</i>	<i>p</i>
Health							
Importance		4.54	0.66	1.08 <sup>3</sup>	1.26	3.09**	0.009
Satisfaction		3.46	1.13				
Financial well-being							
Importance		4.38	0.51				
Satisfaction		4.00	0.91	0.39 <sup>8</sup>	1.04	1.33	0.209
Family relationships							
Importance		4.46	0.88				
Satisfaction		3.62	0.87	0.85 <sup>4</sup>	1.35	2.27*	0.043
Informal supports							
Importance		4.19	0.83				
Satisfaction		3.08	1.24	1.12 <sup>2</sup>	1.24	3.23**	0.007
Formal supports							
Importance		4.77	0.44				
Satisfaction		2.77	1.01	2.0 <sup>1</sup>	1.00	7.21***	<.001
Values							
Importance		4.31	0.63				
Satisfaction		3.46	1.05	0.85 <sup>6</sup>	1.21	2.51*	0.027
Careers							
Importance		3.00	1.47				
Satisfaction		3.15	.90	-0.15 <sup>9</sup>	1.68	-0.33	0.746
Leisure							
Importance		3.69	1.11				
Satisfaction		3.15	1.57	0.54 <sup>7</sup>	1.33	1.46	0.170
Community interaction							
Importance		4.00	1.00				
Satisfaction		3.08	1.50	0.92 <sup>5</sup>	1.32	2.52**	0.027
Total scores							
Importance		4.15	0.55	0.75	0.56	4.65***	0.001
Satisfaction		3.40	0.71				
Global FQOL							
FQOL rating		3.85	0.69				
FQOL satisfaction		3.46	1.05	0.38	0.77	1.81	0.10

Superscript indicates the rank ordering of the nine FQOL domains in descending order

**5.2. Differences between importance and satisfaction ratings**

Results of the t-tests for dependent samples indicated that there was a statistically significant difference between the total scores for family caregivers'

perceptions of the importance of the domains to FQOL and ratings of domain level satisfaction ratings ( $t [12] = 4.57, p = .001$ ). The mean level of importance ratings ( $M = 4.15, SD = 0.53$ ) was significantly higher than the mean level of satisfaction experienced ( $M = 3.28, SD =$



0.80). On a domain level, importance ratings were higher than satisfaction in eight of the nine domains, although these differences approached statistical significance only in four of the domains: *services* ( $d = 2.0$ ,  $SD = 1.00$ ), *others* ( $d = 1.12$ ,  $SD = 1.24$ ), *health* ( $d = 1.08$ ,  $SD = 1.26$ ), *family* ( $d = 0.85$ ,  $SD = 1.35$ ). The greatest discrepancy was noted between importance of *services* to FQOL ( $M = 4.77$ ,  $SD = 0.44$ ) with the perceived level of satisfaction with *services* ( $M = 2.77$ ,  $SD = 1.01$ ). The least difference was observed in *careers* ( $d = -0.15$ ,  $SD = 1.68$ ), and *finances* ( $d = 0.39$ ,  $SD = 1.04$ ). The negative sign indicates directionality where the participants reported a slightly higher level of satisfaction only in the domain of *careers*.

### 5.3. Description of FQOL

The global FQOL score computed from mean rating of overall FQOL and satisfaction with FQOL was  $M = 3.52$  ( $SD = 0.86$ ). A closer examination of the individual contributing items to global FQOL, revealed that the mean rating of overall FQOL ( $M = 3.85$ ,  $SD = 0.69$ ) was a little higher than the mean satisfaction rating ( $M = 3.46$ ,  $SD = 1.05$ ). The difference between these scores was not statistically significant indicating that these items are closely interrelated to be scaled together as global FQOL with an internal consistency of  $\alpha = 0.81$ . The frequency distribution of the ratings revealed that more than half of the participants reported that their FQOL was either very good ( $n = 2$ ) or good ( $n = 7$ ) and the remaining reported that their FQOL was fair. In terms of satisfaction with their FQOL rating, four participants reported that they were dissatisfied with their FQOL while the remaining were either satisfied ( $n = 8$ ) or very satisfied ( $n = 1$ ).

Analysis of the open-ended comments pertaining to factors that influence FQOL revealed that the social isolation experienced due to behavioural problems associated with people with I/DD and dementia and the dynamically changing demands of caregiving attributed to a decline in FQOL. However, many participants were optimistic that service supports could improve their FQOL. In terms of quantity of services, one sibling caregiver stated: "As soon as I can get my sister all the services she needs, things will be better." In terms of quality of services, a parent caregiver expressed frustration over the ongoing fight for better quality residential services for daughter. An undertone

in the comments pertaining to seeking formal services was an optimism that their FQOL will improve when they gained more access to services.

The other two themes that emerged from analysis of the open-ended comments on overall FQOL were related to the caregiving stress and acceptance of the condition. The stress of caregiving was reflected in the comments pertaining to finding service supports and the need to provide care to more than one person in the family, i.e., compound caregiving. One of the seven compound caregivers in the study remarked that it was very stressful to simultaneously care for her father (age 82) and brother (age 49) with Down syndrome and dementia, as it required tremendous time and energy to fulfill the multiple caregiving roles. The dynamic nature of caregiving contributed to the stress of caregiving. For example, a caregiver supporting both her brother with Down syndrome and dementia and her husband stated: "Now that my husband is being treated for cancer. So again, we are in the process of finding our feet." Another caregiver stated, "...we are always in transit. Our lives get better, then worse... as my brother's condition varies and/or the supports we receive change."

Despite the stress associated with the complications of dual diagnoses and dynamic nature of caregiving, there was ample evidence of efforts being made towards acceptance of the condition(s). A family caregiver who was witnessing rapid cognitive decline secondary to dementia stated, "I am understanding that he [her son] probably will never be the same." Another parent who was living with her daughter with Alzheimer's and Down syndrome stated: "Moping about how hard life is does not make things any better or easier." A strong reliance on personal values seemed to enable an acceptance the decline of the condition as evidenced by the comment from a participant who was caring for her husband with cancer and brother with dual diagnoses: "God has been good to us and we trust He will continue to help us with our challenges."

## 6. Discussion

The purpose of this pilot study was to examine the FQOL of individuals living with I/DD who also acquire dementia. Specifically, we were interested in the examining the perceptions of their family

caregivers towards FQOL and the discrepancies between importance and satisfaction attributed to the nine FQOL domains. Findings indicated that the supports they received from formal disability service agencies were most important to their FQOL, followed by the health of the family and the relationships within the immediate family. However, the family caregivers in this study were least satisfied with service supports they received. This finding concurs with literature indicating the dire need for services and supports for adults with IDD and aging adults with dementia (Gibson, Holmes, Fields, & Richardson, 2019; Marsack-Topolewski & Weisz, 2020). Further, the participants in this study expressed satisfaction only with one of the nine FQOL domains- financial well-being, which could imply that although the participants in this study can afford services they seem frustrated with the barriers to accessing the required services. This finding is different from previous literature indicating that financial well-being was a domain that had a low rating (Brown et al., 2006; Ho et al., 2013; Samuel et al., 2016). At least two possibilities arise for the present study's difference in findings: (1) The study participants' older ages and (2) the respondents may be of higher socio-economic means (Ajuwon & Brown, 2012; Brown et al., 2016; Edwards et al., 2018). Past literature also indicates the need to support family caregivers in overcoming the challenges associated with accessing services and caring for their family members living with dual diagnoses (Heller et al., 2018; Janicki et al., 2019).

The greatest discrepancy was noted between perceived importance and satisfaction with supports from formal services for people with IDD and dementia and their families, followed by informal supports, and family health. These discrepancies were over 1.0 or higher which has been noted in past FQOL research as an area of concern that needs further investigation (Roth & Brown, 2017). Given that the mean age of the study participants in this sample was 65.8 years, receiving informal and formal service support may continue to become more important as these family caregivers continue to age and likely experience their own health-related declines. Informal social supports are an area of concern universally across various cultures and types of disabilities (Ajuwon & Brown, 2012; Brown et al.,

2016; Edwards et al., 2018). Informal supports includes the practical and emotional support obtained from relatives, friends, and neighbors often become even more important as the family caregiver ages and the severity of dementia increases, posing additional demands. For family caregivers, help from family and friends can ameliorate the caregiving demands and improve FQOL (Edwards et al., 2018). Likewise, the discrepancy in family health can reflect the increase in the challenges for both the aging caregiver, many of whom are parents, and their care-recipients as they continue to age.

The small differences between the ratings of importance and satisfaction ratings in the domains of finances, careers, and leisure that did not approach statistical significance has clinical implications. For example, the similar ratings of importance and satisfaction with the domains of finances and careers is not surprising given the age and socioeconomic status of the sample. However, in a more diverse sample comprising younger family caregivers who can be forced to choose caregiving over career responsibilities, the satisfaction rates can be much lower. The small difference ( $d = 0.54$ ) observed in the domain of leisure and recreation is also of clinical significance because it can imply that families may not be recognising the value of leisure participation despite the research evidence on the central role of leisure participation in improving family well-being (Hodge et al., 2017; Zabriskie & McCormick, 2003). Past research with family caregivers of aging adults with dementia has also indicated that the domain of leisure and recreation is significantly associated with overall FQOL (Samuel & DiZazzo-Miller, 2019).

Descriptive analysis of the quantitative ratings of overall FQOL revealed that about a third of the respondents ( $n = 4$ ) were dissatisfied with the overall FQOL rating although none rated their overall FQOL as poor or very poor. More than two thirds of the participants reported that their FQOL was either good/very good and the remaining third reported that their FQOL was only fair. These average FQOL ratings are consistent with past research among caregivers of individuals with IDD (Schertz et al., 2016). The lack of significant differences between the mean rating of FQOL and satisfaction with FQOL indicate that these

item ratings are similar enough to be scaled together as global FQOL score as has been reported in past FQOL research (Samuel, et al., 2016).

Thematic analysis of the open-ended statements indicated that FQOL was affected adversely by the dynamic nature of caregiving stress and the social isolation experienced secondary to the behavioural problems of their care-recipients. Past research among parents of people with I/DD indicate that behavioural problems are associated with parental stress, caregiving burden, and social functioning (Lecavalier et al., 2006; Marsack & Hopp, 2019; Samuel et al., 2017). Among families with dementia it was found that unmet community-based needs rather than the process of caregiving or memory problems of the care-recipient that leads to negative outcomes such as caregiving stress and social isolation (Robison et al., 2009). Although the participants in this study were frustrated by the quality and quantity of services available for the dynamically changing needs of their care-recipient aging I/DD progressing through the stages of dementia, they were optimistic that access to services could improve their FQOL.

More than half of the study sample were compound caregivers which is different from younger families represented in FQOL research in the past. (As a point of reference, compound caregivers are caregivers that provide care to more than one loved one, such as an adult child and a spouse [Perkins, 2010].) Despite these challenges, the personal and religious values (e.g., determination to not complain but stay positive, choosing to rely on their faith in God) appear to improve their FQOL. These findings on personal values strengthen the evidence on the role of religious values and beliefs in improving the QOL of family caregivers of people with dementia or I/DD (Agli et al., 2015; Burgener, 1999; Heo, 2014; Taub & Werner, 2016).

## 7. Strengths and Limitations

Although much has been written about the needs of this population there is a dearth of empirical data pertaining to the everyday challenges faced by their family caregivers. Given the paucity of research that has been conducted on individuals with a dual diagnosis of I/DD and dementia and their family caregivers, this pilot study provides an impetus to open

a discussion about the needs of this understudied population. The limitations of this pilot study include the small convenience sample comprising a relatively homogenous group of family caregivers, with most being over the age of 60, female, Caucasian, and higher socio-economic status. Given the recruitment procedures, participants were more likely to interface with support groups and organisations in the United States that were relevant to caregivers of individuals with dual diagnoses of I/DD and dementia. These caregivers volunteered to participate in this web-based pilot study, which limited participants to those who had access to a computer and were familiar with the Internet. Caregivers provided self-report regarding the diagnoses of their care recipient. As such, a limitation is that a screening tool was not used to provide verification for study inclusion. Additionally, due to anonymity afforded by an electronic survey, the geographic location was not available, so little is known about availability of support services or other programs that could benefit both the family caregiver and the person with I/DD and dementia. Despite these limitations, these initial findings contribute to the gaps in caregiving literature by describing the importance and satisfaction of the FQOL domains and the overall FQOL those caring for adults with I/DD who acquire dementia.

## 8. Implications for Practice

This pilot study indicates that family caregivers view the support they receive from family, friends, and professionals as important to their FQOL. However, they are not satisfied with these supports. Determining reasons for the discrepancy is important to address factors that may be contributing to these differences. For example, the difference between the importance of and satisfaction with service support imply that their service support needs were not being met. The availability of professionals who are adequately trained to understand and support the complex needs of caregivers and individuals dually diagnosed with I/DD and dementia may be lacking (Holst et al., 2018). Professionals who work to support both caregivers, as well as individuals with I/DD and dementia, should be aware of the needs of these individuals, as well as resources and supports available for them. As the number of individuals with both I/DD and dementia

continue to increase, the strength, challenges, and desires of their family members should be explored further using the FQOL framework that uses multiple indicators. The FQOL indicators of opportunities, initiative, attainment and stability can throw light on the discrepancies between importance attributed to a domain and the perceived levels of satisfaction and thus inform family-support models of care.

## 9. Future Research

The next steps recommended to increase the validity of our findings include gathering data from a large and more diverse sample of participants by taking targeted steps to locate this hidden population in our local and virtual communities using a more refined tool. In terms of increasing sample size, we recommend data mining from secondary data sources such as social media forums that caregivers frequently use, using a mixed-methods research. The survey used to measure FQOL for this survey needs refinement and validation for use with this population. For example, broadening some of the questions pertaining to support from services to measure specific details to understand if satisfaction is related to the individual providing the services, the physical nature of the services, or the time required to obtain the services. While this would lengthen the survey, the responses would be more meaningful. We also recommend creating a battery of standardised tools to identify the predictors of FQOL such as the caregiver's stress, burden, health; and care-recipient's stage of dementia, severity of disability, and level of functional independence. It will also be beneficial to query the FQOL perspectives of multiple family members and also of the individuals with IDD and dementia in different stages of the disease process.

## 10. Conclusion

This pilot study was an initial examination of perceptions of the importance and satisfaction of nine major life domains associated FQOL among caregivers of individuals diagnosed with both IDD and dementia. The discrepancies between importance and satisfaction indicate the need for further investigation and possible interventions to decrease these differences to improve the FQOL of families caring for aging adults with IDD who acquire dementia in adulthood.

## Conflict of Interest

Authors declares no conflict of interest.

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