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Family Support of Older Caregivers: Factors Influencing Change in Quality of Life

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Abstract:	Understanding factors that can improve the quality of life (QOL) of older caregivers of individuals with intellectual and developmental disabilities (I/DD) is important in broadening participation in family empowerment interventions. The purpose of this study was to identify the factors influencing the QOL of older caregivers (50+) of adults with I/DD who participated in a peer-mediated state-wide family support project. The research study used a quasi-experimental research design grounded in the family quality of life (FQOL) framework with pretest and posttest data gathered from 82 caregivers. Correlation and regression analyses were conducted to identify factors influencing change in QOL of study participants. Findings indicated that improvements in caregiver QOL after participating in the project could be explained by caregiver's employment status, increased global FQOL, and decreased caregiver stress and depression.

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Abstract

Understanding factors that can improve the quality of life (QOL) of older caregivers of individuals with intellectual and developmental disabilities (I/DD) is important in broadening participation in family empowerment interventions. The purpose of this study was to identify the factors influencing the QOL of older caregivers (50+) of adults with I/DD who participated in a peer-mediated state-wide family support project. The research study used a quasi-experimental research design grounded in the family quality of life (FQOL) framework, with pretest and posttest data gathered from 82 caregivers. Correlation and regression analyses were conducted to identify factors influencing changes in the QOL of study participants. Findings indicated that improvements in caregiver QOL after participating in the project could be explained by caregiver's employment status, increased global FQOL, and decreased caregiver stress and depression.

Key words: aging, family caregivers, adults with intellectual disabilities, barriers, peer mentors, systems navigation, family support navigators

Family Support of Older Caregivers: Factors Influencing Change in Quality of Life

Approximately 5.1 million children and 2.1 million adults in the US have intellectual and developmental disabilities (I/DD; Tanis et al., 2021). While most people with I/DD (72%) live with their families, 24% are living with caregivers aged 60 years or more (Tanis et al., 2021). More than half of family caregivers in the US are over 50 years old, and one in five are more than 65 years old (American Association of Retired Persons and National Alliance for Caregiving [AARP & NAC], 2020). Older caregivers often juggle their own age-related needs while trying to support their care recipients with I/DD (Blinded, 2020; Perkins, 2010). In this paper, the term *caregiver* refers to unpaid informal family caregivers of individuals with I/DD.

Caregiving families comprise an informal residential care system that is five times larger than the formal out-of-home residential care system for people with I/DD (Braddock, et al. 2017). Given that caregivers and care recipients are living longer than in the past and with limited formal resources available for those with I/DD, caregiving may endure longer and under more taxing circumstances than in the past (Heller & Schindler, 2009). Most family members of people with I/DD can attest to challenges associated with staying informed about available services, especially as age increases (Gilson et al., 2017). Compounding these realities, less than 7% of national spending is allocated for individuals with I/DD (Braddock et al., 2017). As caregivers age, they are at elevated risk for adverse outcomes affecting their health, finances, and psychosocial well-being that collectively influence their quality of life (QOL; Fernández-Ávalos et al., 2020; Javalkar et al., 2017; Whitley & Fuller-Thomson, 2018). The purpose of this study was to examine factors influencing the QOL of older caregivers (50+) of adults with I/DD who participated in a state-wide peer-mediated family support project. Specifically, how did caregiver stress, burden, depression, employment status, and global family quality of life (FQOL)

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influence the QOL of older caregivers who participated in a peer-mediated intervention?

Understanding how this program helped improve the QOL of older caregivers of individuals with I/DD is important in broadening participation in family empowerment interventions.

Literature Review

The World Health Organization (WHO) defines QOL as an individual's perception of their position in life within their environment, cultural context, and value systems, relative to their personal goals, expectations, standards, and concerns (The WHOQOL Group, 1994). The multidimensional social construct of QOL has had a strong influence on policy and practice among people with I/DD for several decades. Despite the wide use of the term QOL in describing caregiver challenges, little is known about factors influencing the QOL of caregivers, particularly among older families (Fernández-Ávalos et al., 2020). Longitudinal caregiver research indicates that QOL changes over the lifespan and is dependent on caregiving demands of family members with I/DD. Overall, there is a dearth of well-designed studies with caregiver QOL as a primary outcome in caregiving research (Farina et al., 2017). Based on a review of literature, the constructs of FQOL, stress, depression, burden, and employment were identified as factors that could influence caregiver QOL.

The FQOL construct can be defined as a "dynamic sense of family well-being, collectively and subjectively defined and informed by its members, [and] in which individual and family-level needs interplay" (Zuna et al., 2009, p. 262). The FQOL theoretical framework represents a paradigm shift in service delivery for people with disabilities by changing the focus from the individual to the family and focusing on strengths rather than deficiencies (Turnbull et al., 2004; Blinded et al., 2012). The FQOL theoretical framework emerged from two decades of qualitative research with caregivers to understand their strengths, challenges, and needs (Isaacs et

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al., 2007). Nine domains comprise the international FQOL framework, including: health of the family, financial well-being, family relationships, support from others, support from disability services, influence of values, careers/preparing for careers, leisure/recreation, and community involvement (Isaacs et al., 2007). Each of these domains are measured using six dimensions: importance, opportunities, initiative, attainment, stability, and satisfaction. Much of the FQOL research has focused largely on children with I/DD, except for a few studies focusing on needs of aging families (Jokinen & Brown, 2005; Blinded et al., 2022). Given the significant role played by older caregivers in caring for their family members with I/DD, one must consider the reciprocal relationship in lives of caregivers and care recipients, as well as the effects of these linkages over time and their impact on FQOL (Heller et al., 2021).

Stress emerges when an individual's perception of demands exceeds the resources available to cope with their situations (Lazarus, 1966). Symptoms of caregiver stress can include physical, mental, and emotional tiredness (Ingber, n.d.). Caregiving stress typically occurs when caregivers put their physical and mental health on hold while attending to their care-recipients. Time-use studies indicated that parents of children with I/DD can spend more time on routine childcare duties than parents of typically developing children (McCann et al., 2012). Time devoted towards childcare activities and home-based therapies require time that could be invested in self-care, leisure, career, family, and community-oriented activities (McConnell et al., 2015). Further, high parental adherence to home-based therapy demands cutbacks (i.e., parent sacrifice) is negatively associated with overall family well-being (McConnell et al., 2015).

Caregivers also expend time and effort navigating difficult processes associated with gaining access to and use of formal support services. Older parents often become stressed with service fragmentation and discontinuity across the lifespan, such as during life transitions to

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adolescence and adulthood (Blinded et al., 2021). Caregivers can get frustrated with lifelong expectations to devote time, effort, and money to help their family members with I/DD complete daily activities (Grey et al., 2018; Seltzer et al., 2011). Worry and uncertainty associated with future planning to care for each other in the family also contribute to higher stress and anxiety (Blinded, 2020; Dillenburger & McKerr, 2011). Chronic stress can lead to depression, anxiety, and psychosomatic conditions (Eisenhower et al., 2009; Masefield et al., 2020). Despite the acknowledgement of rewards and benefits of caregiving for individuals with I/DD, ample evidence suggests that caregiving is inherently stressful (Lee, 2013; Singer & Floyd, 2006)

Depression that affects an individual's actions, thinking, and emotions can decrease one's QOL. Negative self-evaluation can lead to depression, making everyday tasks challenging for older caregivers, leaving them exhausted and unmotivated. Depression could result in bodily discomfort and suicidal ideation (Beck, 1986). Gogoi et al. (2017) reported that anxiety and depression were positively correlated for mothers of children with I/DD, while both were negatively correlated with maternal QOL. Mothers of children with I/DD are prone to higher rates of depression than mothers of typically developing children (Singer & Floyd, 2006). The negative relationship between depression scores and QOL worsened as mothers and their care recipients aged (Tekinarslan, 2013). In related caregiving literature, higher rates of depression were consistently associated with decreased QOL (Farina, et al., 2017).

Caregiver burden refers to the strain or load associated with providing continuous care for a family member with a disability or chronic condition (Liu et al., 2020). Understanding characteristics of caregiver load is important as the well-being of both caregivers and care recipients are affected. The idea of burden was first put forth by Hoenig and Hamilton (1966), who thought it could be divided into subjective and objective burden. While objective burden is

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defined as occurrences or actions connected to poor caregiving experiences, subjective burden refers to feelings that caregivers develop while providing care to individuals with I/DD.

According to Zarit et al. (1980), burden is “the extent to which caregivers viewed their emotional [and], physical health, social life, and financial position as a result of caring for their relative” (p. 261). Caregiver burden can manifest as psychological distress, physical health problems, financial and social constraints, damaged family ties, a sense of helplessness, as well as other negative tasks associated with caregiving (Collins et al. 1994).

Employment, in addition to being necessary for survival, can be a significant source of autonomy, social connection, and contribution to the greater community. However, previous research indicated that caregivers struggled to balance work and family life across the life span (Bainbridge & Broady, 2017). Parenting demands associated with raising a child with an I/DD is known to adversely impact the careers of parents (Brewer 2018; Eskow et al., 2011). Lifelong caregivers of people with I/DD are more likely to discontinue their involvement in paid employment and give up professional and educational ambitions (Bauer & Sousa-Poza, 2015; Cidav et al., 2012; Schofield et al., 2019). Despite these realities, little is known regarding the effects of employment on caregiver QOL. Caregivers who were not working might have had less access to resources needed to maintain a healthy lifestyle than caregivers who were employed or vice versa. Additionally, older caregivers who are working may view their work as a helpful and desired type of respite that decreases the physical toll of caregiving (Utz et al., 2012).

Family Support Interventions

Although service navigation issues faced by families of individuals with I/DD are acknowledged, little is known about interventions that empower caregivers of adults with I/DD to negotiate healthcare and disability service systems. One common challenge reported by

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families is understanding how to navigate complex systems of care that often are designed around fiscal advantages rather than the needs of the person with the disability (DiGuseppi et al., 2021; Turnbull et al., 2004; Turnbull & Summers, 1987). Family support programs such as Parents Taking Action (Dababnah et al., 2021); Fostering Advocacy, Communication, Empowerment, and Support (FACES; Kaiser et al., 2022); Therapeutic Education Autism and Parenting Program (EATP; Derguy et al., 2017) focus on empowering caregivers of young children with I/DD (Sung & Park, 2012; Zuurmond et al., 2019). Programs addressing the needs of parents of adolescents include the Volunteer Advocacy Program-Transition (VAP-T; Taylor et al., 2017) and Transitioning Together (DaWalt et al., 2018). However, few efforts are focused on addressing the needs of aging families (Heller & Caldwell, 2006; Owen et al., 2021).

Peer mentors can be used to empower families in navigating systems of care by providing caregivers with knowledge and skills necessary to manage future challenges (Berrick et al., 2011; DeBrine et al., 2009; Jamison et al., 2017). Peer mentors frequently work with family members and connect them to needed resources. Older caregivers of individuals with I/DD who often encounter obstacles, including accessibility, acceptability, and affordability of services (Blinded, 2020), may benefit from peer-mediated family support. A gap was found in the literature regarding methods to support older caregivers of family members with I/DD. To help fill this gap, a 2-year program, XX-Older Caregivers of Emerging Adults with Autism and Neurodevelopmental Disabilities (XX-OCEAN), was implemented in the state of XX. Based on the review of literature the following hypothesis were developed:

1. Caregivers' responses from pretest to posttest were expected to decrease for stress, burden, and depression, while changes for FQOL and QOL were expected to increase.
2. Caregivers' positive changes in QOL could be predicted from negative changes in stress, burden, and depression, employment status, and positive changes in FQOL.

Methods

Study Design

A one-group pre- posttest quasi-experimental design was used to evaluate the benefits of participating in a state-wide peer-mediated family support intervention. This type of research design is used when participants are followed over time to determine effects of an intervention (McKillip, 1992). A control group was not feasible due to limited funding and recruitment challenges during the COVID-19 pandemic.

Recruitment

Participants were recruited from May 2019 to December 2020 through email listservs, social media, and partnerships with local organizations connected with aging and I/DD networks. The pandemic that occurred during the project limited face-to-face meetings, with recruitment and intervention continuing via phone and virtual meetings.

Participants

The study's target population was caregivers aged at least 50 years and supporting at least one adult (18+) with I/DD. The inclusion criteria for participants were being a family caregiver (e.g., parent, spouse, sibling, or other relative) of an individual over 18 years of age with I/DD, being at least 50 years of age, having access to the internet, and able to read and comprehend English or Spanish. A participant was excluded if they were a paid caregiver of an adult with I/DD. In the current study, caregivers were generally between the ages of 60 and 69. The demands of aging families (i.e., those with care-recipients 40 years or older) and those who have not accessed the service system are likely to vary, especially given the fact that both caregivers and care recipients face health issues. Most resources and support are provided to

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young children with I/DD and their frequently younger parents, although more than 50% of caregivers in the US are over 50 years of age (AARP & NAC, 2020).

Participants received \$20 and \$30 gift cards upon completion of pre- and posttest surveys, respectively. The posttest amount was increased to promote continued participation and study completion. The funding agency and XXX's Institutional Review Board (IRB) approved the incentive schedule. Power analysis using G*Power 3.1 (power of .80, with an effect size of .15, and an alpha level of .05) indicated that a sample of 82 was appropriate for a multiple linear regression analysis with four predictors (Faul et al., 2009). Eighty-two of the 100 participants completed both pre- and posttests. Four of the 18 who did not complete the posttests dropped out of the study without implementing their individualized action plans (IAP). Study dropout was a result of facing challenging family life events such as illnesses, deaths, and moving out of state. Comparative analysis found no significant differences in the demographic traits of participants and dropouts (Table 1).

Participants were predominantly female, White, and married mothers (Table 1). Most caregivers had college degrees, with household incomes of \$60,000 or more. Fewer than half of caregivers were employed, with almost half reporting chronic health conditions. Most caregivers co-resided with their family member with I/DD and devoted over 20 hours per week to caregiving. Almost half were providing care to more than one person in the family.

The mean age of caregivers was 64.1 ($SD = 6.6$) years, while that of care-recipient with I/DD was 29.8 ($SD = 9.6$) years. Commonly reported primary diagnoses were autism spectrum disorders, unspecified I/DD, epilepsy, cerebral palsy, and Down syndrome. The most frequently reported associated problems were mood/anxiety, behavior, speech/language challenges, and gastro-intestinal issues.

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XX-OCEAN Intervention

XX-OCEAN, a program designed for older caregivers of adults with I/DD, was an extension of the federally funded Projects of National Significance intended to assist low-income parents from racial/ethnic minorities in XX who were raising children with I/DD (Heller & Schindler, 2009). Work with under-resourced families of people with I/DD in the state for over two decades informed the program curriculum summarized in Table 2. The XX-OCEAN program was closely aligned to the Association for Children's Mental Health Program to ensure that the Person-Support-Person model would be expanded in XX to cover adult and aging treatment systems. XX-OCEAN program used peer mediators known as family support navigators (FSNs) to help caregivers find services for their care-recipients. Past research indicated that FSNs can be effective with families of individuals with I/DD (Dababnah et al. 2021; Feinberg et al. 2021).

The project included 14 FSNs who were hired as peer mentors for older caregivers. The FSNs had to be at least 60 years of age and have prior experience using health and disability services in XX. As the FSNs would be working with caregivers from multiple ethnic and age groups, they had to be culturally sensitive (defined as being able to withhold judgment of different cultural practices and beliefs and having the ability to manage these differences effectively; Gottlieb, 2021). They had the contextual knowledge necessary to support older caregivers who were assisting and supporting an adult with I/DD. Living in different locations around the state, the FSNs participated in a comprehensive two-day training course via the Zoom platform. The FSN were trained using the program curriculum that was adapted from past protocols that were developed by stakeholders of three externally funded family support projects from 2003-2012 (see Table 2; Blinded, 2023).

Procedures

Approval was obtained from XXX University's IRB before conducting the study. Each caregiver was matched with an FSN in their geographical region by the program manager following eligibility screening and an intake procedure to ascertain the family's condition, level of need, and current access to resources. Each caregiver accepted in the program received an email with a link to the online pretest survey. Pretest results were reviewed by the project evaluator who performed a preliminary analysis and created an individualized FQOL report based on the pretest responses to FQOL-related questions. The FQOL report for each participant included the names of the three domains with highest importance to their overall FQOL, along with a graphical representation of the five-point ordinal ratings assigned by participants for the remaining five dimensions (opportunity, initiative, attainment, stability, and satisfaction) in each of the nine FQOL domains. The three commonly reported domains that were most important to FQOL were family, health, and finances. After reading the report, the project manager forwarded it to the FSNs so they could distribute it to their assigned caregivers. FSNs were not provided information on other constructs measured on the caregivers' pretest. The confidentiality of the caregiver's pretest responses was assured using this evaluation approach.

The FQOL report served as the FSNs' roadmap for creating the IAP with the family. The IAP for each family included three goals—one long-term and two short-term—as well as networking techniques for gaining access to a range of services. Examples of IAP goals include items such as securing housing for the individual with I/DD, community inclusion, self-determination, and an increase in respite hours for the caregiver. For this project, a long-term goal was defined as a goal that typically takes more than 3 months to complete, while a short-term goal usually can be attained in less than 3 months. To promote communication among

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FSNs, participants, and project personnel, the program manager organized 12 group meetings (2 hybrid, 10 online). Depending on the subject being discussed, participation at monthly group meetings varied from 15 to 30 participants. Each one-hour session offered socializing and structured learning opportunities and allowed caregivers to practice their new skills in establishing their own support and service networks. Each family had a different period of intervention, with the program manager assessing their progress every six months until their goals were achieved. Each caregiver completed a posttest survey after achieving their goals to assess any changes that might have occurred from prior to starting the program. The only difference between pre and posttest surveys was that no demographic data were gathered on the posttest.

Instruments

A survey was created using the Qualtrics Research Suite to gather information on the sociodemographic of the caregiver and the individual with I/DD, the caregiving context, as well as their health and well-being. Survey items were derived from six standardized tools: Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001), brief version of the World Health Organization's Quality of Life scale (BREF-QOL; Skevington et al., 2004), Perceived Stress Scale (PSS-10; Cohen et al., 1983), Zarit Burden Inventory (ZBI-12; Bedard et al., 2001), general version of the Family Quality of Life Survey revised in 2006 (FQOLS-2006; Brown et al., 2006), and World Health Organization Disability Assessment Scale (WHODAS; Andrews et al., 2009). All scales were scored using the published authors' protocols.

Dependent Variables

Quality of life (QOL). Caregiver QOL was measured using a single item from the BREF-QOL both at pre- and posttest (Skevington et al., 2004). Caregivers rated their QOL using

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a 5-point scale (5 = excellent, 1 = poor). The BREF-QOL was reported to be valid and robust for testing factors influencing QOL of people with I/DD and older caregivers (Rosen et al., 2020).

Independent Variables

Caregiver Stress. The 10-item PSS was used to measure caregiver stress (Cohen et al., 1983). The PSS was designed to measure the degree to which life situations are appraised as stressful by an individual in the past month (Cohen et al., 1994). The 10 items were rated using a 5-point scale (0 = never, 4 = very often). Six items were reverse coded before using the items to compute a total score (possible scores 0 - 40), with higher scores indicating greater stress. The PSS-10 has been widely used to measure caregivers' stress in various contexts (Haley et al., 2020). The tool had excellent internal consistency in the present study (Cronbach's $\alpha = .90$).

Depression. The 9-item depression module of the PHQ-9 was used to assess caregiver depression (Kroenke et al., 2001). The 9 items correspond to the DSM- IV criteria for depression, and each was scored as 0 = not at all to 3 = nearly every day. Numeric responses were summed to obtain a total score ranging from 0 - 27 with higher scores indicating greater depression. The PHQ-9 has been used to screen for depression among caregivers of individuals with diverse conditions including I/DD (Willner et al., 2020). The tool had good internal consistency for the present study (Cronbach's $\alpha = .85$).

Zarit Burden Inventory (ZBI). The 12-item ZBI was used to measure caregiving burden (Bedard et al., 2001). Each item was measured using a 5-point scale (0 = never, 4 = nearly always). The numeric ratings were summed to obtain a total score ranging from 0 - 40, with higher scores indicating greater burden. Previous research indicated that the ZBI-12 has been used to measure burden of older caregivers in diverse cultural contexts (Gratão et al., 2019). The tool had excellent internal consistency for the present study (Cronbach's $\alpha=.91$).

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Global FQOL. The FQOLS-2006 was used to measure global FQOL using the mean score computed from the following two questions “Overall how would you describe your family’s quality of life?” (1 = very poor, 5 = very good) and “Overall, how satisfied are you with your family's quality of life?” (1 = very dissatisfied, 5 = very satisfied; Brown et al., 2006). A mean score for the scale was obtained by summing the ratings and dividing by 2, with higher scores indicating better FQOL. The mean score computed from these two items represent global FQOL similar to past investigations using this tool (Blinded et al., 2022; Blinded et al., 2016). The FQOLS-2006 has been found to have good reliability and validity when used with caregivers of individuals with I/DD across the lifespan (Isaacs et al., 2012). The internal consistency of the 2-item subscale for the present study was $\alpha = .89$, indicating excellent reliability.

Covariates

The covariates; gender, race/ethnicity, marital status, employment, caregiver relationship, and living status; were categorical. Annual family income, education, and caregiving requirements in hours per week were ordinal variables. Family size, number of people requiring care, and age of caregivers and care recipients were continuous variables. Age was computed from the actual year of birth of the caregiver and person with I/DD, respectively.

Information on the severity of disability was collected using the 12-item WHODAS that measured impairments consistent with DSM-5 for people with chronic diseases. Caregivers rated their care recipients’ degree of difficulty (1 = None, 2 = Mild, 3 = Moderate, 4 = Severe, 5 = extreme/cannot do) in accomplishing 12 daily living activities. Possible scores ranged from a minimum of 12 indicating no impairment to a maximum of 60 indicating maximum impairment (Andrews et al., 2009). The numeric responses were summed to obtain a total score ranging from

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12 - 60, with higher scores indicating greater impairment. The overall mean scores instead of sum scores were used in Table 1 to make it easy for the reader to determine the level of disability by referring to the original scale of measurement. The scale demonstrated excellent internal consistency for the present study (Cronbach's $\alpha = .91$).

Data Analysis

Data were analyzed using IBM-SPSS version 28.0. Prior to beginning analyses, the data from collected surveys were reviewed to delete duplicate entries and those missing more than 50% of responses. Descriptive statistics were used to provide means, standard deviations, and range of scores for each continuous variable. Frequency distributions were used to describe the sample and provide a profile of the participants caring for adults with I/DD.

Changes in caregiver stress, burden, depression, FQOL, and QOL were computed by subtracting pretest from posttest scores (Table 3). Paired sample t-tests were used to determine significance in change over time with effect size measured to determine practical significance. All assumptions of normality and multicollinearity were met. A correlation matrix was obtained by correlating the covariates (ages, employment, family size, number of care recipients, and disability severity) and change scores for caregiver stress, burden, depression, and FQOL with QOL. Statistically significant correlations from the matrix were used in the multiple linear regression analysis, with QOL change scores used as the dependent variable. All decisions on the statistical significance of the inferential statistical tests were made using a criterion alpha level of .05.

Findings

Table 3 indicated that caregivers who participated in XX-OCEAN reported a decrease in burden ($M = -4.05$, $SD = 6.17$), stress ($M = -1.63$, $SD = 3.48$), and depression ($M = -1.45$, $SD =$

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3.71) after completing the intervention, along with increases in QOL ($M = .16$, $SD = .79$) and global FQOL ($M = .27$, $SD = .67$). The comparisons of the pre- and post-test scores for these variables were statistically significant in the predicted direction, except for QOL, which did not change significantly during the intervention. Cohen's d values indicate the magnitude of observed changes in burden, stress, FQOL, and depression were of medium effect size.

Table 4 summarizes the associations between the variables of interest to this study. Change in caregiver QOL was significantly correlated with the change in depression ($r = -.34$, $p = .002$), stress ($r = -.33$, $p = .002$), and global FQOL ($r = .29$, $p = .008$), in addition to the covariate of employment status ($r = -.23$, $p = .04$). These four variables were used as predictors in the multiple linear regression analysis.

Multiple regression analysis, using simultaneous variable entry, indicated that a 5-factor model comprising stress, depression, burden, global FQOL, and employment status explained approximately 22% of the variance in QOL (Table 5). Four predictors significantly associated with QOL were global FQOL ($\beta = .26$), depression ($\beta = -.23$), caregiver stress ($\beta = -.22$), and employment status ($\beta = -.21$; Table 5). An inspection of the variance inflation factor provided support that multicollinearity was not a factor in the regression analysis findings.

Discussion

The purpose of this study was to identify factors that could explain changes in QOL of caregivers of adults with IDD who participated in the XX-OCEAN. QOL is multidimensional, reflecting factors that influence caregivers' daily lives, such as goals, expectations, standards, and concerns. Specific factors associated with QOL, such as caregiver employment, stress, depression, burden, and global FQOL, were examined.

Caregivers appear to have benefited from participating in the XX-OCEAN as their scores changed significantly with medium effect sizes in the anticipated directions. Medium effect size

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indicates that the intervention program was partially successful in improving perceived caregiver burden, stress, FQOL and depression. Caregivers who reported lower levels of burden, stress, FQOL, and depression after participating in the program were more likely to have higher QOL. Consistent with past research on dementia caregivers, our findings indicated that depression was negatively associated with caregiver QOL (Farina et al., 2017). Older parents experience stress when having problems with service continuity (Blinded, 2021, Seltzer et al., 2011). Demands on their time, money, and efforts to help their care recipient with I/DD complete many activities of daily living (e.g., money management, keeping professional appointments) also contributed to caregiving stress (Grey et al., 2018; Blinded et al., 2021). The reduction in caregiver stress might be due to participation in this intervention designed to empower caregivers by equipping them with tools to navigate complex systems of care. These findings aligned with past research on stress reduction by empowering parents of children to use support services (Bode et al., 2016).

Caregiver QOL was significantly associated with global FQOL. This study required the completion of the FQOL evaluation at pretest that informed the development of the IAP for each family. Working on family goals (e.g., engaging in family-level community participation rather than solely on the needs of the person with I/DD) can be attributed to better family level well-being and changes in QOL at individual and family levels. Equipping caregivers with skills necessary to use a wide range of services to improve the health and well-being of all family members seemed to be associated with better FQOL as evidenced by past research on families of children with autism (Fong et al., 2020). This finding is novel given the lack of empirical evidence linking these two constructs (Boelsma et al., 2017).

While scores for caregiver QOL increased and burden decreased following completion of the intervention, the relationship was not statistically significant. Caregiver burden can include

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unpleasant duties, frustration that can affect emotional and physical health, financial challenges, and strained family ties (Collins et al., 1994, Liu et al., 2020). The responsibility of caring for individuals with I/DD across the lifespan includes both positive and negative aspects which can affect both caregiver QOL and global FQOL. As both caregivers and their care recipients age, the caregiver burden generally increases. After participating in XX-OCEAN, caregiver burden decreased, possibly because of learning to navigate through complex systems of care to manage services for adults with I/DD. Families already play a significant role in providing care for older individuals with IDD and will do so in the future. Given the links between the lives of caregivers and care recipients, as well as the effects of these linkages over time, providing family caregivers with support could improve FQOL of the aging family (Heller et al., 2021).

Employment was associated with changes in caregiver QOL implying that caregivers who were productively employed either on a full or part-time basis had lower QOL. The negative association indicated that caregivers who were not working tended to have higher QOL than those who were employed. Caregivers who are employed might have had additional responsibilities that negatively affected their QOL. This finding was contrary to prior research by Utz et al. (2012) who indicated that caregivers working for pay may have more access to resources necessary to maintain a healthy lifestyle and may consider work as a respite from caregiving responsibilities. Because most participants in the present study were not employed, they may have been using their retirement savings and funds to help finance their caregiving activities.

Practice Implications

Present day service systems evolved from the traditional model of disability intervention in which the child with a disability and the family were viewed as pathological entities that

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needed to be fixed rather than supported (Turnbull et al., 2004). In the mid 1970s, families became entitled to access many publicly funded services. Since then, parents have been encouraged to participate in a professionally dominated approach to supporting their children with I/DD. From the 1980s, disability scholars began advocating for a paradigm shift analogized as the ‘Copernican Revolution’ by Turnbull and Summers (1987). Copernicus shocked the world by reversing the Ptolemaic view of the universe, that the earth was not the center of the universe but a planet like many others, revolving around the sun. Similarly, visualizing the family as the center of the universe and the service delivery system as just one of the many planets revolving around it can inform future policy (Turnbull et al., 2004).

The purpose of the XX-OCEAN program was to improve the health and well-being of caregivers of adults with I/DD by helping them learn to navigate the complex systems of health care and disability services. The findings of this study provided evidence that this program could be extended to caregivers of individuals with other types of disabilities. Peer mentors, experienced in navigating complex systems, could help caregivers struggling to access services. Social workers, therapists, and other professionals working with individuals with I/DD need to understand the role of peer mentors as team members who can connect with caregivers using their lived experiences to improve caregiver QOL.

These findings inform policy makers regarding the value of expanding current parent-to-parent mentoring programs focused on improving child well-being. In XX, services provided by parent mentors are reimbursable by Medicaid, however, mentors can only work on goals for the person with I/DD (Michigan Mental Health Code, 1974). Based on results of the present study, peer mentors were found to be beneficial in improving caregiver and family well-being, especially by increasing global FQOL and decreasing depression and stress. Policy changes are

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needed to permit peer mentors to work directly with caregivers to improve the physical, mental, and emotional health of caregivers and family members.

Limitations

Limitations to consider when interpreting the findings include the sample may not be representative of the larger population of older caregivers. Participants were mostly White, educated, married, and mothers with high family incomes. Caregivers disconnected from service systems, overwhelmed by caregiving responsibilities, and from lower socioeconomic groups may have been inadvertently excluded from the study. Additional research using a more heterogeneous sample could provide a better understanding of the effects of XX-OCEAN on caregivers of adults with I/DD. Another limitation was the use of two data collection periods to determine change due to participation in the intervention. The present study collected data twice, first, prior to starting the intervention and the second, when participants completed their goals. A longitudinal analysis with data collected over several follow-up periods could provide richer understanding of how caregiver QOL changes as families move through stages of aging and life transitions. The lack of a control group is a limitation because it cannot be determined if the intervention was the cause of decreases in depression and stress and increase in FQOL. Due to the nature of the study, a peer control group was not possible due to time and cost constraints. However, positive findings provide an impetus to continue the research, possibly with increased funding to enable the inclusion of a control group. Despite these limitations, this study provides important findings regarding the understudied group of older caregivers of adults with I/DD.

Further Research

Four significant predictors of QOL (stress, depression, FQOL, and employment status) have not been the focus of previous research on caregivers of adults with I/DD. Additional research is needed to determine how professionals can alleviate stress and depression associated

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with caregiving and enhance FQOL as ways to improve caregiver QOL. Research is needed to determine the effects of employment on caregiver QOL because individuals who were not in the paid workforce appeared to enjoy a more positive QOL. Research should expand FSN programs to different geographic areas and provide support to individuals with I/DD and their older caregivers.

Conclusions

Participation in XX-OCEAN enabled caregivers to work with an FSN to develop and accomplish personalized goals related to caregiving for adults with I/DD. Positive changes in caregiver QOL could be explained by decreases in caregiver stress and depression, along with improved FQOL, and caregiver employment status. The caregivers learned to connect with support groups and navigate service systems while advocating for their family. Further research is needed to provide support for the continuance of FSN programs with caregivers of adults with I/DD.

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REVISED VERSION**Table 1.***Participant Characteristics (Comparison of participants who completed all aspects of study with those who dropped out)*

	All participants <i>n</i> = 82 % (<i>n</i>)	Dropouts <i>n</i> = 18 % (<i>n</i>)	Group differences# χ^2
Gender			
Female	84.1 (69)	94.4 (17)	1.30
Living arrangements (% co-residing with person with I/DD)	82.9 (68)	83.3 (15)	0.00
Caregiver has a chronic condition (% Yes)	48.7 (40)	50.0 (9)	0.01
Caregiver relationship			
Mother	73.2 (60)	77.8 (14)	.26
Father	14.6 (12)	5.6 (1)	
Sister	4.9 (4)	16.7 (3)	
Other (nephew, aunt, uncle, etc.)	7.3 (6)	-	
Marital status			
Married or domestic partnership	74.4 (61)	61.1 (11)	.31
Not married (widowed, divorced or separated)	4.9 (4)	38.9 (7)	
Single/ never married	20.7 (17)	-	
Race/Ethnicity (<i>Participants could report multiple categories</i>)			
Caucasian/ White	77.3 (68)	66.7 (12)	2.01
Black/ African American	9.1 (8)	16.7 (3)	
Hispanic American	2.3 (2)	5.6 (1)	
Asian/ Arabic/ Pacific Islander	7.3 (6)	5.6 (2)	
Native American/ Alaskan native	1.0 (1)	11.1 (2)	
Other/ Mixed Race	2.3 (2)	-	
<i>Missing</i>			
Education			
High school	14.6 (12)	16.7 (3)	.86
Some college	14.6 (12)	22.2 (4)	
Bachelor's degree	29.3 (24)	33.3 (4)	
Graduate or higher	41.5 (34)	27.8 (7)	

Missing

Employment status

Full-time paid work	23.2 (19)	27.8 (5)	2.71
Part-time paid work	11.0 (9)	22.2 (4)	
Retired	36.6 (30)	27.8 (5)	
Not working (e.g., homemaker, stay at home caregiver, disability)	26.8 (22)		
Unemployed/ unable to work	2.4 (2)	22.2 (4)	

Missing

Annual household income

			5.43
Below \$30,000	11.7 (9)	33.3 (6)	
\$31,000-60,000	23.4 (18)	27.8 (5)	
\$61,000-90,000	36.4 (28)	16.7 (3)	
Above \$90,000	28.6 (22)	22.2 (4)	

Missing

Family size

	5		
	<i>M (SD)</i>	<i>M (SD)</i>	<i>t</i>
Total number of family members (Min-Max: 1-10)	3.99 (1.87)	3.50 (1.51)	1.04
Family members needing care (Min-Max: 1-5)	1.72 (.97)	1.53 (.72)	.76

Disability severity (WHODAS scores: 1-5)

	2.96 (.83)	3.05 (1.07)	0.39
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Age of caregiver

	64.11 (6.59)	64.64 (6.65)	0.30
		36.83 (12.66)	

Age of person with I/DD

	29.83 (9.62)	36.83 (12.66)	2.63
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Notes: #: The 2-tailed *p* values associated with the test statistic (χ^2 and *t* values) were above 0.05 indicating that there were no significant differences between the groups.

Table 2.*MI-Ocean Curriculum used to guide FSN training and monthly meetings*

Introduction	MI-OCEAN Project Summary, Goal and Objectives, Eligibility requirements
Chapter 1	An Introduction to Peer Models of Practice: Building & Sustaining Successful Partnerships with Caregivers
Chapter 2	Resources for Caregivers
Chapter 3	Federal & State Resources for People with Developmental Disabilities
Chapter 4	Mindfulness Based Stress Reduction: Self Care and its Role in Quality of Life
Chapter 5	Multicultural Pluralism & Cultural Competency
Chapter 6	MI-OCEAN Family Quality of Life Assessment and Goal Setting for Caregivers
Chapter 7	Instructional Review Board, Confidentiality & Privacy
Chapter 8	Teaching Empowerment & Advocacy Skills to Caregivers
Chapter 9	Family Support & Family Centered Practices
Chapter 10	Developing the Individualized Action Plan
Chapter 11	Transition Planning and Fading
Chapter 12	Home Visiting, Safety and Confidentiality
Chapter 13	Grief & Loss

Table 3*Change in Study Variable Scores*

		Pretest	Posttest	Change	<i>t</i>	<i>d</i>
		<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>		
1	QOL	3.57 (0.93)	3.73 (0.92)	+.16 (.79)	1.81	.20
2	Stress	22.49 (4.48)	20.86 (4.39)	-1.63 (3.48)	-4.21***	-.47
3	Depression	6.99 (5.39)	5.54 (4.97)	-1.45 (3.71)	-3.54 ***	-.39
4	Burden	34.69 (10.03)	30.64 (9.07)	-4.05 (6.17)	-5.91 ***	-.66
5	FQOL	3.33 (0.90)	3.60 (0.95)	+.27 (.67)	3.56 ***	.39

*Note**** $p < 0.001$ ** $p < 0.01$ * $p < 0.05$

“-” indicates effect size (d) indicates that the means decreased from pretest to posttest

Table 4*Correlations of Changes in Caregiver QOL with Stress, Depression, Burden, Global FQOL, and Covariates*

		Study variables						Covariates				
		1	2	3	4	5	6	7	8	9	10	11
1	QOL	1										
2	Stress	-.332**	1									
3	Depression	-.340*	.404***	1								
4	Burden	-.057	.244*	.257*	1							
5	FQOL	.293**	-.179	-.130	-.214*	1						
6	Caregiver age	.083	.027	.007	-.073	.023	1					
7	Caregiver employment	-.229*	.028	.101	.094	.016	-.424***	1				
8	Family size	.057	-.163	.11	-.069	-.017	-.093	.294	1			
9	# Care recipients	.072	0.03	.037	-.107	-.107	-.079	-.001	.134	1		
10	Disability severity	-.034	-.009	.235*	.141	.111	.067	-.083	-.050	.026	1	
11	Person with I/DD age	.003	.050	.047	-.091	.220*	.439***	-.190	-.359***	-.137	.160	1

Note *** $p < 0.001$ ** $p < 0.01$ * $p < 0.05$

Δ For study variables, - indicates a negative change from pretest to posttest

Table 5*Factors Influencing Change in Caregiver QOL after MI-OCEAN Participation*

Predictors	β	t	p
Stress	-.219	-1.988	.050
Burden	.131	1.241	.218
Depression	-.232	-2.102	.039
FQOL	.255	2.496	.015
Employment status (1= employed)	-.214	-2.136	.036
<i>F</i>		5.49***	
df		5,75	
<i>N</i>		80	
<i>R</i>		.518	
Adj <i>R</i> ²		.219	

Note. * $p < .05$; ** $p < .01$; *** $p < .001$