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Cover Page Footnote

This study was funded by the Michigan Health Endowment Fund (R1807143067). We are very grateful to our research assistants Erika Beals, and Iswat Alade. Special thanks to each of the family members who took the time to participate in this study and helped with recruitment by informing their social networks.

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Peer-Mediated Family Support Project: Evaluation of Changes in Family Quality of Life

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Plain Language Summary

The Family Quality of Life (FQOL) approach views people with disabilities as needing support not fixing. Aging families of people with disabilities face many problems in getting services. We know little about the best ways to support aging families. To address this knowledge gap, we tested a family support project using peer mentors in the state of Michigan. The aim of this study was to see if FQOL of aging caregivers who participated in the project changed. We conducted quantitative analyses of data collected from 82 older caregivers before and after the study. Results indicated that the scores in global FQOL and eight of the nine domains improved. Changes in global FQOL score correlated with changes in domain-level outcomes of five FQOL domains: family, informal support, values, leisure, and community. Increased informal support could explain 16% of the variance in global FQOL. Findings point to the need to find ways to improve informal social support for aging families. Using peers in support programs can improve the mental health of aging caregivers of adults with disabilities.

Abstract

The Family Quality of Life (FQOL) approach represents a paradigm shift from fixing to supporting people with intellectual/developmental disabilities (I/DD) by changing the focus from the individual to the family and highlighting strengths rather than deficiencies. Aging family caregivers of individuals with I/DD often encounter obstacles, including accessibility, acceptability, and affordability of services. Little is known about best practices to support aging families of adults with I/DD. Understanding how a state-wide peer-mediated family support project implemented in this study helped improve the FQOL of aging caregivers is important in broadening participation of other caregivers in these types of programs. To address these gaps in the literature, Michigan Older Caregivers of

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Emerging Adults with Autism and Neurodevelopmental Disabilities (MI-OCEAN), a peer-mediated state-wide family support project program, was implemented. The purpose of this study was to examine global and domain-level FQOL changes among aging caregivers of adults with I/DD after participating in MI-OCEAN. This study used a quasi-experimental research design grounded in the FQOL framework with pretest and posttest data gathered from 82 caregivers. Quantitative analyses were conducted to (a) identify changes in domain and global levels of FQOL after participating in MI-OCEAN and (b) how these changes influenced global FQOL. Results of the dependent sample t tests indicated statistically significant changes in eight of the nine domains and global FQOL. Correlation analysis indicated that five of the nine domains (family relationships, support from others [informal support], influence of values, leisure/ recreation, and community participation) were significantly associated with changes in global FQOL. Multiple regression analyses indicated that about 16% of the improvement in global FQOL could be explained by the FQOL domain of informal support. Results highlight the need to invest in improving informal social support for aging caregivers. This study adds to emerging evidence of the benefits of MI-OCEAN in improving the mental health and well-being of aging family caregivers. Peer-mediated family support programs can be an effective method of improving the mental health of aging caregivers of adults with I/DD.

Introduction

Approximately 48 million Americans provide informal unpaid care to an adult family member or friend. Further, in 2019 it was estimated that 7.39 million people in the U. S. had an intellectual and/or developmental disability (I/DD), 60% of whom continue to live with a family member (Residential Information Support Project [RISP], n.d.). Studies have shown that most individuals with disabilities prefer to remain at home, a preference that family members typically share (Shaw et al., 2011; Stone, 2018). Although families have historically played a central role in caregiving for individuals with I/DD, families had out-of-home caregiving options (I. Brown & Brown, 2003). In the medical model of disability care, institutionalization was viewed as the best choice to improve the well-being of the child and the rest of the family (Turnbull et al., 2004). However, greater life expectancy of people with IDD, increased cost of maintaining institutions, recognition of civil rights of persons with disabilities, and better outcomes through community inclusion, along with the gradual push towards replacing the disability paradigm from *fixing* the individual to *fixing* the environment, the family once again has become the nexus of caregiving and intervention (R. I. Brown et al., 2010; Rubin et al., 2016; Turnbull et al., 2004).

Providing care for individuals with I/DD can be a lifelong responsibility that can take a toll on the health and well-being of the aging family caregiver (Gutowska, 2022; Javalkar et al., 2017; Whitley & Fuller-Thomson, 2018). Family support is essential for staying in one's home and community, but often has substantial cost implications for caregivers, families, and society. If family caregivers were no longer available, the economic cost to the U.S. health care and long-term services and supports systems would increase exponentially. The estimated economic value of unpaid contributions of about 38 million caregivers was approximately $600 billion in 2021. This number was based on an average of 18 hours of care per week for a total of 36 billion hours of care with a value of $16.59 per hour (Reinhard et al., 2023). However, these estimates are for family caregivers in general but not specific to caregivers of adults with I/DD.

Caregiving for an adult with I/DD is a family affair. Family members are linked to each other and their environment; what impacts one member impacts the family quality of life (FQOL) of all members. The FQOL approach represents a paradigm shift from fixing to supporting people with I/DD by changing the focus from the individual to the family and highlighting strengths rather than deficiencies (Samuel et al., 2012). The FQOL construct is defined as a dynamic feeling of family well-being, which is based on how individual and family-level demands interact (Zuna et al., 2009).

The international FQOL framework includes nine domains: (1) *health* of family, (2) financial well-being (*finances*), (3) *family* relationships, (4) support from *others* (informal social support), (5) support from disability *services* (formal social support), (6) influence of *values*, (7) *careers*/preparing for careers, (8) *leisure*/recreation, and (9) *community* interaction. These domains were identified after decades of qualitative research to determine what matters most to the quality of life of family caregivers (I. Brown & Brown 2003; R. I. Brown et al., 2010). Unlike many quality of life frameworks that only evaluate the participant's satisfaction with each domain, this framework examines each domain using six dimensions: (6) *importance* of the domain to FQOL*;* (2) *opportunities* available to families to engage in domain-related activities; (3) *initiative* that enables family members to take advantage of the available opportunities*;* (4) *attainment* of the degree to which the family experiences domain-related activities at a desirable level; (5) *stability* regarding the degree to which circumstances within a domain are likely to improve, decline, or stay the same; and (6) *satisfaction* with domain-related activities that a family experiences. The international FQOL framework describes *attainment* and *satisfaction* as outcome dimensions, with the remaining four dimensions being explanatory in nature (Isaacs et al., 2007). Hence, this paper focused on attainment and satisfaction dimensions of each domain.

Most FQOL research focused on younger families of children with I/DD, with aging populations the subject of few studies (Jokinen & Brown, 2005; Samuel et al., 2022; Wang et al., 2022). FQOL can be improved through individualized family support programs using peer mentoring (DeBrine et al., 2009; Jamison et al., 2017; Sung & Park, 2012; Zuurmond et al., 2019). However, many of these programs focused on empowering parents of children and adolescents with I/DD (Dababnah et al., 2021; DaWalt et al., 2018; Kaiser et al., 2022; Derguy et al., 2017; Taylor et al., 2017). The few programs that exist for aging caregivers addressed the need for future planning, as many of these caregivers are likely to outlive their adult children with I/DD (Heller & Caldwell, 2006; Lee & Burke, 2020; Owen et al., 2021). Older caregivers often encounter obstacles, including accessibility, acceptability, and affordability of services (Marsack-Topolewski & Weisz, 2020). Peer mentoring to navigate systemic challenges might be helpful for older caregivers. A gap was found in the literature regarding programs to support older caregivers of family members with I/DD. To address this gap, a 2-year program, Michigan Older Caregivers of Emerging Adults with Autism and Neurodevelopmental Disabilities (MI-OCEAN), was implemented in the state of Michigan. Understanding how a state-wide peer-mediated family support project implemented in this study helped improve the FQOL of aging caregivers is important in broadening participation of other caregivers in these types of programs.

The purpose of this study was to examine global and domain level FQOL changes among aging caregivers of adults with I/DD after participating in MI-OCEAN. Specifically, the research questions were:

a. What were the changes in global and domain level FQOL after participating in the study?
b. Which domain level changes contributed to changes in global FQOL?

Methods

This study used a one-group quasi-experimental research design grounded in the FQOL framework, with pre- and posttest data gathered from family caregivers of adults with I/DD. Participants for the state-wide, peer-mediated support intervention were recruited from May 2019 to December 2020, using email, listservs, social media, and partnerships with local organizations that were connected to aging and I/DD networks. Because of COVID-19 pandemic restrictions, recruitment was continued using virtual meetings and phone calls.

Participants

The inclusion criteria for this study included being a family caregiver, such as being a parent, spouse, sibling, or other relative of an individual over 18 years of age with I/DD, being at least 50 years old, having access to the internet, and ability to read and comprehend English or Spanish. Paid caregivers were excluded from the study. After completing pre- and posttest surveys, each participant received $20 and $30 gift cards, respectively. The incremental increase of the posttest gift card amount was intended to promote study completion and was approved by the funding agency and Wayne State University's Institutional Review Board (IRB).

Both pre- and posttest surveys were completed by 82 of the 100 participants. Of the 18 who did not complete both surveys, 4 did not implement the individualized action plan (IAP). Reasons for participant attrition included challenging family life events (e.g., illness, death, and moving out of state). The comparative analyses indicated no statistically significant differences in the demographic characteristics of the participants and study dropouts (Table 1).

Most caregivers were female, White, and married mothers (Table 1). The caregivers had a mean age of 64.1 (*SD* = 6.6) years, while care-recipients with I/DD averaged 29.9 (*SD* = 9.6) years. As the greatest number of caregivers had completed college degrees, their household incomes generally were $60,000 or more. Less than half of the caregivers were working either part- or full-time. Approximately half of the caregivers reported having chronic health conditions. Most adults with I/DD were living with their family caregivers who devoted an average of more than 20 hours a week to providing care. Almost half of the caregivers were providing care to more than one family member. Commonly reported diagnoses for adults with I/DD included autism spectrum disorders, unspecified I/DD, epilepsy, cerebral palsy, and Down syndrome. Mood/anxiety problems, behavior problems, speech/language difficulties, and gastro-intestinal problems were typically reported by the caregivers.

Table 1

Participant Characteristics: Comparison of Participants Who Completed the Study with Those Who Dropped Out

	All participants *N* = 82				Dropouts *N* =18				Group differences[a]	
Demographic characteristics	*n*	%	*M*	*SD*	*n*	%	*M*	*SD*	χ^2	*t*
Gender										
Female	69	84.1			17	94.4			1.30	
Living arrangements (co-residing with person with I/DD)	68	82.9			15	83.3			0.00	
Caregiver has a chronic condition (Yes)	40	48.7			9	50.0			0 .01	
Caregiver relationship										
Mother	60	73.2			14	77.8			.26	
Father	12	14.6			1	5.6				
Sister	4	4.9			3	16.7				
Other (nephew, aunt, uncle, etc.)	6	7.3			-	-				
Marital status										
Married or domestic partnership	61	74.4			11	61.1			.31	
Not married (widowed, divorced, or separated)	4	4.9			7	38.9				
Single/never married	17	20.7			-	-				
Race/Ethnicity (*Participants could report multiple categories*)										
Caucasian/White	68	77.3			12	66.7			2.01	
Black/African American	8	9.1			3	16.7				
Hispanic American	2	2.3			1	5.6				
Asian/Arabic/Pacific Islander	6	7.3			2	5.6				
Native American/Alaskan native	1	1.0			2	11.1				
Other/Mixed Race	2	2.3			-	-				
Education										
High school	12	14.6			3	16.7			.86	
Some college	12	14.6			4	22.2				
Bachelor's degree	24	29.3			4	33.3				
Graduate or higher	34	41.5			7	27.8				
Employment status										
Full-time paid work	19	23.2			5	27.8			2.71	
Part-time paid work	9	11.0			4	22.2				
Retired	30	36.6			5	27.8				
Not working (e.g., homemaker, stay at home caregiver, disability)	22	26.8								
Unemployed/unable to work	2	2.4			4	22.2				
Annual household income									5.43	
Below $30,000	9	11.7			6	33.3				
$31,000-60,000	18	23.4			5	27.8				
$61,000-90,000	28	36.4			3	16.7				
Above $90,000	22	28.6			4	22.2				
Missing	5									

(*table continues*)

	All participants *N* = 82				Dropouts *N* =18				Group differences[a]	
Demographic characteristics	*n*	%	*M*	*SD*	*n*	%	*M*	*SD*	χ^2	*t*
Family size										
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
Age of caregiver			64.11	6.59			64.61	5.65		.30
Age of person with I/DD			29.83	9.62			36.83	12.66		2.62**
Disability severity (WHODAS scores: 1-5)			2.96	.83			3.05	1.07		0.39

[a] The 2-tailed *p* values associated with the test statistic (χ2 and *t* values) above 0.05 indicate that there were no significant differences between the groups.

**p < .01.

MI-OCEAN Intervention

MI-OCEAN, an extension of the federally funded Projects of National Significance, is a program to assist aging caregivers of adults with I/DD. The original project focused on helping low-income parents from racial/ethnic minorities who had children with I/DD (Heller & Schindler, 2009). The program was designed to align with the Person-Support-Person model of the Association for Children's Mental Health Program to ensure that Michigan's mental health services would include adult and aging treatment systems. The international FQOL framework described by Isaacs et al. (2007) served as the foundation for the MI-OCEAN curriculum used to educate caregivers on system navigation and service brokerage across the lifespan. Table 2 presents an outline of the MI-OCEAN curriculum that focused on empowering family caregivers in accessing needed resources.

The MI-OCEAN program used 14 family system navigators (FSN) who were hired to work as peer mentors to help participants find services for their family care recipients. Such FSN programs using peer mentors have been found to be effective for families of individuals with I/DD (Dababnah et al., 2021; Feinberg et al., 2021). The criteria to be hired as an FSN were that they had to be at least 60 years of age with personal experience in accessing and using Michigan's health and disability services. The FSN's were from different geographical locations around the state and diverse cultural contexts. All FSNs participated in a comprehensive two-day training course via the Zoom platform. The FSN training curriculum, parallel to the MI-OCEAN curriculum described in Table 2, used in this study was adapted from past protocols informed by stakeholders of three externally funded family support projects from 2003-2012 (Milberger et al., 2023). Modifications to the FSN training curriculum included adding details on age-related supports to ensure that all FSNs understood the context and challenges of aging families in Michigan.

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

Procedures

After obtaining IRB approval from Wayne State University, the program manager started screening potential participants for eligibility. An intake procedure was used to ascertain the family's condition, level of need, and current access to resources. All eligible participants were then matched with an FSN in their geographical region and sent a link to the pretest survey. The project evaluator reviewed the pretest responses and conducted a preliminary analysis of FQOL-related questions. An individualized FQOL report was generated for each participant that included the three domains identified to be most important to their overall FQOL. In addition, a graphical representation of the 5-point ordinal ratings assigned by participants for the remaining five dimensions (opportunity, initiative, attainment, stability, and satisfaction) in each of the nine FQOL domains was included. Reports were also sent to FSNs to be used to guide discussions with their assigned caregivers. The FSNs were not given information about other parts of the pretest that included measurement of constructs such as caregiver stress, burden, and depression to protect confidentiality of participants and not bias their discussions with caregivers (Milberger et al., 2023).

The FQOL report served as the FSNs' roadmap for creating the IAP that included three goals—one long-term and two short-term—as well as networking techniques for gaining access to a range of services. A long-term goal in this study referred to a goal that would require more than 3 months to achieve, while a short-term goal referred to goals that could be accomplished in less than 3 months. The program manager organized 12 monthly group meetings (2 hybrid, 10 online) to promote communication among study participants, FSNs, and other project personnel.

Attendance to these sessions was not mandatory for participants or FSNs. Typically, 15 to 30 participants attended these hour-long sessions that provided opportunities for socialization and structured learning activities. This gave participants a chance to practice newly acquired skills in establishing their own support and service networks. Each family had a different period of intervention to achieve their IAP goals, with the program manager evaluating progress every 6 months until stated goals were achieved. Each caregiver completed a posttest survey following goal attainment. This helped to assess any changes that had occurred since entering the program. The only difference between pre- and posttest surveys was that no demographic data were gathered during posttesting.

Instruments

A survey was created using the Qualtrics Research Suite to gather sociodemographic information 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 the general version of the FQOL survey revised in 2006 (I. Brown et al., 2006).

Dependent Variable

The FQOLS-2006 was used to measure global FQOL using 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; I. Brown et al., 2006). The mean score computed from these two items represent global FQOL like past investigations using this tool (Samuel et al., 2016; Wang et al., 2022). 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 excellent (α = .89).

Independent Variables

The international FQOL framework has nine domains (*health*, *finances*, *family*, *others*, *services*, *values*, *careers*, *leisure,* and *community)* and six dimensions (importance, opportunities, initiative, attainment, stability, and satisfaction; Isaacs et al., 2007). Each domain was measured using objective ratings of the dimensions. Domain-level outcomes in this study were computed from the mean level of attainment and satisfaction in that domain. For example, in the domain of health, *attainment* was measured by asking all participants to rate the degree to which the family experiences good health (5 = a great deal, 1= hardly at all). *Satisfaction* was measured by asking, “All things considered how satisfied are you with the health of your family? (5 = greatly improve, 1 = greatly decline).” The participants were asked to think of their family as a unit when responding to these questions and prompted with the following definition of family: *Family members are people related by blood or by close personal relationship who are closely involved in the day-to-day affairs of your household* (I. Brown et al., 2006).

Data Analysis

Data were analyzed using IBM-SPSS version 29.0. Prior to beginning analyses, the data from collected surveys were reviewed to delete duplicate entries and those missing more than 50% of values. Descriptive statistics were used to provide means, standard deviations, and range of scores for each continuous variable. Crosstabulations and chi-square were used to compare survey completers with survey dropouts and describe the participants caring for adults with I/DD.

Changes in global and domain level FQOL scores were computed by subtracting pretest from posttest scores (Table 3). Paired samples *t* tests were used to determine significant changes over time. All assumptions of normality and multicollinearity were met. A correlation matrix was obtained by correlating the domain-level FQOL scores with global FQOL. Statistically significant correlations from the matrix were used in the multiple linear regression analysis, with global FQOL 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.

Table 3

Change in FQOL Domain Level Outcomes and Global FQOL Scores

	Pretest		Posttest		Change			
Domain outcomes	*M*	*SD*	*M*	*SD*	*M*	*SD*	*t*	*d*
1. Health	3.37	.96	3.57	.86	.22	.65	2.98**	.65
2. Finances	3.46	.96	3.67	.89	.22	.65	2.98**	.65
3. Family	3.49	1.00	3.76	.93	.29	.86	3.04**	.34
4. Others	2.77	.85	2.97	.96	.21	.78	2.39*	.27
5. Services	2.67	.97	2.90	.95	.22	.90	2.17*	.24
6. Values	3.47	.83	3.52	.81	.05	.73	.61	.07
7. Careers	2.77	1.02	3.02	.98	.23	.89	2.29^{*}	.26
8. Leisure	2.70	.94	3.00	.93	.30	.82	3.25^{***}	.36
9. Community	2.77	.85	2.91	.99	.13	.75	1.55	.17
10. Global FQOL	3.33	.90	3.60	.95	.27	.67	3.56^{***}	.39

$^{*}p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$.

Findings

Caregivers who participated in MI-OCEAN reported a significant increase in global FQOL (*M* =.27, *SD* =.67) and in all domains except values and community. The comparisons of the pre- and posttest scores for these variables were statistically significant, with participants reporting increased global FQOL and outcomes for seven of the nine domains (see Table 3).

Table 4 summarizes the associations between the variables of interest to this study.

Change in global FQOL was significantly correlated with the change in *others* (r = .38), *family* (r = .33), *community* (r = .27), *leisure* (r = .26), and *values* (r =.24). Changes in the remaining domain-level outcomes were not significantly associated with changes in global FQOL. These five variables were used as predictors in the multiple linear regression analysis. Using simultaneous variable entry, the findings indicated that a 5-factor model comprising family, social support, values, leisure, and community explained approximately 16% of the variance in global FQOL (Table 5). Only one of the domains (*others*) was a statistically significant predictor of global FQOL (β =.25).

Table 4

Correlations of Changes in Global FQOL with FQOL Domain-Level Outcomes

Variables	1	2	3	4	5	6	7	8	9	10
1. Global FQOL	1									
2. Health	.20	1								
3. Finances	.16	.29**	1							
4. Family	.33**	.19	.37***	1						
5. Others	.38***	.13	.26*	.43***	1					
6. Services	.18	.08	.001	.01	.21	1				
7. Values	.24*	.19	.17	.41***	.23*	.23*	1			
8. Careers	.06	.28*	.29*	.36**	.47***	.23*	.26*	1		
9. Leisure	.26*	.19	.32**	.27*	.30**	.08	.16	.36**	1	
10. Community	.27*	.11	.24*	.31**	.32**	.19	.00	.20	.56***	1

$^{*}p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$.

Table 5

FQOL Domains Influencing Change in Global FQOL After MI-OCEAN Participation

Predictors	β	t	p
Family	.11	.91	.37
Others	.25	2.11	.04
Values	.12	1.08	.29
Leisure	.08	.61	.54
Community	.11	.83	.41
F		4.02**	
df		5,75	
N		80	
R		.46	
R^2		21	
Adj R^2		.16	

** $p < .01$.

Discussion

The purpose of this study was to identify changes in domain level and global FQOL following caregivers' participation in MI-OCEAN. Because FQOL is a multidimensional construct, domain-level predictors of global FQOL were examined. As evidenced by positive change scores for all domains, caregivers indicated their families appear to have benefited from participating in MI-OCEAN. Caregivers who reported better informal social support (*others*) after participating in the program were more likely to have higher global FQOL.

Except for the domains of *values* and *community*, the remaining seven domains showed statistically significant positive changes, with *health* and *finances* having medium to strong effect sizes. MI-OCEAN focused on connecting caregivers with their FSNs who provided support and helped them learn to navigate complex service networks. Further, the timing of the study and the impact of the COVID-19 pandemic on study participants could be attributed to the positive change in the domain of *health* and a lack of change in the *community* domain. During the pandemic, attention was concentrated on maintaining the health of each person in the family. Interactions with other people in the community were limited by fear of spreading COVID-19, which may have affected the outcome for the *community* domain. Lack of change in the domain of *values* was expected, given the focus of the intervention was to improve family access to systems of support.

Although the highest changes were noted in family's *leisure* and recreation participation followed by *family* relationships, the effect sizes were weak to moderate. These findings aligned with past literature on the benefits of family support via peer mentoring for younger families of children with I/DD (Dababnah et al., 2021; DaWalt et al., 2018; Derguy et al., 2017; Pearson, & Meadan, 2021; Taylor et al., 2017). These studies indicated that parent education efforts, some with peer mediators, could reduce family distress by improving knowledge of available services, advocacy, and social connectedness. The improvement of the FQOL domain of *finances* could be explained by participants gaining an awareness of their eligibility for financial assistance programs (e.g., Social Security, Medicaid). Results from the parent study indicated that a greater number of participants reported Medicaid as their insurance following their completion of the intervention (Milberger et al., 2023).

One domain, informal social support (*others*), was a statistically significant predictor of global FQOL. Although four other domains (*family*, *values*, *leisure*, and *community*), were significantly related to global FQOL, they were not significant predictors. Changes on informal social support were linked to positive improvement in FQOL. Findings from this study expand past research from young families, indicating that informal social support is associated with family well-being (Boehm & Carter, 2019). Taub and Werner (2016) reported that informal social support was associated with better FQOL of children in Israel. Au et al. (2009) reported that informal social support was associated with well-being of caregivers of individuals with dementia. Past research among other caregivers indicated that improving informal social support could reduce the burden of female caregivers and increase caregiving satisfaction for both men and women (García-Mochó et al., 2019). Robinson et al. (2016) reported that informal support reduced the burden of caregivers of adults with I/DD. Together, these studies underscore the importance of informal social support as a contributing factor to FQOL for caregivers of adults with I/DD and their families.

Practice Implications

The overarching goal of the MI-OCEAN program was to help aging caregivers of adults with I/DD learn to navigate complex systems of health care and disability services. Study findings indicate that programs focused on equipping families with strategies to overcome their day-to-day challenges while navigating complex systems of care for themselves and their adult child with I/DD can improve their informal social supports and global FQOL. These findings also indicated that researchers and practitioners should recognize the value of supporting aging caregivers in practical ways that can improve mental health of caregivers and individuals with I/DD. While psychosocial interventions such as mindfulness and yoga for caregivers can alleviate stress in caregiving families, there is a need for practical interventions focusing on the family as a unit and their interconnected strengths and challenges as they grow older. Participating in a program that connected caregivers with peer mentors experienced in navigating complex systems helped caregivers overcome service access barriers. Practitioners need to understand and recognize the important role of peer mentors. They can be key team members who can connect aging caregivers of adults with I/DD to informal supports, thus positively impacting their global FQOL. The value of having sources of support with their own first-hand experience and understanding of what family caregivers of individuals with I/DD face is invaluable. This aligns with recent work from Schiltz et al. (2023) that highlighted the importance of "knowledge, values, and characteristics" for those supporting caregivers of adults with I/DD.

These findings can be used to inform policy makers regarding the value of expanding current parent-to-parent mentoring programs focused on improving child well-being. In Michigan, services provided by parent mentors are reimbursable by Medicaid. However, mentors are only allowed to work on goals set for the person with I/DD (Michigan Mental Health Code, 1974). Policy makers need to be aware that as children transition into adulthood, caregiving needs change. Parents need help adjusting to these changes as they place increasing demands on a daily regimen that was established when their child with I/DD was school age. Given the limited services available in adulthood for individuals with I/DD, family caregivers struggle to understand these changes. Based on the present study's results, peer mentors were found to be helpful in improving outcomes in most FQOL domains; thus, increasing global FQOL. Changes in current policy are needed to permit peer mentors to work directly with aging caregivers to improve their physical, mental, and emotional health and the quality of life for all family members.

Limitations

There are limitations to consider when interpreting the findings of this study. First, the sample may not be representative of the larger population of aging 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 unintentionally excluded from the study. Future recruitment strategies designed to attract diverse participants could include outreach in local communities, including faith-based organizations, transportation hubs, urban medical centers, senior centers, and local community facilities. Additional research using a more heterogeneous sample could provide a better understanding of the benefits of MI-OCEAN on several types of families of adults with I/DD.

Another limitation was the use of two data collection periods to determine change because of participation in the intervention. The timing of this study during the pandemic may have limited the participants' ability to meet with their FSNs and achieve their individualized goals. Because of the pandemic, family caregivers faced increased challenges in obtaining needed services. The present study collected data twice, one 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 FQOL changes as families move through stages of aging and life transitions. The lack of a comparison group, because of time and cost constraints, was a limitation because it could not be determined if the intervention was the cause of improved FQOL. However, positive findings provide an impetus to continue the research, possibly with increased funding to enable the inclusion of a peer comparison group. Despite these limitations, this study provides important findings regarding the understudied group of aging caregivers of adults with I/DD.

Further Research

Domain-level predictors of global FQOL have not been the focus of previous research on aging caregivers of adults with I/DD. More research is needed to determine how professionals can improve caregiver's connections with informal social supports to improve global FQOL. Research is needed to determine the effects of sociodemographic factors on global FQOL and its domain-level indicators to inform future family support programs.

Part of the intervention was the development of IAPs based on the participants' responses to FQOL-related items on the pretest survey. The IAPs included three goals unique to the caregiver and their family, which needed to be achieved prior to completing the posttest. Additional research is needed to investigate available data on the factors that determined the goals and if the goals were related to the family characteristics, caregiver burden, health satisfaction, stress, and depression.

Conclusion

Participation in MI-OCEAN enabled caregivers to work with a peer mentor to develop and achieve individualized family-level goals associated with providing care for adults with I/DD. Improved changes were found for seven of the nine domains from pre- to posttest. In addition, a positive relationship was found between global FQOL and informal support. Caregivers, working with their peer mentors, learned to connect with support groups and navigate service systems while advocating for their family members. Further research is needed to provide support for extending peer mentor programs with caregivers of adults with I/DD that focus on using a strengths-based approach embodied by the FQOL paradigm.

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