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Family Caregiving During the COVID-19 Pandemic

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Plain Language Summary

The COVID-19 pandemic made life difficult for families of adults with disabilities. We had a group discussion of 30 family members on the pros and cons of staying at home. Family members said that it was hard to get medicine and see their doctor. Many struggled to use the internet to talk to people. They did not like to stay home all the time. They felt alone because they could not see their family and friends. There were also some good changes. They liked staying connected with family and friends online. They also liked that the slow pace of life was more relaxed. Many of these problems are not new but have gotten worse because of the pandemic. Understanding the pros and cons of staying at home can help us decrease the burden on families.

Background

The Coronavirus Disease-2019 (COVID-19) pandemic has taken a disproportionate toll on people with intellectual and developmental disabilities (I/DD) as well as their family caregivers. In the United States, approximately 5.1 million children and 2.1 million adults are living with I/DD (Braddock et al., 2015). The majority (72%) of individuals with I/DD live with their family, with 24% of these individuals living with family caregivers above the age of 60 (Tanis et al., 2021). Similarly, in Michigan, 66% of the 225,925 adults with I/DD live with their families (Tanis et al., 2021).

Family caregivers may experience emotional and physical burdens that can lead to negative health consequences, such as increased depression, anxiety, and lower quality of life (Javalkar et al., 2017). These consequences are especially true for older family caregivers, many of whom assume dual or compound caregiving roles, while they face their own age-related challenges (Marsack-Topolewski, 2020; Perkins, 2010).

In the wake of the COVID-19 pandemic, caregivers are now supporting their family member(s) with I/DD around the clock because of school closures and diminished in-person support opportunities (Manning et al., 2020). Many families require in-person care or therapeutic support within their homes and are likely to face challenges in hiring staff to provide in-home

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support because of fears of contracting the virus. Caregiver stress is likely to increase with little backup or systemic coverage for prolonged interruption of services.

While millions of people are using screen-based technologies to mediate personal connection, this technology can be challenging for many people with I/DD. Virtual interaction can be an inadequate substitute for human connection (Annaswamy et al., 2020). Limited access to trained caregivers and community service providers, who can assist people with I/DD to use web-based technology adds to the underutilization of web-based services (Constantino et al., 2020).

The Centers for Disease Control and Prevention (CDC, 2021) have indicated that people with I/DD are at increased risk of infection and complications from COVID-19. Adults with disabilities are three times more likely to have heart disease, stroke, diabetes, or cancer than their peers without disabilities (Constantino et al., 2020; Friedman & Spassiani, 2018). Additionally, a number of genetically based developmental disabilities are associated with health liabilities that may adversely affect individuals with I/DD who contract the virus. This disproportionate impact must be offset by clarifying the extent to which pre-existing health conditions are exacerbated by COVID-19. Limited in-person medical appointments and/or rationing of care may negatively impact individuals with I/DD who have pre-existing conditions (Constantino et al., 2020).

The World Health Organization (WHO, 2020) reported that people with disabilities may also be at greater risk of contracting COVID-19 because of their inability to participate in basic hygiene measures. Poor hygiene can be attributed to physical limitations (i.e., not being able to rub hands together when washing) and cognitive/behavioral challenges (e.g., inability to comprehend the need for effective handwashing routines). Some people with I/DD may not be able to tolerate masks because of underlying sensory processing challenges resulting from atypical neurological systems (Dorfman & Raz, 2020). Social distancing may be difficult for them because of their need for one-on-one support and their inability to understand social distancing requirements (WHO, 2020). These health conditions may be linked to an increased risk of more serious health outcomes if people with I/DD contract the virus.

Understandably, many family caregivers are concerned about increased health risks when a loved one is exposed to COVID-19, especially for their family members with disabilities. These concerns and fears place an added layer of stress in their lives as they navigate a new world, where previously safe and enjoyable activities are now possible health risks for their family member with a disability and others in the family. This research brief presents findings from a virtual discussion group with family caregivers of adults with I/DD to understand how the COVID-19 pandemic has affected their lives. The following research questions were addressed.

1. What challenges are family caregivers of adults with I/DD facing because of COVID-19?
2. What is working well for them (i.e., “silver linings”)?

Method

This study is a subset of a larger project using participants from the Michigan Older Caregivers of Emerging Adults with Autism and Neurodevelopmental Disabilities (MI-OCEAN) program, a statewide service navigation program for aging caregivers of adults with I/DD. The project is grounded in a family quality of life framework and uses a peer-support model of support to identify and address various issues that may negatively impact caregivers' health and well-being. Family Support Navigators (FSNs) reported that they were hearing from the caregivers they were serving about challenges they were experiencing because of COVID-19. Prior to holding the meeting, Wayne State University's Institutional Partial Review Board determined that this study conformed to recognized human subjects research standards.

Recruitment

Family caregivers who were providing care for their adult family members with I/DD were recruited through the aging caregiving project email listserv and the University Center for Excellence in Developmental Disabilities (UCEDD) Education, Research, and Service's social media platforms, such as Twitter, Instagram, and Facebook.

Participants

The inclusion criteria for participation in the support group meeting included being a family caregiver supporting an adult (at least 18 years old) with I/DD. Participants had the option to remain anonymous and did not have to register for the Zoom discussion group. As expected, since the impetus for having the discussion group came through our project on aging caregivers, the majority (56.7%) of family caregivers in this study were 50 years of age or older. Most were parents (53.3%) while others were siblings or other family members. All participants were supporting family members with I/DD ranging in age from 20 to 57 years old. Participants came from 10 counties across Michigan (see Table 1).

Procedures

A 1-hour caregiver discussion group meeting was held in April 2020. The session used Zoom as a meeting platform. The meeting was recorded and then transcribed by a research assistant. All participant identifiers were redacted from the transcript, which was analyzed by two independent researchers to identify common themes using content analysis. A qualitative phenomenological research methodology was used to examine challenges and "silver linings" faced by family caregivers of adults with I/DD during COVID-19. Phenomenology is an approach to qualitative research that focuses on the commonality of a lived experience within a particular group. The fundamental goal of the approach is to arrive at a description of the nature of the phenomenon (Creswell, 2013). Typically, an interview is conducted with a group of individuals who have first-hand knowledge of an event, situation, or experience. The data are then read and reread and culled for like phrases and themes that are then grouped to form clusters of meaning

(Creswell, 2013). Through this process, the researcher may construct the universal meaning of the event, situation, or experience and arrive at a more profound understanding of the phenomenon.

Table 1

Participant Demographics (N = 30)

Characteristics	<i>n</i>	%
Age of participant		
Under 50	7	23.3
50 and over	17	56.7
Missing	6	20.0
Gender of participant		
Male	3	10.0
Female	25	83.3
Missing	2	6.7
Race of participant		
African American/Black	2	6.7
Caucasian/White	20	66.7
Hispanic	1	3.3
Arab American	1	3.3
Missing	6	20.0
Relationship to care-recipient		
Parent	16	53.3
Sibling	4	13.3
Spouse	1	3.3
Other Relative (aunt, cousin)	4	13.3
Missing	5	16.7

Results

Two overarching themes (challenges and silver linings) were illustrated by caregivers of individuals with I/DD. A summary of themes with corresponding subthemes is presented in Table 2.

Challenges

Described below are some of the challenges that were faced by caregivers of individuals with I/DD.

Table 2*Themes and Subthemes from Discussion Group*

Themes/subthemes	Examples
Challenges	
Obtaining medical services	Difficulties with receiving medical services not related to COVID-19
Transitioning to technology	Use of telehealth without appropriate training for users/clinicians
Covid-19 Prevention Efforts	Difficulties with wearing masks and social distancing
Social Isolation	Lack of socialization with family and friends
Silver linings	
Social Connectedness	More time with immediate family
Coping Strategies	Use of creative physical and social activities to break isolation routines during the pandemic

Obtaining Medical Services

The most common challenge identified by participants was difficulties associated with obtaining medical services, such as cancellation of appointments and getting medications. One caregiver stated,

Medical treatment is huge for my sister, she had breast cancer and is now having some issues that make us suspect recurrence, but we can't see the doctor.

Evidence of anticipatory anxiety was present because of rumors regarding possible medication shortages, as illustrated in the following comment.

I've heard a lot of horror stories about medication that people got very quickly before and now they can't get them.

Transition to Technology

The quick transition to telehealth without adequate training for users or clinicians was also seen as a challenge. Practitioners had to rely on information that was being reported in lieu of actually observing the person. The difficulty of the shift to telehealth is best reflected by this participant comment.

His telemedicine appointments have been difficult because we really don't have some of the technology that's required for him right now and his iPad is not working so, you know, you go through all of these challenges.

Telehealth was especially challenging for non-English speakers who found it difficult to communicate with their doctors, therapists, and pharmacists in this manner. The increased use

of technology also presented difficulties in other areas of life, such as education and employment. These difficulties were related to inadequate equipment, internet service, having to share the limited equipment, insufficient experience using technology, and taking more time to support the technology user. One participant stated,

Working from home is creating challenges since it's our whole family and it is hard carving out office space and having boundaries in our house.

COVID-19 Prevention Efforts

Efforts to prevent infection from COVID-19 were an area of concern for caregivers. They worried about their family member's ability to communicate symptoms, should they arise. For example, one participant shared,

My brother is the kind of person that unless you physically saw him sick, he wouldn't say anything. He wouldn't say I have a headache, or I have a stomachache. You would have to see him not getting up or some of those things.

Caregivers expressed frustration in training their care-recipients to use masks properly. Proper and regular use of the mask was also raised, and they found it difficult to enforce social distancing because of the nature of their family member's support needs, such as the need to provide physical cueing to complete activities of daily living.

Social Isolation

Caregivers reported feeling isolated because they could not leave their homes and were not able to see family or friends. This social isolation was reflected in caregiver comments. One caregiver stated,

Everything's changed, like literally, everything, we've now been isolated for two months and my husband's a first responder so he has to be isolated in a different part of the house.

While another caregiver shared, *"Not being able to kiss your loved ones has been really hard."*

While caregivers discussed social isolation, they also described frustration of being together all the time and not being able to get out, especially in inclement weather. One caregiver shared,

It feels very restricted, my son has decided to move his life onto the couch rather than in his room, which is frustrating as a parent and he's okay until evening when he starts to get a little cranky.

Caregivers also described the negative impact the pandemic is having on their family member (e.g., lack of routine, not able to meet with people, loss of skills, increased anxiety, hard to fill the day with activities, bored). One parent expressed,

Our son thrives on routine because he has autism so one of the things that has been challenging is everything has changed, like literally everything...so he is losing a lot of the skills that he's been able to acquire.

Online school was identified as a challenge, yielding frustration for both students and caregivers. Caregivers had the extra job of encouraging students to stay on task during online classes. Screen overload and inequitable school-related resources were also mentioned in the discussion.

Silver Linings

Caregivers also reported several unexpected positive consequences, referred to as “silver linings.”

Social Connectedness

A common theme was that the pandemic allowed for greater family social connectedness. Caregivers indicated that because of the pandemic, the pace of life slowed, allowing for more flexibility and time with their families, as well as gratitude for everyday things. While technology was discussed as a challenge, it was also mentioned as a positive because it allowed for social connectedness. Several creative uses of the Zoom meeting platform to connect with family and friends were discussed, including virtual game nights, dance parties, cocktail parties, and happy hours. Some shared that their family members were able to make friends more easily online where they had difficulties doing so in person. Although too much togetherness was discussed as a challenge, it was also identified as a positive. Some participants highlighted the benefits of staying at home and being together more.

Coping Strategies

Helpful strategies to cope with the pandemic included physical activity (e.g., walking, dancing, yoga, etc.), hobbies (e.g., sidewalk chalk art, puzzles, scavenger hunts, beading, adopting a pet), and games (virtual and outdoors). One caregiver stated,

We've been having game nights—even my grandma was on the game night via Zoom. My brother really likes music, so we'll play music and dance around and he'll come and join us occasionally.

Another described,

It was my son's birthday and we usually have people over and it's a big deal because cognitively he's still a little kid and we couldn't do that this year;

however, my friend arranged for us to have his birthday outside and the police and the fire department came by and did the sirens. My son volunteers at the police department so it was pretty special for him.

Discussion

The purpose of this study was to better understand how the COVID-19 pandemic has affected the lives of family caregivers of adults with I/DD. The impact of COVID-19 has placed considerable challenges on society as a whole. However, family caregivers of adults with I/DD face considerable challenges as they navigate the many responsibilities to balance the demands of caregiving and daily life. Simple things like wearing a mask and maintaining social distance can be exceptionally difficult for individuals with I/DD. Caregivers often prefer social isolation with their care recipients than trying to make their loved ones wear masks and enforce social distancing.

The duration of COVID-19 and its ramifications are unknown. Many challenges experienced by family caregivers are not new, rather they are intensified because of the pandemic (Constantino et al., 2020). Family caregivers indicated challenges and needs related to accessing medical services and use of telehealth. Evidence is available that supports the many challenges that family caregivers of adults with I/DD experience with regard to accessing appropriate services in normal times (Marsack-Topolewski & Weisz, 2020). Consistent with past research, accessing medical services using telehealth has been a challenge for family caregivers of individuals with I/DD (Zhou & Parmanto, 2019). This challenge is exacerbated because of the pandemic. Addressing realistic strategies to provide accessible, quality medical care using telehealth is needed. Service delivery systems should consider the needs of individuals with I/DD and their families.

Another challenge that appears to affect family caregivers of individuals with I/DD is increased use of technology. Schools are using virtual instruction, which requires students to use computer platforms such as Zoom. These programs may be unfamiliar to caregivers who have limited computer skills or experience. In addition, students with I/DD are required to sit for long periods in front of a computer screen, making it more difficult for caregivers who are responsible for helping to teach them. Working family caregivers may need extra help in supporting their family member's online experience while at the same time managing their own work schedules (Garbe et al., 2020).

Family caregivers also shared "silver linings," or unanticipated positive outcomes, such as staying connected to family and friends as well as making new friends. Although socially isolated because of the inherent challenges posed by the COVID-19 pandemic, family caregivers found innovative ways to connect with others in their social networks. The pandemic was instrumental in making life proceed at a slower pace, lending itself to greater flexibility, and providing time for things that are most important.

Strategies that build on family caregivers' concerns and strengths are needed to offset the burden posed by COVID-19. In the present study, family caregivers recounted positives surrounding coping strategies, such as the use of physical activity. These types of diversions can involve playing games, walking, bike riding, and other outdoor activities that can help ease feelings of boredom and isolation. The pandemic also puts both individuals with I/DD and their family caregivers at risk for mental health challenges, such as loneliness, anxiety, and depression; with physical activity having the potential to serve as a powerful outlet (Ameis et al., 2020; Bazzano et al., 2015).

Study Limitations

Several limitations regarding these findings should be acknowledged. Given the sudden circumstances associated with the pandemic, this support group was convened to address an emerging need. As family caregivers volunteered to participate in the group, they may not be representative of family caregivers across the state or nation. The sample was homogeneous and consisted mainly of older Caucasian women. In addition, to have known about this support group opportunity, caregivers were likely to be more connected with community supports and agencies. Future studies should seek to recruit a more diverse group of family caregivers and extend recruitment efforts to reach subsets of caregivers who are less connected to increase the generalizability of findings. In addition, while there were 30 caregivers in the discussion group, we are unable to quantify if involvement was equally shared across participants or whether the information shared is primarily from a few individuals. The facilitator of the discussion group was a social worker with decades of experience leading group discussions and redirecting the conversation if it was being dominated by a few individuals.

Conclusion

The pandemic has placed many challenges on society as a whole, particularly for groups such as family caregivers of individuals with I/DD. During the pandemic, family caregivers were more likely to be stressed as they navigated changes in lifestyle and to their support networks. FSNs and other supportive individuals can play integral roles in helping family caregivers during these unprecedented times. These supportive individuals need to be aware of the pre-existing challenges (e.g., the challenges prior to the COVID-19 pandemic) that family caregivers of individuals with I/DD experienced and new challenges resulting from the COVID-19 pandemic.

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