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COVID-19 Special Section

Mental health and COVID-19: The impact of a virtual course for family caregivers of adults with intellectual and developmental disabilities

J. K. Lake,[1,2] T. Volpe,[1] L. St. John,[1] A. Thakur,[1,2,3] L. Steel,[1] A. Baskin,[1] A. Durbin,[4] M. A. Chacra[1] & Y. Lunsky[1,2]

1 *Azrieli Adult Neurodevelopmental Centre, Campbell Family Mental Health Research Institute, Centre for Addiction and Mental Health, Toronto, Canada*

2 *Department of Psychiatry, Temerty Faculty of Medicine, University of Toronto, Toronto, Canada*

3 *Surrey Place, Toronto, Canada*

4 *Li Ka Shing Knowledge Institute, St. Michael's Hospital, Toronto, Canada*

Abstract

Background The COVID-19 pandemic has significantly impacted family caregivers of adults with intellectual and developmental disabilities (IDD). This study evaluated a virtual course for family caregivers from across Canada, focused on supporting the mental health and well-being of adults with IDD and their families. The evaluation examined the feasibility and acceptability of the course, as well as the impact of the intervention on participants' overall health and well-being.

Methods The 6-week virtual course, informed by a parallel Extension for Community Healthcare Outcomes (ECHO) course for service providers, combined didactic instruction with applied activities. A total of 126 family caregiver course participants consented to be part of the research evaluation delivered over three cycles between October 2020 and April 2021.

Attendance was measured at each weekly session. Satisfaction was assessed weekly and post-program. Learning, self-efficacy, and well-being were assessed pre- and post-course, and again at follow-up (8 weeks post-course). Mixed-effects models assessed changes between and within individuals across time.

Results Participants had consistent attendance, low-dropout rates, and reported high satisfaction, with 93% of participants reporting that their expectations for the course were met. Compared with pre-course, participants reported improved self-efficacy and well-being post-course, which were maintained at follow-up.

Conclusions An interactive and applied virtual education course delivered to a large group of family caregivers of adults with IDD was both feasible and acceptable. It positively impacted participants' well-being by offering much needed mental health support and creating a peer-led community of practice.

Keywords COVID-19, family caregivers, intellectual and developmental disabilities, mental health, virtual psychoeducation

Correspondence: Dr Johanna K. Lake, Azrieli Adult Neurodevelopmental Centre, Campbell Family Mental Health Research Institute, Centre for Addiction and Mental Health, 1025 Queen St. W., Toronto, Ontario M6J 1H4, Canada. (e-mail: johanna.lake@camh.ca).

Background

The COVID-19 pandemic has had a significant impact on the health and well-being of adults with intellectual and developmental disabilities (IDD). Research conducted internationally and within Canada has demonstrated that adults with IDD are at greater risk compared with the general population for negative outcomes related to COVID-19, including increased positivity rates, hospitalisations, and mortality (Clift *et al.* 2021; Gleason *et al.* 2021; Lunsky *et al.* 2021; Williamson *et al.* 2021). As well, pandemic-related public health restrictions have been particularly challenging for this population, including ongoing disruptions to activities and routines, increased isolation, and reduced access to health care services and supports (Doody & Keenan 2021; Flynn *et al.* 2021; Flynn *et al.* 2021; Lunsky *et al.* 2022).

The pandemic has also had a significant impact on family caregivers supporting adults with IDD (hereinafter referred to as caregivers). Caregivers are often responsible for providing the majority of home-based care and support to their loved ones, yet, there remain few community services and programs to support them. Pre-pandemic, many caregivers reported high levels of stress, depression, anxiety and poorer mental health (Rydzewska *et al.* 2021; Scherer *et al.* 2019), and since the start of the pandemic, with continued closures and restrictions, caregiver fatigue has evolved into exhaustion and distress for many (Bailey *et al.* 2021; Flynn *et al.* 2021; Flynn *et al.* 2021; Gadermann *et al.* 2021; Gillespie-Smith *et al.* 2021; Lee *et al.* 2020; Majnemer *et al.* 2021; Patel *et al.* 2021; Redquest *et al.* 2021; Willner *et al.* 2020).

While there have been efforts to develop resources in support of caregivers, recent studies have shown that they can be difficult to access and that sharing information in a passive, didactic format may not foster a sense of community (Castro *et al.* 2021; Chick *et al.* 2020; Kennedy *et al.* 2021; Krohn *et al.* 2021). Similarly, while there is evidence that families benefit from peer support programs (Bray *et al.* 2017; Fisher *et al.* 2020; Muralidharan *et al.* 2021; Suresh *et al.* 2021), few interventions involve caregivers in their design and delivery. Research has shown that involving family caregivers as leaders or peer supports in interventions that benefit other caregivers can reduce feelings of isolation and provide opportunities for personal growth, connection and learning (Bray *et al.* 2017; Burke *et al.* 2020; Dodds & Singer 2018; Muralidharan *et al.* 2021; Shilling *et al.* 2013). Involving families is also consistent with patient oriented research more generally, as well as family centred models of health care delivery. It would make sense that family involvement would be of particular importance during the pandemic because other families would know best about their unique stresses and pressures.

To address this need, a virtual mental health capacity-building course was developed building off the Extension for Community Healthcare Outcomes (ECHO) model (Arora *et al.* 2010) applied to adults with IDD. Project ECHO is a guided practice model and telementoring approach that utilises a hub and spoke format to connect a central team of experts (the hub) with geographically dispersed participants (the spokes). This approach brings together a team of teachers with different areas of expertise and combines brief didactic instruction with applied activities to relate concepts to participating individuals and promote a community of practice, reducing one's sense of isolation.

The ECHO model has been successfully applied to many clinical populations including primary care providers supporting children with autism (Mazurek *et al.* 2017), as well as health and social service providers supporting adults with developmental disabilities (Thakur *et al.* 2021). Given the benefits reported by providers across these groups, a similar model may also benefit caregivers of people with IDD to provide them with relevant information and resources to support their mental health and the mental health of their loved ones during the COVID-19 pandemic, as well as to foster a virtual community of practice.

In Canada, healthcare is publicly funded, and there are very limited specialised mental health care services for adults with IDD, although there is variation in both health and social care delivery by province or territory (Gough & Morris 2012). During COVID-19, many in-person health and social services for those with IDD were unavailable because of pandemic restrictions, but which services and to what extent they were available, varied by region. Across the country, there were concerns about how the pandemic was impacting the mental health of adults with IDD, and limited supports were available. The current study evaluated the effectiveness of a national COVID-19

mental health virtual course to caregivers of adults with IDD. More specifically, we aimed to evaluate the feasibility and acceptability of this approach, to understand how the intervention impacted participants' overall health and well-being.

Methods

Course teaching team

The course teaching team included two mothers of adults with IDD, two psychologists (one of whom was also a sibling caregiver) and two operations staff. Additional guest clinicians (occupational therapist, psychiatrist and family physician) joined for specific sessions.

Curriculum development and implementation

Informed by learnings from a pre-COVID drop-in webinar series for caregivers and an existing ECHO Mental Health Program (Thakur *et al.* 2021), we designed a 6-week course for family caregivers. Similar to the ECHO program, each weekly session was 90 minutes in length and included the following components: (1) general COVID-19 news updates from across Canada, as well as specific news relevant to the IDD community; (2) a wellness activity (e.g. brief mindfulness practice); (3) didactic teaching on a specific topic (co-led by family caregivers and clinicians); and (4) time for participants to engage and interact with one another (e.g. smaller breakout rooms, answering polls and/or using the chat function to share experiences, answer questions and reflect on/apply the material presented). Following each session, all participants received an email containing a summary of that week's learnings and a link to the course website, which housed slides from each week's teaching, relevant links to tools and resources and a summary of participant comments collected during the session. Topics covered included health care communication, mental health assessment and treatment, grief and loss, health care planning and decision making, and caregiver mental health (Table 1). These topics were guided by the 6-week ECHO Mental Health and IDD Program (Thakur *et al.* 2021), and adapted based on input from our caregiver teaching team, caregiver advisors from our centres, and feedback from family webinars developed pre-pandemic.

Participants

Caregivers (i.e. parents, siblings and grandparents) were recruited from across Canada through national and provincial developmental disability networks. Participants were eligible for registration in the course if they (1) identified as a family member of an adult with an intellectual or developmental disability (age 18 and up); (2) lived in Canada; (3) were able to

Table 1 Course session content

Session	Content
Session 1: Assessment: Getting help for mental health concerns	Risk factors for mental health issues and strategies for promoting wellness during COVID-19.
Session 2: Empowering family caregivers to improve health care communication	Communication tools to support adults with IDD and their families get better health care.
Session 3: Managing mental health during COVID-19: An introduction to strategies for mental health concerns	The impact of COVID-19 on the mental health of people with IDD, including strategies to manage mood and anxiety difficulties, and knowing when and where to get help.
Session 4: Healthcare planning: Promoting decision-making capabilities	Healthcare decision-making for families and adults with IDD, including advance care planning.
Session 5: The impact of grief and loss during the pandemic	The impact of grief and loss during COVID-19, including strategies to support people with IDD grieving during this time.
Session 6: Caregiver mental health	The family experience of caregiving during COVID-19, including awareness of family distress screening tools and evidence-supported interventions to promote caregiver well-being

provide informed consent; and (4) had access to telephone or internet services.

Procedure

The course was offered three times (twice across Canada and a third time for Ontario residents only) between October 2020 and April 2021. During the 3-week period prior to the start of each course, select national and provincial family organisations shared the course recruitment flyer through their email and social media networks. Interested individuals could proceed to the online registration form or contact a course operations staff for more information and support. All participants enrolled in the course signed a Statement of Collaboration outlining expectations for participating in the program, including attendance and engagement. They were also invited to participate in a research project evaluating their involvement in the course.

Prior to the first session, an online orientation session was offered to familiarise participants with the video conferencing platform to be used (i.e. WebEx Meetings) and to determine if they needed accommodations or support to fully participate. Participants were encouraged to attend a minimum of three sessions and, if possible, to turn on their video camera to promote engagement and discussion at each session. During the sessions, course facilitators invited participants to comment or ask questions using the chat function or raising their virtual hand. Technology issues were resolved through support from an operations team member prior to and during the sessions.

Course evaluation

The research evaluation was made optional to course participants. This was done in an effort to make the course content accessible to as many people as possible, recognising that some individuals might benefit from being in the course but may not have time to complete additional research measures. To encourage participation in the research, a member of the research team explained the study to course participants at the orientation, and an honorarium was made available.

Design

We utilised Moore's evaluation framework for continuing education programs (Moore *et al.* 2009), specifically focusing on levels 1 through 5. Course participants who consented to be part of the research study completed pre- (1 week prior to the start of the course), post- (1 week after course completion) and follow-up measures (8 weeks following course completion). At each time point, for completing the measures participants received an honorarium in the form of a $20 e-gift card or a hard copy of the COVID-19 Self-Help Booklet Series, developed in the UK (Maguire *et al.* 2022) and used as a resource in the course.

Measures and data collection

Data across the three time points were collected via REDCap. Survey measures, outlined below, were supplemented with open-ended questions, to gather more feedback about specific aspects of the course including course format, curriculum, course facilitators, as well as examples of change in practice and well-being. The study was approved by the Institutional Research Ethics Board, and all participants provided informed consent prior to commencing the study.

Participation (Level 1) was measured according to drop-outs, weekly attendance and the proportion of participants who attended at least half of the sessions over the number of participants who attended at least one session (retention). Demographic information was collected for all research participants pre-course.

Satisfaction (Level 2) was assessed weekly (8 items) and post-course (18 items). All satisfaction measures used 5-point Likert scales (1 = strongly disagree and 5 = strongly agree) and targeted areas such as course content and delivery. In addition, participants were asked post-course whether the course met their expectations (Yes/No).

Learning and Self-efficacy (Levels 3 & 4) were assessed pre- and post-course, and again at follow-up. Participants rated their confidence in four core competencies related to health care and IDD during the pandemic using a previously published 100-point confidence slider scale (higher number = higher confidence) (Sockalingam *et al.* 2018).

Change in Practice (Level 5) was evaluated post-course through the question 'Has participation

in the course resulted in any changes for you and your family?' (Yes/No); and asked to provide examples of what they were doing differently now. Participants also rated how helpful they found the tools and resources presented during the course on a 3-point Likert Scale (1 = not at all helpful, 2 = somewhat helpful, 3 = very helpful).

At follow-up, participants were asked which health care tools (e.g. About My Health, My Health Care Visit and COVID-19 Advanced Care Planning Tool) or approaches (e.g. practised self care, widened my circle of support and accessed new mental health treatment options for my family member with an IDD), they or their family member had used since attending the course using a 3-point Likert scale (0 = none, 1 = a little, 2 = a lot).

Well-being was evaluated at pre- and post-program, and again at follow-up using the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant *et al.* 2007). The scale consists of 14 items targeting feeling and functioning aspects of mental well-being, and has been used in a number of studies with caregivers (Fancourt *et al.* 2019; Hodiamont *et al.* 2019; Sin *et al.* 2021; Salomone *et al.* 2018).

Analysis

Descriptive and inferential statistical analyses were conducted using R Studio version 1.3 (R Studio, 2020). Frequencies and percentages were described for categorical variables, and medians, means and standard deviations for continuous variables.

Participants' pre-program and post-program self-efficacy scores and well-being scores were matched across time by their program participant ID. Mixed effect models were used to determine changes between and within individuals across time. An unstructured covariance model was used so that any variance was uniquely fitted to the data. This type of model adjusts for any missing data across the three time points.

Open-ended survey items were analysed by counting the number of times a particular tool or topic was referenced and used to contextualise quantitative results (Hsieh & Shannon 2005).

Results

Participation

Descriptive statistics for participants are outlined in Table 2. The majority of participants were female (n = 116, 92%) with an average age of 55.8 years

Table 2 Demographic information for family caregivers of adults with IDD (N = 126) who participated in a virtual course between October 2020 and April 2021, across three delivery cycles

Variables	*N* = 126	%
Male	10	7.9
Female	116	92.1
Region		
Western Canada	20	15.9
Prairie Canada	3	2.4
Ontario/Quebec	96	76.2
Atlantic Canada	7	5.6
Race		
Asian – East (i.e. China, Japan, Korea)	1	0.8
Asian – South (i.e. India, Pakistan, Sri Lanka)	6	4.8
Asian – South East (i.e. Malaysia and Filipino)	2	1.6
Black – North American (i.e. Canadian and American)	2	1.6
Black – Caribbean (i.e. Barbadian and Jamaican)	1	0.8
Indigenous/Aboriginal	1	0.8
Latin American (i.e. Argentinean, Chilean and Salvadorian)	1	0.8
White – European (i.e. English, Italian and Portuguese)	29	23
White – North American (i.e. Canadian and American)	73	57.9
Mixed heritage	2	1.6
Other	5	4
Prefer not to answer	3	2.4
Relationship to family member with IDD		
Mother	94	74.6
Father	7	5.6
Brother	2	1.6
Sister	10	7.9
Other	13	10.3
Family member with IDD		
Living situation		
Lives with caregiver	86	68.3
Lives independently or with part-time support	18	14.3
Lives in a residential supervised setting	14	11.1
Other	5	4.0

(SD = 11.3). Approximately three quarters (n = 94, 75%) identified as a mother of an adult with IDD and approximately three quarters (n = 96, 76.2%) resided in Ontario or Quebec. The average age of family members with IDD was 29 years (SD = 10.6), and approximately two thirds of participants (n = 86, 68%) reported that their family member with IDD lived with them.

Across the three cohorts, 306 individuals registered for the course and of those, 126 consented to be part of the research evaluation. The median attendance for those in the research evaluation was four sessions (range of 0 to 6). Retention rate across the three cohorts was 84%, that is, 84% attended at least half (three sessions), with 76% attending two thirds (four sessions), and 43% attending all of them.

Satisfaction

Overall weekly satisfaction ratings for all participants ranged from a mean of 4.15 to 4.46 out of 5, and comments suggested that participants enjoyed the topics and interactive aspects of the sessions. Post-course satisfaction data are presented in Table 3. Over 80% of participants either agreed or strongly agreed with items pertaining to the structure and delivery, curriculum and content, and relevance of the course, for example; the opportunity to share strategies with other families (93%); and the course content was easy to understand (95%) and interesting (92%).

One exception was that 59% of participants agreed or strongly agreed with the item asking whether having a family member co-facilitate enhanced their learning. For this item, 36% were unsure, and 5% disagreed or strongly disagreed.

Post-course, 93% of participants reported that their expectations for the course were met.

Suggestions for course improvement included having a recording available immediately after the session, providing printed materials (i.e. slides) in advance of the session, offering longer sessions, offering the course at a different time of day to accommodate other time zones, incorporating more and/or longer small group breakout sessions organised according to region or diagnosis of their family member with an IDD, and including more caregiver course facilitators to reflect the diverse range of families' lived experiences.

Learning and self-efficacy

As shown in Table 4, participants reported increased self-efficacy in the four core competencies related to

Table 3 Post-course satisfaction results: mean scores, number and percent of participants who reported agreement or strong agreement (n = 121)

Item	Mean	%	*n*
Structure and Delivery			
It was easy to understand the content presented in the course.	4.54	95%	113
I appreciated the opportunity for us to share strategies with other family members.	4.49	93%	112
I felt comfortable participating (i.e. asking questions, providing recommendations) during the sessions.	4.13	84%	101
This course has helped me to feel supported and part of a virtual community of practice.	4.23	84%	101
I felt comfortable with the number of individuals I participated with in this program.	4.06	82%	98
Having a family member co-facilitate enhanced my learning.	3.78	59%	71
Curriculum and Content			
I thought the course content was interesting.	4.37	92%	110
The time dedicated in session to share COVID updates and resources was valuable to me.	4.28	89%	107
I was provided with new information throughout the course.	4.33	88%	106
The mindfulness activity in session was beneficial to me.	4.04	81%	97
Relevance			
The course content was relevant for me and/or my family.	4.25	89%	107
I felt supported and valued throughout the course.	4.31	88%	105
I plan to continue using the skills I learned in the future.	4.22	85%	102
The course addressed goals that were important to me.	4.19	85%	101
The course gave me skills that I can use in my everyday life.	4.15	83%	99

Table 4 Change in health care competencies over time

				Change across time	Individual change
Core competency	**Pre M (SD)**	**Post M (SD)**	**Follow-up M (SD)**	***P***	***P***
I am confident in my ability to communicate effectively and prepare for health care for my family member with an IDD during the COVID-19 pandemic	61.99 (24.76)	68.56 (21.53)	70.29 (20.14)	0.008	0.015
I am confident in my ability to support and manage the mental health of my family member with an IDD during the COVID-19 pandemic	47.58 (24.19)	59.28 (22.37)	59.75 (23.39)	0.001	0.014
I am confident in my ability to appropriately manage burnout and build resilience in myself during the COVID-19 pandemic.	46.59 (24.25)	55.57 (22.82)	55.55 (24.21)	0.002	0.0005
I am confident in my ability to work effectively across health and social systems during the COVID-19 pandemic	49.06 (24.71)	57.96 (22.56)	60.44 (22.74)	0.0003	0.002

Note: M denote mean value; *p* denotes the calculated p-value.

health care and IDD during the pandemic (i.e. communicating and preparing for health care visits, supporting and managing mental health, managing burnout and building resilience, and working effectively across health and social systems) from pre- to post-course, which were maintained at follow-up.

Change in practice

Post-course, 78% of participants reported that participating in the course resulted in changes for them and their family. As well, over 80% of caregivers shared that they found the tools and models discussed during the course somewhat helpful or very helpful (Table 5).

At follow-up, approximately half of participants reported some use of the tools and approaches presented (e.g. health care communication tools, HELP Model, widening their circle of support), with practising self-care endorsed most often (67%). Fewer participants (36%) reported that they had accessed new mental health treatment options for their family member with an IDD (Table 6).

When asked what they had been doing differently since attending the course, the most common examples shared in open-ended responses included using the health care communication tools, engaging in health care planning, making time for self-care (i.e. mindfulness), making space for their own emotions (i.e. anxiety and sadness), and reducing their own

Table 5 Efficacy of tools and approaches

Please rate how helpful you found the following tools and models discussed throughout this course	***n* (somewhat/ very helpful)**	**% (somewhat/ very helpful)**
About My Health	109	92%
My Health Care Visit	108	90%
HELP Model	105	88%
Hospital Patient Transfer Tool	101	84%
Canadian Developmental Disability Primary Care Guidelines	99	83%

Table 6 Change in practice: using tools and approaches

Since attending the course, have you …	%-A Little	%-A Lot
Practised self-care	67%	26%
Used communication health care tools for my family member with IDD (e.g. About My Health/My Health Care Visit)	62%	11%
Explored widening my circle of support	58%	19%
Used the HELP Model	54%	13%
Used CAMH [COVID-19 Self-help] Mental Health booklets for my family member with an IDD	48%	8%
Used the [COVID-19] Advanced Care Planning Tool	43%	6%
Accessed new mental health treatment options for my family member with an IDD	36%	9%

expectations, knowing what they were doing was good enough at that moment.

Well-being

Results from the Warwick-Edinburgh Mental Wellbeing Scale across the three time points are presented in Table 7. Scores improved and were maintained at follow-up, $F(2,371) = 5.94$, $p = 0.002$ (Figure 1). Specifically, scores significantly increased by 4.09 points from pre- to post-course, and by 3.49 points from pre-course to follow-up.

Discussion

The 6-week virtual mental health course designed with and for caregivers of adults with IDD improved participants' well-being and received high satisfaction rates across all three cycles. There was also consistent attendance and low dropout rates, despite the course being held during a time of high stress and competing demands for many caregivers. Participants reported improved self-efficacy and well-being post-course, which were maintained at follow-up. This suggests that virtual education programs, similar in structure to programs designed for service providers (Sockalingam *et al.* 2018), can benefit family caregivers and be provided to a large group at once, to create a community of practice and offer peer support. One of the main objectives of the intervention was to build mental health capacity and support overall health and well-being. Findings demonstrated an improvement in participants' well-being and positive changes in their lives, which were maintained over time. Significantly, participants' reported improvements in their well-being at a time when COVID-19 cases were on the rise in Canada (Cycle 1: Wave 2; Cycles 2 & 3: Wave 3; Our World in Data, 2022) and caregivers were experiencing significant distress (Flynn *et al.* 2021; Flynn *et al.* 2021; Gadermann *et al.* 2021; Redquest *et al.* 2021; Willner *et al.* 2020). Pre- to post-course, participating caregivers also reported increased self-efficacy in areas related to health care and IDD during the pandemic, which were maintained at follow-up. These improvements were relevant because many families reported challenges using health care services during this time (Jeste *et al.* 2020; Rosencrans *et al.* 2021).

Table 7 Warwick–Edinburgh mental wellbeing scale scores over time

	N	Mean	SD	95% CI	Change across time	Change across individuals
Pre	126	41.7	10.96	39.8–43.7	0.002	0.05
Post	124	45.8	9.77	44.1–47.5		
Follow-Up	120	45.3	9.89	43.5–47.1		

P-values represent change across the entire model.

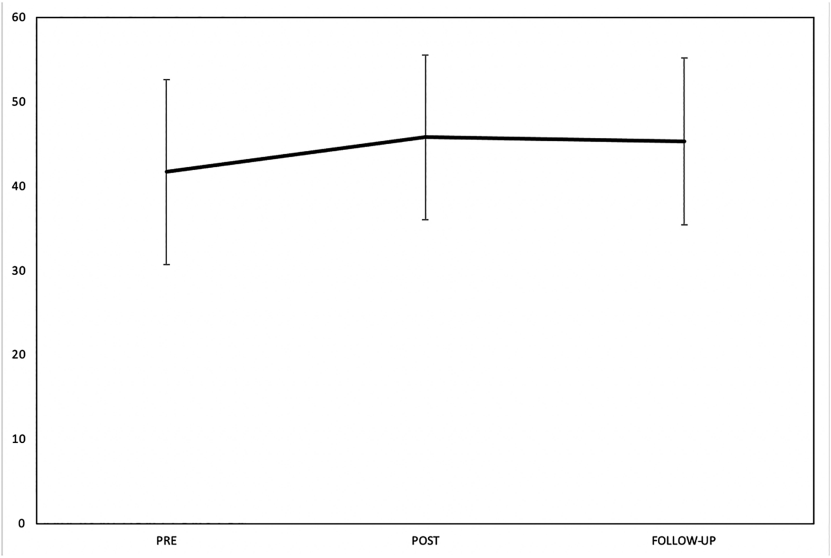

Figure 1. Change in well-being across time.

The finding that improvement in participants' well-being was maintained 2 months after the course ended is significant. Follow-up data demonstrated that over three quarters of caregivers reported that participating in the course resulted in changes for them and their family (e.g. using health care communication tools, engaging in health care planning, making time for self-care, and making space for their own emotions). Similarly, over three quarters of participants shared that they found the tools and strategies presented in the course helpful and even 8 weeks later; some were able to apply and use them. It is important to note that participants may not have had an opportunity to incorporate certain tools and strategies into their lives at the time of follow-up (e.g. accessing new mental health treatments, Advance Care Planning Tool), because of contextual factors such as service limitations and life circumstances, however, approaches that were more readily accessible (i.e. practised self-care) were endorsed quite frequently.

The course format, incorporating an interactive and peer-led pedagogy, likely contributed to its success. Through our prior family webinar experiences, and emerging literature on online education during the pandemic, we learned that providing information in a passive, didactic format is not as effective or readily applicable to learners (Castro *et al.* 2021; Chick *et al.* 2020; Kennedy *et al.* 2021; Krohn *et al.* 2021). As such, building off of teaching strategies utilised within the ECHO model (Sockalingam *et al.* 2018), multidisciplinary course facilitators engaged with caregiver participants through relevant, applied activities. Sessions were interactive, with didactic components lasting no longer than 30 minutes. Caregiver examples were embedded throughout, recognising that the lived experience of families makes them experts in their own right, consistent with the 'all teach, all learn' philosophy of ECHO. Similarly, using our knowledge about the value of peer support (Muralidharan *et al.* 2021; Suresh *et al.* 2021) and the benefits of caregivers and clinicians working in partnership (Srinivasan *et al.* 2021; White *et al.* 2018), the involvement of family caregivers as course designers and instructors was critical to its success (Johnson *et al.* 2021). Caregiver course facilitators helped ensure the content and goals of the course were relevant and meaningful to participants, as was highlighted in the post-course satisfaction survey. As co-teachers during each of the sessions, caregiver facilitators were also able to demonstrate how the tools and resources shared could be applied to caregivers' everyday lives. Caregiver course participants also provided support to one another during each session in the breakout portion. Indeed,

93% of participants reported that they appreciated the opportunity to share strategies with other family members in smaller breakout rooms.

Course participants not only came from different regions across Canada with different COVID-related public health restrictions, but also with family members with IDD who were of different ages, support needs, diagnoses, and in different living situations. Despite these differences, caregivers reported benefitting from the course. The virtual format made the program accessible to caregivers during a time when most in-person services were unavailable, and made it possible for caregivers to participate who were living in places where there were fewer services available or who may have difficulty leaving their home. Importantly, it fostered a sense of community, which was particularly helpful during a time of global crisis and intense isolation.

Limitations

Several limitations should be considered when interpreting these findings. First, fewer than half (41%) of participants consented to participate in the research evaluation of the course. Although we provided an honorarium for participating in the research, caregivers shared that they experienced a number of barriers. These included feeling too busy or overwhelmed, not understanding the process to participate (i.e. participants had to opt-in before they had a conversation with research staff), not understanding what the research evaluation was about, and not feeling confident in their ability to complete the online evaluation surveys. Going forward, it will be important to understand the experiences of caregivers who participated in the course, but did not opt to do the research. Second, although the first two cycles of the course were open to caregivers from across Canada, most participants resided in Ontario (50.5% in Cycle 1 and 72% in Cycle 2), and so findings may not be representative of all caregivers. Similarly, most participants identified as women (92%) and as mothers (75%). Third, we did not collect information about the well-being or mental health of adults with IDD who were family members of participating caregivers. In addition to understanding the impact of the course on the well-being of caregivers, it will be important to understand how interventions like this impact adults with IDD. Finally, all of the caregivers who participated in the course had access to technology to participate. In future work, it will be important to find ways to support caregivers who are unable to access technology (i.e. supply devices) or who have less comfort or familiarity with virtual programs. Pre-COVID, someone could go to their local library to participate in an online program, but in many parts of Canada, libraries were closed when the course was offered.

Conclusions

It was feasible and effective to bring together a large group of family caregivers, virtually, to learn, build skills and connect with one another. Combining the expertise of clinicians and family members, and including both teaching and the opportunity to connect and apply information, was an effective approach to deliver the educational program. As the pandemic situation evolves, it will be important to adapt the course based on current learner needs and COVID-related contextual factors. It will also be important to find ways to broaden the reach of courses (e.g. people residing in remote communities, people who do not have access to technology, caregivers who identify as men) to help ensure equitable access. As well, it will be important to evaluate benefits of family caregiver education not only on caregivers, but also on their family members with disabilities.

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Conflict of interest

No conflict of interest was reported by the authors.

Ethics approval

The study was approved by the Institutional Research Ethics Board.

Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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