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

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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.

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

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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. |
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          | 2       | 1.6 |
| (i.e. Canadian and American)    | 1       | 0.8 |
| Black – Caribbean (i.e. Barbadian and Jamaican) | 1 | 0.8 |
| Indigenous/Aboriginal Latin American (i.e. Argentinean, Chilean and Salvadorian) | 1 | 0.8 |
| White – European (i.e. English, Italian and Portuguese) | 29 | 23 |
| White – North American 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     | 18      | 14.3|
| part-time support               |         |     |
| 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

| 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

| 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.

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%                      |

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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 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% |

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.

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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 benefiting 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.

Acknowledgements
The authors would like to thank the study participants for their time and thoughtful contributions. We also want to thank our team of clinicians and research staff for their contributions to the course development and delivery.

Source of funding
Canadian Institutes of Health Research: MS2-173090.

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.

References

Arora S., Kalishman S., Thornton K., Dion D., Murata G., Deming P. et al. (2010) Expanding access to hepatitis C virus treatment – Extension for Community Healthcare Outcomes (ECHO) project: Disruptive innovation in specialty care. Hepatology 52, 1124–33.

Bailey T., Hastings R. P. & Totsika V. (2021) COVID-19 impact on psychological outcomes of parents, siblings and children with intellectual disability: Longitudinal before and during lockdown design. Journal of Intellectual Disability Research 65, 397–404.

Bray L., Carter B., Sanders C., Blake L. & Keegan K. (2017) Parent-to-parent peer support for parents of children with a disability: A mixed method study. Patient Education and Counseling 100, 1537–43.

Burke M. M., Lee C. E., Carlson S. R. & Arnold C. K. (2020) Exploring the preliminary outcomes of a sibling leadership program for adult siblings of individuals with intellectual and developmental disabilities. International Journal of Developmental Disabilities 66, 82–9.

Castro M., Calthorpe L. M., Fogh S. E., McAllister S., Johnson C. L., Isaacs E. D. et al. (2021) Lessons from learners: Adapting medical student education during and post COVID-19. Journal of the Association of American Medical Colleges 96, 1671–9.

Chick R. C., Clifton G. T., Peace K. M., Propper B. W., Hale D. F., Alseidi A. A. et al. (2020) Using technology to maintain the education of residents during the COVID-19 pandemic. Journal of Surgical Education 77, 729–32.

Clift A. K., Coupland C. A., Keogh R. H., Hemingway H. & Hippisley-Cox J. (2021) COVID-19 mortality risk in Down syndrome: Results from a cohort study of 8 million adults. Annals of Internal Medicine 174, 572–6.

Dodds R. L. & Singer G. H. (2018) Parent-to-Parent support providers: How recruits are identified. Journal of Applied Research in Intellectual Disabilities 31, 435–44.

Doody O. & Keenan P. M. (2021) The reported effects of the COVID-19 pandemic on people with intellectual disability and their carers: A scoping review. Annals of Medicine 53, 786–804.

Fancourt D., Warran K., Finn S. & Wiseman T. (2019) Psychosocial singing interventions for the mental health and well-being of family carers of patients with cancer: Results from a longitudinal controlled study. BMJ Open 9, e026995.

Fisher E. B., Miller S. M., Evans M., Luu S. L., Tang P. Y., Valovcin D. D. et al. (2020) COVID-19, stress, trauma, and peer support—observations from the field. Translational Behavioral Medicine 10, 503–5.

Flynn S., Hayden N., Clarke L., Caton S., Hatton C., Hastings R. et al. (2021) Coronavirus and people with learning disabilities study: Wave 1 report March 2021 full report. University of Warwick, Coventry, UK.

Flynn S, Hayden N, Clarke L., Caton S., Hatton C., Hastings R. et al. (2021) Coronavirus and people with learning disabilities study: Wave 3 results September 2021.

Gadermann A. C., Thomson K. C., Richardson C. G., Gagné M., McAuliffe C., Hirani S. et al. (2021) Examining the impacts of the COVID-19 pandemic on family mental health in Canada: Findings from a national cross-sectional study. BMJ Open 11.

Gillespie-Smith K., McConachie D., Ballantyne C., Auyeung B. & Goodall K. (2021) The impact of COVID-19 restrictions on psychological distress in family caregivers of children with neurodevelopmental disability in the UK. Journal of Autism and Developmental Disorders, 1–15.

Gleason J., Ross W., Fossi A., Blonsky H., Tobias J. & Stephens M. (2021) The devastating impact of Covid-19 on individuals with intellectual disabilities in the United States. NEJM Catalyst Innovations in Care Delivery 2.

Gough H. & Morris S. (2012) Dual diagnosis public policy in a federal system: The Canadian experience. Journal of Policy and Practice in Intellectual Disabilities 9, 166–74.

Hodiamont F., Allgar V., Currow D. C. & Johnson M. J. (2019) Mental wellbeing in bereaved carers: A Health Survey for England population study. In: BMJ supportive & palliative care.

Hsieh H.-F. & Shannon S. E. (2005) Three Approaches to Qualitative Content Analysis. Qualitative Health Research 15, 1277–88.

Jeste S., Hyde C., Distefano C., Halladay A., Ray S., Porath M. et al. (2020) Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions. Journal of Intellectual Disability Research 64, 825–33.

Johnson J. K., Batalden P., Foster T., Arvidsson C., Batalden M., Forcino R. et al. (2021) A starter’s guide to learning and teaching how to coproduce healthcare services. International Journal for Quality in Health Care 29, i662.

Kennedy E. & Rose D. (2021). Lessons learned online that will shape education after the pandemic. EdSurge. Available at: https://www.edsurge.com/news/2021-01-19-the-lessons-learned-online-that-will-shape-education-after-the-pandemic (retrieved 19 May 2021).

Krohn K. M., Sundberg M. A., Quadri N. S., Stauffer W. M., Dhawan A., Pogemiller H. et al. (2021) Global health education during the COVID-19 pandemic: Challenges,
adaptations, and lessons learned. *The American Journal of Tropical Medicine and Hygiene* **105**, 1465–7.

Lee V, Albam C, Tablon M. P., Ahmad F., Gorter J. W., Khanlou N. et al. (2020) Impact of COVID-19 on the mental health and wellbeing of caregivers and families of autistic people: A rapid synthesis review. Report prepared for the Canadian Institutes of Health Research.

Lunsy Y., Durbin A., Balogh R., Lin E., Palma L. & Plumptre L. (2021) COVID-19 positivity rates, hospitalisations and mortality of adults with and without intellectual and developmental disabilities in Ontario, Canada. *Disability and Health Journal* **15**.

Lunsy Y., Jahoda A., Navas P., Campanella S. & Havercamp S. M. (2022) The mental health and well-being of adults with intellectual disability during the COVID-19 pandemic: A narrative review. *Journal of Policy and Practice in Intellectual Disabilities* **19**, 35–47.

Maguire R., Pert C., Bains S., Gillooly A., Hastings R. P., Hatton C. et al. (2022) Adapted guided self-help booklets for supporting the well-being of people with intellectual disabilities during the COVID-19 pandemic: An evaluation of impact. *Tizard Learning Disability Review*.

Majnemer A., McGrath P. J., Baumbusch J., Camden C., Fallon B., Lunsy Y. et al. (2021) Time to be counted: COVID-19 and intellectual and developmental disabilities. *Royal Society of Canada*. Available at: https://rsc-src.ca/en/news/covid-19/time-to-be-counted-%C2%A9covid-19-and-intellectual-and-developmental-disabilities

Mazurek M. O., Brown R., Curran A. & Sohl K. (2017) ECHO autism: A new model for training primary care providers in best-practice care for children with autism. *Clinical Pediatrics* **56**, 247–56.

Moore D. E., Jr, Green J. S. & Gallis H. A. (2009) Achieving desired results and improved outcomes: integrating planning and assessment throughout learning activities. *Journal of Continuing Education in the Health Professions* **29**, 1–15.

Muralidharan A., Ppeesle A. D., Hack S., Fortuna K. L., Klingman E. A., Stahl N. F. et al. (2021) Peer and non-peer co-facilitation of a health and wellness intervention for adults with serious mental illness. *Psychiatric Quarterly* **92**, 431–42.

Our World in Data COVID-19 Data. (2022) “COVID-19 data explorer”. Available at: https://ourworldindata.org/explores/coronavirus-data-explorer?facet=none%26pickerSort=asc%26Interval=7-day%26Bolling%26Baverage%26Relative%26To%26Population=true%26Color%26By%26Test%26Positive%26Country=%26ECAN%26Metric=Confirmed%26Deaths (retrieved 21 February 2022).

Patel V., Perez-Olivas G., Kroese B. S., Rogers G., Rose J., Murphy G. et al. (2021) The experiences of carers of adults with intellectual disabilities during the first COVID-19 lockdown period. *Journal of Policy and Practice in Intellectual Disabilities* **18**, 254–62.

Redquest B. K., Tint A., Ries H. & Lunsky Y. (2021) Exploring the experiences of siblings of adults with intellectual/developmental disabilities during the COVID-19 pandemic. *Journal of Intellectual Disability Research* **65**, 1–10.

Rosenkrans M., Arango P., Sabat C., Buck A., Brown C., Tenorio M. et al. (2021) The impact of the COVID-19 pandemic on the health, wellbeing, and access to services of people with intellectual and developmental disabilities. *Research in Developmental Disabilities* **114**.

Rydzewska E., Dunn K., Cooper S. A. & Kinnear D. (2021) Mental ill-health in mothers of people with intellectual disabilities compared with mothers of typically developing people: a systematic review and meta-analysis. *Journal of Intellectual Disability Research* **65**, 501–34.

Salomone E., Leadbitter K., Aldred C. et al. (2018) The association between child and family characteristics and the mental health and wellbeing of caregivers of children with autism in mid-childhood. *Journal of Autism and Developmental Disorders* **48**, 1189–98.

Scherer N., Verhey I. & Kuper H. (2019) Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLoS ONE* **14**, e0219888.

Shilling V., Morris C., Thompson-Coon J., Ukoumunne O., Rogers M. & Logan S. (2013) Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. *Developmental Medicine and Child Neurology* **55**, 602–9.

Sin J., Elkes J., Batchelor R., Henderson C., Gillard S., Woodham L. A. et al. (2021) Mental health and caregiving experiences of family carers supporting people with psychosis. *Epidemiology and Psychiatric Sciences* **30**, 1–9.

Sockalingam S., Arena A., Serhal E., Mohri L., Alloo J. & Crawford A. et al. (2018) Building provincial mental health capacity in primary care: An evaluation of a project ECHO mental health program. *Academic Psychiatry* **42**, 451–7.

Srinivasan S. M., Su W. C., Cleffi C. & Bhat A. N. (2021) From social distancing to social connections: insights from the delivery of a clinician-caregiver co-mediated telehealth-based intervention in young children with autism spectrum disorder. *Frontiers in Psychiatry* **12**.

Suresh R., Alam A. & Karkossa Z. (2021) Using peer support to strengthen mental health during the COVID-19 pandemic: A review. *Frontiers in Psychiatry* **12**, 1119.

Tennant R., Hiller L., Fishwick R., Platt S., Joseph S., Weich S. et al. (2007) The Warwick-Edinburgh mental wellbeing scale (WEMWBS): Development and UK validation. *Health and Quality of Life Outcomes* **5**, 1–13.

Thakur A., Pereira C., Hardy J., Bobbette N., Sockalingam S. & Lunsky Y. (2021) Virtual education program to support providers caring for people with intellectual and developmental disabilities during the COVID-19 pandemic.
pandemic: rapid development and evaluation study. *JMIR Mental Health* 8, e28933.

White C. L., Overbaugh K. J., Pickering C. E., Piernik-Yoder B., James D., Patel D. I. *et al.* (2018) Advancing care for family caregivers of persons with dementia through caregiver and community partnerships. *Research Involvement and Engagement* 4, 1–7.

Williamson E. J., McDonald H. I., Bhaskaran K., Walker A. J., Bacon S., Davy S. *et al.* (2021) Risks of covid-19 hospital admission and death for people with learning disability: Population based cohort study using the OpenSAFELY platform. *The British Medical Journal* 374, n1592.

Willner P., Rose J., Stenfert K. B., Murphy G. H., Langdon P. E., Clifford C. *et al.* (2020) Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 33, 1523–33.

*Accepted 13 July 2022*