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Pandemic impact, mitigation strategies and peer support: a qualitative analysis of youth, parent, clinician and administrator perspectives

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Abstract

Objectives This study describes views on the impact of the COVID-19 pandemic on eating disorder symptoms in youth, as well as the impact on care, and the possibility of peer support as a mitigating strategy from the perspectives of youth and parents with lived experience with eating disorders, as well as clinicians and administrators.

Methods A national purposive sample was recruited through websites and social media platforms. Those recruited were asked to complete a demographic questionnaire and to partake in an individual, virtual, semi-structured qualitative interview. Guided by a qualitative descriptive approach, interview data was transcribed and analyzed using qualitative content analysis.

Results Fifteen parents (93% female; age 48.9 ± 6.9 years), 14 youth (93% female; age 15.3 ± 1.2 years), 16 clinicians (93.8% female; age 41.19 ± 15.7) and 12 administrators (83.3% female; age 47.75 ± 12.2 years) participated. Thirteen parents (87%) said they would attend a parent peer support group and all 15 (100%) said it should be offered routinely in community and hospital settings delivering eating disorder care. Benefits and risks were discussed by participants. Youth, clinicians and administrators agreed that parental peer support groups would be helpful but were not as convinced that youth peer support groups would be beneficial to youth with eating disorders.

Conclusions Those with lived experience view parental peer support as beneficial and feel it should be offered routinely. Clinicians and administrators also voiced support for parental peer support with certain caveats regarding training and oversight.

Plain English Summary

This study describes views on the impact of the COVID-19 pandemic and the possibility of peer support as a mitigating strategy from the perspectives of those with lived experience with eating disorders, as well as clinicians and administrators. Through qualitative interviews, those with lived experience view parental peer support as

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beneficial and feel it should be offered routinely. Clinicians and administrators voiced support with conditions of training and oversight.

Keywords Peer support, Adolescents, Parents

Introduction

Eating Disorders (EDs) cause significant disruptions in mental and physical health [1] and have one of the highest mortality rates of all psychiatric illnesses [2]. These disorders are known for being chronic and difficult to treat, especially if intervention is not received within the first three years of symptom onset [3]. Eating Disorders are common, with pre-pandemic Canadian studies reporting 2.2% of males and 4.5% of females under 18 years of age meeting criteria for an ED [4], and subclinical EDs among Canadian adolescents affecting approximately 25% of males and 30% of females [5–7]. The COVID-19 pandemic has only worsened conditions for individuals with EDs. Dramatic increases in the number of youth suffering from EDs and those requiring hospitalization have been reported in Australia and Canada [8–10]. Although reasons for this increase have not been studied in a systematic fashion, experts suggest that isolation, lack of daily structure, lack of access to health care, and social media focused on pandemic weight gain have been core factors in the increase in the population-level incidence and prevalence of EDs [11–13]. Accordingly, young people around the world, experienced, and continue to experience, significantly long wait times for ED treatment. Similarly, programs are struggling to manage this surge of new ED cases and research with youth and their parents indicate that they are experiencing unmanageable levels of uncertainty and anxiety while waiting for ED care [14]. Although post-pandemic ED hospitalization rates of new cases in the last two years suggest some decline, rates still remain elevated compared to pre-pandemic levels in the US and Canada [15, 16]. Thus, continued investment in research and program development that understands the evolving impacts of the COVID-19 pandemic on children, youth, and families living with an ED, as well as what best meet their needs, must remain a priority.

The most widely used evidence-based treatment for children and adolescents living with EDs is Family-Based Treatment, which has been adapted for virtual delivery with success [17–19]. With guidance from a trained therapist, parents are tasked with refeeding their child in efforts to interrupt disordered eating behaviours [20]. It is possible that this model of treatment, although highly effective, further exacerbated pandemic-related burdens experienced by families. The benefits of parent led peer support groups for parents of children with disabilities are well-described in the literature [21–23], and momentum is growing in the EDs field as well [24, 25]. These groups alleviate burden by reducing social isolation, facilitating connections with others, sharing problem solving skills, and enabling a sense of power and self-efficacy [21, 24, 25]. In the recently published *Canadian Practice Guidelines for the Treatment of Children and Adolescents with Eating Disorders* and its addendum on virtual care recommendations—peer support was highlighted as a gap in the ED care continuum [26, 27]. A recent commentary further expresses the need for peer support in the ED field, particularly for parents [28]. The evidence for the effectiveness of peer support for youth with EDs is also growing [29, 30]. Furthermore, previous work demonstrates that peer support is an important component of care within a full suite of ED services and is evidence-based [31, 32], and Canada's *Mental Health Strategy* calls for an expansion of peer support as an essential component of mental health services [33]. In this paper, peer support refers to structured and formal peer support, as opposed to informal peer support.

Both parent-led and youth peer support has traditionally been excluded from pediatric ED programs. Given the findings that peer support can reduce social isolation, and that one of the pandemic impacts has been found to be social isolation, we wondered about the views on peer support as a potential mitigating strategy. Understanding the barriers and facilitators associated with the adoption of peer support, from the perspectives of multiple stakeholders, including administrators, clincians, youth, and parents, is important for implementation, evaluation, and sustainability. Given the unexpected surge in new ED cases among youth in Canada, the continued elevated rates of hospitalization and waiting lists, as well as, the increased burden placed on parents of children with EDs during the COVID-19 pandemic, there was an urgent need to better understand the impact as well as explore mitigation strategies for the impact of the COVID-19 pandemic with respect to this population, and learn of opportunities that may help in this realm. Thus, this qualitative study has several aims: (1) to understand the impact of the COVID-19 pandemic on youth, parents, clinicians and administrators with personal and/or professional experience with EDs in terms of eating disorder symptoms in youth, as well as the impact on care, (2) to explore mitigating factors (any strategies that could alleviate the impact), (3) to describe stakeholder views on youth peer support, and (4) to explore views on parental peer support.

Methods

The principles of qualitative description guided the sampling, data collection, and analytic decisions in this study [34]. This qualitative approach is appropriate for identifying the core aspects of experience and perception of a phenonmenon and for providing a comprehensive summary that can inform pragmatic action. To this end, our methodology allowed our team to invite and coalesce perspectives from across Canada on the impact of the COVID-19 pandemic on youth, parents, clinicians and administrators with personal and/or professional experience with EDs, potential mitigating strategies, attitudes toward peer support for youth, and views on parental peer support. Data collection took place between June and November 2022. Ethics approval was obtained from the Hamilton Integrated Research Ethics Board.

Participants and data collection procedures

A purposeful sample of 70 stakeholders including parents, youth, clinicians, and administrators from each of Central (ON, QC; $n = 20$), Eastern (NS, NL, PE, NB; $n = 20$), Western (BC, AB, SK, MB; $n = 20$), and Northern Canada (NU, YT, NT; $n = 10$) with personal or professional lived expertise with EDs were invited to partake in an individual virtual semi-structured qualitative interview with a member of the research team. Participants were recruited through the posting and sharing of study recruitment materials on websites and social media accounts of The National Initiative for Eating Disorders (NIED) and the National Eating Disorders Information Centre (NEDIC) and in clinical ED programs. Parents and youth who were awaiting services, actively in treatment, or post-treatment were eligible to participate in this study. Eligible clinicians and administrators were required to work with youth with EDs (clinicians) or to lead teams who treat youth with EDs (admininstrators). The clinicians and administrators were mutually exclusive groups. The administrators were managers of programs that had decision-making power over hiring/firing of staff. We thought is was important to include the views of administrators of programs as they would have decision-making power over whether to adopt and fund peer support within programs. Youth were defined as those under age 18 years. The interview guide (see supplemental material) was constructed in alignment with the qualitative description approach [34]. The guide focused on four main topics: (1) the impact of the COVID-19 pandemic, (2) potential mitigating strategies, (3) views on peer support for youth, (4) views on peer support for parents. Thus, the four main categories within our qualitative findings were pre-defined, and subcategories were built inductively. Video-recordings of the interviews were transcribed verbatim. Participant demographics were collected immediately following the completion of consent procedures to help describe the diversity of participants and were documented on a standardized demographic-information form.

Analysis

Qualitative data were managed using NVivo software and analyzed using qualitative content analysis and the constant comparison technique. Two types of qualitative content analysis—conventional and summative—were blended in the present study [35]. In alignment with conventional content analysis, the transcripts were read multiple times by two coders (MN, CW) to derive initial codes based on participant-generated words. Initial codes were sorted into categories to generate a written narrative of the data. Illustrative quotes were used to support coding categories. Next, summative content analysis was used to count the number of mentions and participants who expressed each perspective. Representative quotes were used to exemplify major categories.

Using the constant comparative technique, qualitative data collection and analysis occurred simultaneously; codes and categories generated from interim analysis were further explored in subsequent interviews. Specifically, iterative reviews of text within and across transcripts were completed by two members of the research team to identify codes and the salient aggregate themes characterizing the impact of the COVID-19 pandemic, potential mitigating strategies, and attitudes toward peer support for youth and parents. Codes were built separately for youth, parents, clinicians and administrators. The application of codes and their aggregate themes to the data were confirmed via group-based consensus meetings among the analytical team; disagreements in coding were also resolved via the same process.

Researcher characteristics and reflexivity

Researcher characteristics may have influenced participant interactions or data interpretation. The authors who coded and analyzed the data (MN, CW) have multiple years of research and/or clinical ED experience which may have impacted data interpretation (e.g., development and collapsing of categories). However, both members consulted with one another to reflect upon any biases that could impact their analysis of the data. The methodology decisions (e.g., selected approach, design, analysis) were likely influenced by the authors' previous research experiences. The primary researcher is a white woman who has worked for 20 years within public systems treating children and youth with EDs.

Strategies to enhance rigour of qualitative data

Lincoln and Guba's four principles were followed to enhance the trustworthiness in this qualitative study [36]. To address credibility, member checking (asking new participants to elaborate upon previous insights) and investigator triangulation (multiple researchers to analyze data) were used. To promote transferability, a dense description of study methods and their rationale were provided. A comprehensive audit trail of documents and any changes was completed to address the dependability and confirmability principles. Lastly, the team engaged in reflexivity to reflect on how researcher attitudes and contributions may have influenced data collection or interpretation.

Results

Demographic information describing study participants is contained in Table 1. Overall, the sample consisted of 57 participants with 89.7% of them being female and just over one-third (34.5%) residing in Ontario. The sample contained 14 youth, 15 caregivers (who all identified as parents), 16 clinicians and 12 administrators. There were five parent-child dyads in this sample. Just over half of the youth were experiencing current symtpoms (*n* = 8, 57.1%), and 71.4% had a current or past diagnosis of anorexia nervosa (AN; *n* = 10). In terms of the parents, 80% (*n* = 12) of the participants were married and 64.1% reported having a child with AN. Of the clinicians participating (*n* = 16), nine (56%) worked in a public system, four (25%) in a private system, and three (19%) worked in both public and private systems. The clinicians were composed of various disciplines (five social workers, four physicians, three psychologists, two dieticians and two other) and they had been in their current role for an average of over eight years. Of the administrators (*n* = 12), eleven (92%) worked in a public system, and they reported being in their current role for an average of seven years. Some administrators had a clinical background while others did not (five were nurses, four were social workers, and three had other backgrounds). The interviews lasted an average of 51 min (SD 15 min, range 21 to 86 min).

Qualitative findings are presented in Tables 2, 3, 4 and 5 and are divided into the following categories: (1) the Impact of COVID-19, (2) Potential Mitigating Strategies, (3) Views on Peer Support for Youth and (4) Views on Peer Support for Parents. Please note that only the most important sub-categories are mentioned in the text below. Please see the tables for a more thorugh description.

The impact of COVID-19

All of the youth described that the pandemic was socially isolating and that this social isolation had a negative impact on their ED symptoms. The lack of activities and sports led to greater restriction and solitary exercise. In addition, many youth discussed a negative impact of more time spent on social media. Interestingly, parents also highlighted these two factors (isolation and social media) as having a negative impact on their children in terms of increasing ED symptoms. The majority of clinicians (11/16) described higher caseloads with greater

Table 1 Demographics of youth, parents, clinicians and administrators

Variable	All Participants (*n* = 57)		Youth (*n* = 14)		Parent (*n* = 15)		Clinician (*n* = 16)		Administrator (*n* = 12)	
		Mean (SD)		Mean (SD)		Mean (SD)		Mean (SD)		Mean (SD)
Age, ***years***		38.23 (17.07)		15.29 (1.20)		48.87 (6.92)		41.19 (15.74)		47.75 (12.25)
	N	%	n	%	n	%	n	%	n	%
Gender										
Female	52	89.7%	13	92.9%	14	93.3%	15	93.8%	10	83.3%
Male	4	6.9%	1	7.1%	0	0.0%	1	6.3%	2	16.7%
Gender non-conforming	1	1.7%	0	0.0%	1	6.7%	0	0.0%	0	0.0%
Province										
Ontario	20	34.5%	5	35.7%	5	33.3%	5	31.3%	5	41.7%
Alberta	15	25.9%	5	35.7%	4	26.7%	4	25.0%	2	16.7%
Nova Scotia	9	15.5%	2	14.3%	3	20.0%	3	18.8%	1	8.3%
Newfoundland	6	10.3%	1	7.1%	2	13.3%	2	12.5%	1	8.3%
British Columbia	4	6.9%	0	0.0%	0	0.0%	1	6.3%	3	25.0%
Manitoba	1	1.7%	0	0.0%	1	6.7%	0	0.0%	0	0.0%
Prince Edward Island	1	1.7%	1	7.1%	0	0.0%	0	0.0%	0	0.0%
Yukon	1	1.7%	0	0.0%	0	0.0%	1	6.3%	0	0.0%
Ethnicity										
White	47	81.0%	12	85.7%	15	100.0%	12	75.0%	8	66.7%
Indigenous	3	5.2%	0	0.0%	0	0.0%	1	6.3%	2	16.7%
Black	3	5.2%	1	7.1%	0	0.0%	2	12.5%	0	0.0%
Chinese	2	3.4%	0	0.0%	0	0.0%	0	0.0%	2	16.7%
Latinx	2	3.4%	1	7.1%	0	0.0%	1	6.3%	0	0.0%

Table 2 Qualitative findings on the impact of COVID-19 on the youth with the ED, from the perspectives of youth, parents, impact on workload from perspectives of clinicians and impact on staff from perspective of administrators

Participant	Response Categories	Example Quote	Number of Individuals	Number of References
Youth	Isolation	"Prior to COVID, I was very active. I was a competitive swimmer. And like I ate pretty normally. Then when we were put into quarantine, we were stuck at home, so I wasn't able to do competitive swimming anymore, so then I got concerned and I started running on a treadmill we had, and then restricting certain foods." EY003	14	24
	Social media	"Then when we all started like… Like when everyone was at home during the pandemic, everyone wanted to make like TikToks or something, right? And then it got to the point where it's like, "Okay, they don't really see you for your personality. Now it does not matter what your personality is. It's solely based on your looks" kind of deal. So that hit hard, and stuff like that." WY002	8	8
	Focus on Exercise	"… a lot of people were doing these online workouts and these glow-ups at home and stuff like that, and I was like, "Oh, I have to do that now," not realizing I didn't have to do that and doing that just made it a lot worse." WY001	4	4
	Stress, powerlessness, loss of control and fear	"I think the stress just led me to continue on my eating disorder because it started with this idea to get healthy, but then all the stress and anxiety I felt about everything that was going on, the loss of control I felt, that's what really made my eating disorder so dangerous." WY005	3	3
Parent	Isolation	"Yes. I feel the events of the pandemic and change to the structure, the change to school, like being at home… And I'm not saying teachers had any other choice but to go home, so that's just the way it was. But I definitely feel those circumstances led up to her having the eating disorder" WP004	13	20
	Social media	"I definitely feel that social media had an influence. Maybe not Netflix, but TikTok probably, like looking back on it, or YouTube videos or clicking videos of eating healthy were all very negative effects on her" WP004	7	8
	Stress, powerlessness, loss of control and fear	"One, I think the stress brought on this maladaptive coping strategy because she already has underlying mental health. And she's already sort of predisposed to not handle stress very well and change very well. Yeah, I think COVID was a dumpster fire for many kids" CP004	6	6
	Wanted to look good for return to in person activities	"And I think there was a lot of pressure from them being at home online than for when they went back in person. I think there was a lot of pressure of how they were going to look" CP001	1	1
Clinician	Higher caseload and number of referrals	"Higher caseloads that are more severe, so much so that we basically devoted all of our resources to the care of those who urgently required it, and that caused our waiting list, for kids who are not dying, to expand." CC001	11	12
	Higher Acuity Cases	"We're seeing sicker clients showing up or more acute clients coming for outpatient services, often just because they can't into inpatient or residential services." WC005	4	5
	Transition to virtual care	"During the pandemic, there was a drastic increase in workload because we had to attend all of these extra meetings around extra privacy and doing virtual work, and everything was, like I say, manual labour." CC003	2	2
	Nature of private work is different	"… kids who are having a hard time getting into the hospital were referred to me as a private practitioner. And that was difficult because I don't have a whole team. I just… I connect with a physician and so on, but I don't have a nutritionist and I don't have… I can refer, but it's different than having a team that you're working with." EC004	2	2
	Changes on team (e.g. people leaving, retiring, going part time)	"As I mentioned, at the same time as that happening we did have two of our dieticians have to step back just in the pandemic with kids being at home that they couldn't take on more clients at that time and then eventually did have to step back." WQC005	1	1
	Structural changes to programs (e.g., split up ED programs, new spaces)	"It has changed in that our outpatient and inpatient programs used to be together. They used to be at the same place. And it has changed in that because we could not allow people to go in and out of the institution with our inpatients, who are a little bit more immunocompromised and just because of hospital policy, and so we have more outpatients now because we have a bigger space and we are able to accommodate more of the outpatients." WC004	1	1

Table 2 (continued)

Participant	Response Categories	Example Quote	Number of Individuals	Number of References
Administrator	Exhaustion, burnout, and compassion fatigue	"I would say that the degree of compassion fatigue and burnout is much higher than prior to the pandemic." WA004	7	8
	Increased anxiety and fear	"So, my sense is that there was a lot of anxiety because there were so many process changes. So, you go from in-person to not having that ability to do that anymore, and you're then now trying to figure out this virtual world. You know that it's increasing. Your waitlist is increasing, but you don't have the capacity or the ability to kind of ramp up and see lots of people. So, I think there was a lot of anxiety amongst the staff" CA002	5	5
	Fears about contracting COVID	"so some of the staff that were asked to work in the day hospital, if they weren't comfortable with exposing themselves to patients who were coming and going in the program, then we had to work around that." WA002	3	3
	Reduced team cohesion	"The other part I found, and not just with them but in general as an outpatient manager, was it really did do some damage to the team approach. We tend to do a lot of the face-to-face kind of sitting around a table kind of meeting… that you do build a rapport, and you kind of do stuff, whereas when they went to this kind of virtual piece like you and I, sometimes that gets in the way, that it breaks the bonds within a team because they're not physically seeing one another." EA001	3	3
	Difficulties maintaining fidelity to treatment models, and adjusting existing treatments due to pandemic impacts	"So, how do parents do meal support when the meal is kind of left at the end of the doorway because now people are self-isolating because parents either have COVID, kids have COVID. So, how do you do meal support with somebody that you can't have access to because there has to be six feet of separation? So, staff said they were encountering the weirdest things that they didn't even know… Like, how do you do FBT when the whole family is self-isolating and nobody can be close to each other?" CA002	1	2
	Staff leaving the profession or desiring part-time, instead of full-time, switching to private practice	"I think people have kind of re-evaluated things. I think there's a lot of people that want to work part-time now…and we're getting a lot of people leaving the profession." WA003	1	3

*Participant coding – First initial indicates Eastern Canada (E) including Nova Scotia, Newfoundland, Prince Edward Island; Central Canada (C) including Ontario; Western Canada (W) including British Columbia, Alberta, and Manitoba; and Northern Canada (N) including the Yukon. Second initial indicates Youth (Y), Parent (P), Clinician (C), or Administrator (A)

severity during the pandemic. Administrators commented on the exhaustion and burnout within their staff (7/12), along with increased fear and anxiety during the pandemic, and a high turnover of staff (either leaving the profession completely, switching from the public to the private system, or reducing their hours).

Potential mitigating strategies

Some youth (5/14) and approximately half of the parents (7/15) emphasized that increased education and awareness in schools and amongst healthcare professionals about EDs would have helped to mitigate the impact of the COVID-19 pandemic on ED symptoms by identifying youth who needed help earlier. Youth described that greater opportunities to socialize with friends would have helped to ease feelings of social isolation, whereas parents discussed that uninterrupted treatment and more support for parents would have been helpful. Youth emphasized that virtual school could have included some time just to socialize. Clinicians had varied responses to the question of what could have helped the provision of care during the pandemic; some (4/16) mentioned that continuing to provide care through virtual means made a "big difference" in terms of continuity of care. A few administrators also commented on the benefits of virtual care, but also commented that access to an information session and resources would have been helpful especially for those waiting for treatment.

Views on peer support for youth

Peer support groups for youth were probed as a possible mitigating strategy to help with feelings of isolation. Over half of the youth (9/14) thought they would have accessed such support, had it been available. Many benefits of

Table 3 Potential mitigating strategies for COVID-19 pandemic impacts on the youth with the ED from the perspectives of youth and parents, as well as care provision from the perspectives of clinicians and administrators

Participant	Response Category	Example Quote	Number of Individuals	Number of References
Youth	Increased ED education and awareness (for parents, schools, healthcare professionals, for people in general)	"So yeah. I mean I think just having more education around eating disorders, so that my family could have been more aware. I mean they did catch it pretty early considering, but there were still multiple months of just eating nothing. So yeah, I think having more awareness about that. If my parents had have known, they could have stopped it a bit earlier." EQY003	5	7
	Socializing with friends	"And then I don't really know because it's a really tough situation because a lot of people really depend on friends and stuff. But maybe an online school, try to change it a little bit so that people… so that there's more social aspects in it. Like, you can talk to your friends more during online school, because isolation did affect a lot of people." WY003	4	4
	Peer support for youth	"I think definitely being able to talk to more people that were going through the same thing as me or have recovered from it. Because all I wanted to do was find new strategies to be able to just not think about the food and just eat it. And I think that if I were to talk to more people that were going through it with a good mindset, that it would have been really helpful for me during the pandemic. Because I just had nobody to talk to, and whenever I was talking to my friends, they didn't really understand." CY003	3	3
	Reduced social media use	"I think having less access to social media would have been better. I mean especially TikTok. If I could go back, I probably would have never downloaded that." EY003	3	3
	More available, affordable treatment options	"I know it's easier said than done, but more availability like with the healthcare to people who need it." WY003	3	3
	Improved communication between parent(s) and child with ED	"My parents were doing the best they could. I think just maybe asking me questions instead of resorting to books and doctors. Like asking me what I needed to feel better. Because they didn't." CY001	2	2
Parent	Increased ED Education and Awareness (for parents, schools, healthcare professionals)	"… there's a lot of red flags that I think parents need to be aware of and that family doctors need to share with their patients." EP004	7	14
	Uninterrupted ED Treatment during lockdowns (e.g., Continued therapy, in-person medical monitoring)	"I think that removing the barriers to in person appointments would be critical, especially when there's concern about weight loss and what I now know is the potential for medical instability." WP002	4	6
	More support, information, and guidance for parents	"… if families can be armed with good information sooner and feel supported, I think it will really help them and, in turn, their child." CP002	3	4
	Parent Peer Support (e.g., forum, website, group, one on one)	"if the hospital had where you could call in to a family who's gone through it or they reached out and said, "Hey, we hear that your daughter's just been diagnosed. If you have any questions, we're not experts, but our family has gone through it. If you need to reach out ever, then give us a call," that would have been helpful." CP002	3	3
	Reduced social isolation	"I don't know, I really question the stopping of the kid's sports and activities. I think in the years to come there's going to be volumes on the unintended harms of the pandemic restriction" WP002	3	3

Table 3 (continued)

Participant	Response Category	Example Quote	Number of Individuals	Number of References
	Shorter Wait times, more resources	"But again, we need to do something about the wait lists. It's astronomical. And where we live in particular, the only program that's covered by the government is the program at X." CP004	3	4
	Peer Support for Youth	"So, I think that would be the biggest thing is peer support. She hasn't reached out for any at this point, other than seeing her psychologist, but I'm learning that there's even a couple little things that are for the youth that have an eating disorder that she could participate in or go to. So, I just talked to her about it this week just to say… because I'm sure… that's why I said to her too, "I find it lonely, so I can only imagine you would find it extremely lonely – you know, you feel like you're doing this journey alone, that there's nobody else." So, I think that would be the biggest thing, just having other people to kind of talk to and come alongside and offer hope." EP003	2	2
	More treatment options (e.g., day hospital programs)	"Day treatment. Even that level of care, we don't have that here in PROVINCE. Like day treatment. Yeah, like a day treatment may have stopped her from getting that far. I don't know. But here we don't have day treatment. It's either you are home with your parents spiraling or you're crashing and you're admitted. So there's that in-between spot that we just don't have any treatment for that I'm really concerned about, that I think… because we would have had her in day treatment. If that was available to us, we definitely would have had her in that months before and maybe would have avoided the extreme lengths that this disease went to. I don't know. It's hard to say. Yeah." EP004	2	3
Clinician	Offering (or continuing to offer) virtual treatment	"I think more virtual education and meal supports would make a big difference. Where you have… because I know in the paediatric world, the Maudsley model, modified Maudsley, whatever it is, it is about parents taking charge of meal times. But I think that's really daunting even without COVID. So I think having the professional there but not there in their home environment could make a big difference to how we could support those families." EC003	4	4
	Improving Access to Services While Waiting (e.g. self guided, information)	"While people are on the waitlist, one thing that's super helpful is parents having access to even like self-guided interventions they can use, education, so that they are getting consistent information. And then when they are able to access treatment, they've already started those things, and it's not like the eating disorder has just worsened, worsened, worsened and then starting." CC003	3	3
	At least initial appointments in person	"I think having the ability to have at least initial appointments, especially when you're meeting a healthcare provider for the first time, in person would be really helpful. Because I think sometimes it doesn't hit home the same way when you're charging the family, for example, via Zoom."EC002	1	1
	Parent-only sessions, as part of regular treatment approaches	"I think as well, adding in even a couple sessions as part of eating disorder treatment, we don't often support parents, having like parent-only sessions to just validate them and support them. Whether that's through… Like some people will do well in a group-based setting, but some parents might have social anxiety or a lot of shame around that and not be willing to go. So I think being conscientious of that could be beneficial." CC003	1	1
Administrator	Access to an information session, information, and resources, especially as they are waiting for treatment	"So, we have a "while you wait to see someone, here's some of the things that you can take on yourself or look into and kind of do." So, that certainly would've helped in the beginning, but again, that's stuff that we've learned as we've gone through." EA001	3	5
	Offering (or continuing to offer) virtual treatment	"Well, I am a big advocate of the FBT skills group."… "It's something that we've adopted here at XX Hospital. It's done virtually, and it's done, really, to the parents. It's helping the parents to then help the kids in terms of recovery from an eating disorder. That has been very successful,…"… "…but the one problem with it is that it can't be provided solely virtually because the patients are followed by a physician, and the physician really needs to be knowledgeable in the FBT principles. So, really, the two go together." WA003	2	2

Table 3 (continued)

Participant	Response Category	Example Quote	Number of Individuals	Number of References
	Timely support/shorter waitlists	"I think honestly if we could have seen more kids faster it would have been helpful, but we just weren't in a position to be able to do that with staff taking leaves, understandably so, people getting COVID, not having space. I think there was just so many factors in play that if more kids could have received service and the waitlist didn't get so long…" CA004	2	2
	In-person care	"… if we could have started up our in-person appointments I think a little bit sooner. We didn't have our space. We were actually asked to leave our clinic. It became an ICU overflow during COVID. So we were kind of homeless for a while off and on. So I think if we would have had availability to offer more in person, that would have been helpful." CA004	2	2
	Practical Aspects (Workshop on how to use Zoom, Clear Communication on directives)	"One thing probably that could've been helpful is to have, actually, Zoom 101 – like, how do you actually sign on for your virtual care appointment – and actually maybe have, I don't know, a little workshop or something on things like that could've been helpful." EA002	2	2

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peer support for youth were discussed, including reduction in social isolation, having someone who understands you, and learning strategies for recovery. However, several potential risks related to exacerbating ED symptoms were also described, including triggering each other in a negative way, competing with each other, and learning strategies to become "more sick". Similarly, over half of the parents (9/15) described that they felt peer support for youth would be helpful, and raised similar concerns about the potential risks of youth learning ED strategies and competition. Some parents felt that peer support for youth should be delivered by a clinician. Clinicians voiced concerns about the readiness of youth peer supporters and wanting to ensure that they are "truly in a place of recovery". A small number of administrators were in support of making youth peer-support available, but also shared similar concerns about the peer supporter being properly vetted and trained in the peer support model.

Views on parental peer support

Over half of the youth commented that their parents could benefit from parental peer support (9/14) and most felt that these services should be routinely offered for parents (11/14). An even greater proportion of parents themselves reported that they would access this service if it existed (13/15) and all of the parent participants felt that it should be offered routinely within programs. Parents reported on possible risks and benefits of parental peer-support. Benefits included lessening social isolation and learning new skills to support their child. Possible risks of peer support described by parents included the risk of making unhelpful comparisons and perceiving to be negatively judged by others. The vast majority of clinicians were in full support of parental peer support (15/16), and over half felt it should be routinely offered (9/16). Over half of administrators were also in favour (7/12), but voiced some hesitancy, with some suggesting it required clinical oversight and would require funding. Only two of the twelve administrator participants reported that they felt parent peer support should be routinely offered by ED programs.

Discussion

This study adds to the literature on the impact of COVID-19 for those with personal or professional lived experience with an ED, and is the first to capture clinician and administrator views on peer support as a potential mitigating strategy. Interestingly, youth and parents most commonly spoke about the negative impact of social isolation and increased use of social media. Clinicians and administrators highlighted increased workload and burnout. Mitigating strategies were largely focused on reducing social isolation and increasing continuity of care through virtual care. Clinicians and administrators spoke about the implementation of virtual care as being helpful to continue to offer services during the pandemic. In terms of views on peer support, youth and parents were generally in support of this intervention for both youth and parents, although there were many more potential risks reported for youth and for the individuals delivering the peer support. Parents were resoundingly in favour of peer support for themselves and all parent participants recommended that parental peer support be offered routinely in pediatric ED care. Youth, parents, clinicians, and administrators were cohesive in their support of parent peer support groups, although administrators described caveats related to clinical oversight and funding.

Table 4 Views on peer support for youth, including benefits and risks from the perspectives of youth, parents, clinicians and administrators

Participant	Response Category	Example Quote	Number of Individuals	Number of References
Youth	Less alone	“… with the peer support you just wouldn’t feel as alone, and you would be able to talk to somebody about your experience without feeling ashamed of it or feeling that you’re the only one that’s going through it.” CY003	5	6
	Talking with someone who gets it	“Just having somebody who understands your point of view instead of having to try to explain to people what you’re thinking and why you’re thinking it. But with peer support, it would be like they know already and they get what you’re feeling.” EY002	7	9
	Learn Strategies for recovery	“it’s a good way to manage triggers, because triggers are a big thing that are brought up in peer support. So it’s a good way to overcome those in a safe space.” WY001	4	4
	Make friends	“And honestly you can make friends. I know it sounds weird, but like you meet other people and it’s really nice.” WY001	3	3
	Positive stories of recovery	“I think it was great to have a positive influence, to look up to someone who has recovered, and it gave me hope, strategies, and it’s everything.” CY002	2	2
	Motivating	“Like, I could look around, and I could be like, “Maybe I don’t want to do it, but that lady over there, she’s eating her food, too. She’s getting her calories in too, and she’s gaining weight, too.” WY005	2	2
	Could trigger each other or influence in a negative way	“I feel like it would maybe bring up maybe old feelings, because especially if you’re pretty deep into recovery and then there’s somebody new and then they’re talking about all their struggles, it might send you back there and remind you of everything you had to go through.” EY002	6	10
	Could lead to a competition	“Or just a big thing within eating disorders is comparison, and so if I see somebody that potentially looks more sick than me in my mind, I might say, “Oh my God. I’m not doing this right. I need to keep going.” WY004;	6	8
	Learning ED strategies or secrets from each other	“… they could share strategies they use to become more sick” WY004	4	4
Parent	Helpful to have and give the support and feel less alone with a shared experience	“Yeah, I think it would be definitely beneficial and great. I know personally that’s what helped me, whether they’re open to it or not. I mean, usually they’re not at the beginning. But I think being around other people that are also struggling through the same thing and you just… I guess they understand more what you’re going through. So I think that would be beneficial for sure, if they’re able to meet as a group.” CP005	9	11
	It depends on the kid’s stage of recovery and readiness	“Oh, that’s a tricky one because it depends on the kiddo and what they’re receptive for.” WP002	4	4
	Needs to be run by a professional	“You could not do that one without a professional moderator. A 100%. There’s no way. Unless you’ve got a professional there to moderate, I think you’re asking for more trouble than you’re going to get benefit from.” WP001	3	4
	Should be run by someone older and recovered	“I could see if it was… What I think might be beneficial is if that person with the eating disorder met – like a teenager – like somebody who’s between 18 and 30 who successfully recovered from eating disorder. That’s what I think would be supportive. Because at her age, and I can even see it for my daughter, who’s 15, her brain is a bit altered from the eating disorder and I don’t feel she could connect with another eating disorder person, like a peer. I don’t think the peers could help each other at this point.” WP004	1	1
	Learning ED strategies or secrets from each other	“Simply because, in my experience, kids learn well from other kids, and if somebody’s more severe with a disorder, you tend to get kids sharing more tricks that they don’t… that shouldn’t be shared.” WP001	10	12

Table 4 (continued)

Participant	Response Category	Example Quote	Number of Individuals	Number of References
	Competition of who is sicker	"I mean there's probably some that are not helpful, right? They start to introduce a level of competitiveness – "Oh, I'm sicker than you. I'm thinner than you are," that sort of thing, and that's horribly bad obviously. You don't want your child in that group." CP003	4	4
Clinician	Hearing from someone who has been there	"I think peer supports for teen and adolescents are so important so that we can share our stories. And I think they also help them stay accountable to the recovery. It's one thing to hear from me as a therapist. But I will say, hearing it from someone besides your therapist, even if I do have my own lived experience, hearing it from someone else is so powerful." CC004	3	3
	Depends on factors regarding the peer supporter (e.g., their stage of recovery, developmental stage, amount of training/screening)	"I would want to ensure that the peer support individual or the person leading the group, for example, is truly in a place of recovery and will be able to catch and pick up on even some of the subtle comments that patients in treatment often make around body image and eating and recovery and address that. And I would hate for any of the eating disorder behaviour to be normalized by the peer support worker or group leader because they've been in their illness for so long that maybe they don't see that that…." EC002	9	9
	Anxious about competitiveness	"I struggle with the idea of peer support in the eating disorder world in general because of the psychopathology of eating disorders and the fact that it's competitive by nature. I think when the people in the room are in the space to use it appropriately, I think peer support is always good. I'm a huge supporter of peer support model of care in general. I would worry about it in the context of paediatric eating disorders because of (a) where their brains are at in development and then that very insidious, competitive nature of eating disorders…So, peer support for teenagers with eating disorders makes me anxious." CC002	2	2
Administrator	Sharing experience	"I think it's fantastic. I really do support peer support. " "I see it for different reasons, right? I think, for the youth, for peer-to-peer with the youth, I think they then get to talk to somebody else who's kind of gone down that rabbit hole and has came out the other side and not unscathed and not perfect and probably lots of scars and wounds and trauma still, but still made it to the other side and can share that experience" CA002	4	4
	Depends on factors regarding the peer supporter (e.g., their stage of recovery, amount of training/screening)	"I think the challenge with any peer support model is ensuring that those that are in the peer role, that they themselves are in a healthy place with their own recovery." WA001	4	4
	Depends on factors regarding the youth needing support (e.g., their ED stage, ED type)	"So, in order to do that piece, you really need to understand where each adolescent child is in their journey, and their parents. It's a bit more work, I think, than just bringing a bunch of kids together and then setting them around and, "Let's chat about stuff," because it's such an individual journey for them, and it depends on their severity of their condition and those kinds of pieces." EA001	1	1

Table 4 (continued)

Participant	Response Category	Example Quote	Number of Individuals	Number of References
	Requires clinical oversight	"I think it has to be managed by professionals. I think it would be great if it's able to be done right, and so there's specific topics. There's kind of rules and guidelines on what we talk about and how we talk about things. And I think it's important to also have people with lived experience who are on the other side and able to really speak to what that's been like, yeah." CA005	1	1
	Anxious about competitiveness	"Well, if you'd asked me that before I started in eating disorders, I would have been apprehensive about two people with like… well, I shouldn't say that. I find that eating disorders, it's very competitive. They're competitive with each other. So I would have to temper my opinion of peer support, was it helpful or was it more detrimental? Where you wouldn't think of that in the medical world. We have groups of diabetics who get together and share their experiences and help each other. Where can you buy this equipment? Or what was helpful with your circulatory problems?" WA002	1	1

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Our findings map onto previous literature describing the impact of the COVID-19 pandemic on those with lived experience with EDs. Obeid and colleagues [37] completed a survey followed by qualitative interviews and discussion groups on the impact of the COVID-19 pandemic with youth, primary caregivers, clinicians and decision-makers. With a focus on the financial and social impacts of the COVID-19 pandemic, results of their work highlighted financial costs of private services, transportation, and the inability to attend school or work as influential on the well-being of those with lived experience of an ED. Clinicians and decision-makers mentioned increased work expectations along with turnover to private practice [37], which was also noted in our study. In their study investigating virtual care, Novak and collegues [38] also noted that clinicians reported strain related to responding to increased ED-service demand with insufficient resources.

Little work has been done on exploring the potential mitigating factors for the COVID-19 pandemic and its aftermath. Youth and caregivers in our study mentioned enhanced educational efforts across the board in terms of healthcare, schools, and the general public. They also mentioned increased social contact as a mitigation strategy for isolation. Youth mentioned that reduced access to social media would have been helpful. Some youth had creative ideas for having social time on Zoom as part of their virtual school day. Both groups emphasized peer support as a potential mitigating strategy. Clinicians and administrators mentioned virtual care as a mitigating strategy to maintain or improve the the availability of ED care, as well as being able to provide some sort of education to people on a waitlist for services.

Furthermore, our results resonate with others who study peer support, particularly for parents. Our participants, especially the parents themselves, resoundingly endorsed the need for parent peer support. This finding is echoed by Ohara and colleagues [39] who found that 87.3% of their survey respondents ($n = 314$) who were family members caring for a person with an ED indicated that they believed a group peer support system was necessary. Evidence is growing that peer support for those with EDs, but also for caregivers, can have a meaningful impact on well being and could impact treatment trajectory [24, 25, 30, 40]. The burden on caregivers of children with EDs is enormous [41] and calls for novel ways to enhance caregiver peer support are emerging [28]. A recent large survey of parents in Australia ($n = 439$) with a child with an ED reported worse psychological and physical health, (relative to parents who did not have a child with an ED), as well as significant financial impacts related to this caregiving role, including high work-absenteeism impacting on work (mean of 70 days missed from work) and out-of-pocket expenses ($10,000 to $20,000 AUD) [41]. Collectively, the evidence detailing the impacts of caring for a child with an ED has caused several authors to propose some key mechanisms to improve the health care system including parent peer support [28, 41]. Although the COVID-19 pandemic has officially been declared "over", the ramifications continue to exist with long waiting lists and continued parental burden [28, 41]. Creative solutions are needed to help overcome these ongoing issues.

In order to address the concerns about peer support raised by participants in this study, we recommend that peer support be formalized in that peer supporters in eating disorders have completed a training program, are supervised on an ongoing basis and have a minimum of two years of recovery, or in the case of parent peer support providers, that they are two years beyond the

Table 5 Views on peer support for parents from the perspective of youth, parents, clinicians and administrators

Participant	Response Category	Example Quote	Number of Individuals	Number of References
Youth	Learn Strategies	"And so I feel like it could be not only beneficial to them but beneficial towards us, because although most parents I hope have best interests of their kids, for example my mom, but it's hard to navigate what is a good move to make and what's not because everything can be so tricky." CY002	9	9
	Less alone	"But yeah, I think it would be really helpful because, just as we're alone, they're really alone too, and it's hard too because I feel like they don't know what is helpful, what is not." CY002	7	9
	Manage Emotions	"I know that my mom talking to… she had… like, the friends that I was talking about, their parents were talking to my mom. And I know that it was just very, very good for her. She was able to kind of vent about her… rant about her experiences to her friends. I think that that would be so helpful for parents that are going through it because it's so hard for parents to see their kids struggle that much." CY003	2	2
	Not helpful - overwhelming	"… they went to the eating disorder support group, and they came back and they were like, "I don't know if I can do that again," because it's extremely overwhelming to go to this group of people and hear all these horrendous stories because eating disorders are horrendous things. They ruin everything." WY005	3	3
Parent	Decrease isolation	"With eating disorders, I feel like, even now, it's pretty secretive. I find it very private, for myself, just from a protection side of it for my child. But I think it's important to have people to talk to and talk about it with so that you don't feel so alone." EP003	11	14
	Acquire knowledge, solutions, and information	"Practical living advice, not booky "This is what it is," but the nitty-gritty of living with the person." WP001	12	14
	Feel understood	"But also a reality check of, "this is hard". A safe place to cry and to say this is really, really awful and to know that someone who has lived in this bizarre, upside down world can hear and understand you because it's bizarre." WP002	6	10
	Decrease guilt and shame	"Like, I think it's going to lift… it'll lift shame and guilt. And with shame and guilt out of the way, that person will feel more empowered to walk with their child and tackle it." CP004	1	1
	Recovery Stories	"… sometimes there's recovery stories on there, which on the bad days gives me motivation to keep going because I love hearing the recovery stories. [laughs] It hopes one day that we'll be there too." EP005	1	1
	Not as bad as others	"In some ways it allows me to feel thankful that we are where we are, because we've never had to be tube-fed and never had… like he's never not eaten anything, just eaten very little, never thrown up, never binged or purged. So in some ways, when I read it, I feel thankful that we could be in a worse place than we are." EP005	1	1
	Reducing stigma	"Reducing the stigma." WP002	1	1
	Empowerment	"Feeling a set of… feeling almost the ability to become empowered. Inspired." WP002	1	1
	No healthcare professionals	"… or most of us aren't health care professionals and we all have differing opinions.… But I guess at some point there just has to be trust about it. Like we're all just parents with sick kids who really need each other" CP002	6	6
	Feeling sad, upset, or desperate after hearing other parents' negative stories	"… there is an element of sadness and despair when you hear some of the worst stories. Even if that hasn't happened to you yet or may never happen to you, but your mind immediately goes to "Well, they probably didn't think it was going to happen to them too, and now look." So that part wasn't great. That part actually left you sad." CP003	4	5
	Formal Training	"Oh yeah, you'd have to vet your leaders extremely well. I think you'd probably have to give them some sort of formal training. They'd have to have experience in conflict resolution. They'd have to know how to mediate, and if things were getting to be offtrack or inappropriate, they'd have to be able to shut it down. So you'd have to have somebody strong enough to be able to [think 27:43]. And just the dynamics. You'd have to make sure that the group worked, because there's people sometimes that just don't work well together. You get somebody who talks nonstop and then somebody who just sits." WP001	3	4
	Feeling judged by other parents	"So if it was a local community, you wouldn't want all the other parents judging you." EP001	2	2

Table 5 (continued)

Participant	Response Category	Example Quote	Number of Individuals	Number of References
	Breach of confidentiality	"The other thing I think too is that the other risk probably would be risk of more disclosure than could be helpful. If the child doesn't know that their parents are disclosing this all about them and it got back to them, I think that could be a problem. I'm not sure how that would happen. Confidentiality would be huge. You'd have to make some sort of agreement." WP001	3	3
Clinician	Prior experience	" We have an eating disorder foundation here in PROVINCE [39:24] that was developed by a family who had lost a child to an eating disorder. And they have been offering for many years now peer support groups. So the people that ran those groups were individuals who had children with eating disorders in the past." EC003	4	4
	Should be organized by treatment received	"The danger with the parent support is if you are getting family-based therapy, it would be best to have someone in the peer support leadership that knew family-based therapy and knew the "why you do this" and how it works and all of that." EC004	1	1
Administrator	Prior experience	"At XX Organization, [0:31:21] our therapists were running a support group for parents, and I think it was maybe 12 or eight sessions long, and then after that, the parents themselves decided to carry on with their group. So, in a way, it's kind of like a grassroots peer support program and where they have been inviting other parents into it." WA003	2	3
	Depends on child's stage of recovery	"I think parents find it extremely helpful when they have someone who is further along in… or their loved one is further along in recovery. For those that are in their initial stages of recovery and they're so brand new to eating disorders, I don't feel that would be helpful to another parent. In fact, it can be very confusing for them, and it doesn't broaden their lens on recovery" WA005	2	2
	Should be organized by type of treatment received	"o, that's why I wonder about the matching. Would it be helpful to have parent support for children who have been hospitalized, parent support for children who have been in FBT, parent support for children that have been in CBT-T?" EA002	1	1
	Requires Clinician Oversight	"If I tell you that it's going to be okay, as a clinician, as a unit manager and I'm telling you the parent, I know it's scary but it's going to be okay. That's one thing. But if I were a parent who has been through it with my child and I tell you it's going to be okay, I think there's more substance to it, more believable. And so I think moving outside of… or cracking the door open for somebody who is not a trained professional, is a little frightening. It can go really, really well, but I suppose it could go really, really badly as well. So maybe there's some apprehension there. But just… we've sort of intuitively been heading towards peer support just because we're seeing little slips of success. Like, we didn't go out and say, geez, we want you guys to be peers and support each other. It's been happening, just organically happening. And so we're seeing the benefit of it. So why not get behind it?" WA002	2	2
	Requires Funding	"That would be awesome if we had the funding. [laughs] Yeah, I would love to do that." WA005	2	2

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recovery of their child. These criteria are currently standard recommendations within many peer support programs that exist in Canada. Certification in peer support is available through Peer Support Canada and would be recommended (see Peer Support Canada www.pscportal.ca). These training programs address boundaries, self care and the narrative style of support that is non-clinical in nature. We believe that these elements would enhance confidence in peer support as a safe and valid intervention on the continuum of care for eating disorders for youth and parents.

Our research has several strengths in that this was a national and diverse sample of stakeholders from across Canada. Seven provinces and one territory were represented. Youth largely reported a diagnosis of AN, however, clinicians and administrators reported experience delivering care to individuals and families with a range of ED diagnoses. Private and public health systems were represented. Clinicians were composed of a group of a variety of different disciplines. The data collected from youth, parents, clinicians and administrators provides a comprehensive view of the impact of COVID-19 pandemic, strategies for mitigation, as well as the potential for peer support to support the pediatric ED care continuum.

In terms of limitations, our sample was comprised of primarily white and female participants. We recruited through national ED organizations and may not have been able to reach vulnerable and equity deserving populations. It would be important to understand further how the views of fathers, as well as boys and gender diverse youth might differ or align with our current findings.

Conclusions

Our study sheds valuable light on the impact of the COVID-19 pandemic on those with lived experience with EDs, as well as clinicians and administrators working in this field. The potential mitigating factors are still relevant as strain from the pandemic remains. Decreasing social isolation, increasing education, and access to care while limiting social media are strategies to improve ED symptoms. Although views on peer support varied amongst this participant group, there was unanimous support to move forward with the implementation of parental peer support routinely, with the caveats of proper training, oversight, and funding. Our findings indicate that peer support should be considered as a component of the continuum of care for youth and parents of youth with EDs. Standard training programs for peer support providers is needed in order for administrators and clinicians to feel confident with its implementation within their programs. Funding for peer support providers also needs to be available. Futher research is needed to provide evidence of cost effectiveness and added benefit of peer support to traditional models of care. This evidence would also be helpful in advocating to policy-makers for obtaining training and funding for peer support providers.

Supplementary Information

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Supplementary Material 1

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Author contributions

This project was developed by JC along with contributions from MN, CW, GD, NO, MK, TL, AMC, EC, SJ, SM, CT, WP, GM, and LW. JC took the lead in drafting the manuscript. Subsequently, all authors actively participated in the critical review and provided valuable insights to enhance the intellectual content of the paper. Their collective efforts contributed to the final approval of the manuscript before its submission. All authors have carefully read and approved the final version of the manuscript, signifying their agreement with its content and findings.

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Data availability

Due to privacy and confidentiality concerns, de-identified data is only available upon request.

Declarations

Ethics approval and consent to participate

This study was reviewed and approved by the Hamilton Integrated Research Ethics Board.

Competing interests

The authors declare no competing interests.

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