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On the Journey: a qualitative study of a community-based, client-centred eating disorder recovery group

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Abstract

Background Community-based eating disorder (ED) treatment frequently includes manualized group-based psychoeducation facilitated by a mental health clinician. Body Brave, a non-profit ED organization, developed a novel, participant-guided, community-based virtual healthcare provider (HCP)-facilitated support program called On the Journey (OtJ). The program was designed for people with longstanding EDs who had previously participated in group or individual ED programs but require continued support in their recovery. The purpose of the study was to describe the development and components of OtJ and to understand participant perceptions of the program and its effect on their recovery.

Methods Using a formative and community-engaged research design, we conducted semi-structured interviews with three OtJ facilitators and focus groups with twelve OtJ clients. Transcripts were analyzed using Braun and Clarke's six-stage approach to reflexive thematic analysis.

Results Four main themes were generated from the data (1) "Designing and Evolving OtJ" (2) "Is OtJ a Treatment or Support Group?" (3) "Fostering a Safe Environment throughout Program Delivery" and (4) "The Power of Lived Experience." Clients noted several strengths of the OtJ program: fostering a sense of community, valuing client autonomy, and providing accessible ED support.

Conclusions Key considerations for other organizations looking to offer programming similar to OtJ include having skilled and clinically trained facilitators and prescreening discussion topics to ensure that conversations are productive towards recovery. OtJ supports people with longstanding EDs, and other organizations could consider adopting a similar model of care. This study contributes to the growing body of including lived ED experience in research.

Plain language summary

On the Journey (OtJ) is a community-based eating disorder (ED) support program that is facilitated by healthcare providers. It was created by Body Brave, a non-profit organization from Hamilton, Ontario, Canada. This program is for people who have had an ED for at least two years and want low barrier support from a qualified clinician and others facing similar struggles as they continue to recover. This study describes the creation and implementation of OtJ and describes themes from interviews of clinicians and focus groups with clients of the program. Four main

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themes were identified (1) “Designing and Evolving OtJ” (2) “Is OtJ a Treatment or Support Group?” (3) “Fostering a Safe Environment throughout Program Delivery” and (4) “The Power of Lived Experience.” Other ED organizations could consider implementing a similar program for their clients with longstanding EDs looking who are seeking accessible support.

Keywords Eating disorder, Disordered eating, Treatment, Community, Virtual, Support, Recovery, Qualitative

Background

Eating disorders (EDs) are serious mental illnesses characterized by disruptive behaviors and attitudes involving eating, weight, and body shape concerns [1]. In Canada, an estimated 2.9 million individuals are affected by an ED, such as anorexia nervosa, bulimia nervosa, binge ED, or other eating-related concerns [2]. EDs can have vast physical, psychological, and social impacts, contributing to poor quality of life, and are associated with some of the highest mortality rates of any mental illness [2], second only to the opioid crisis [3].

With timely access to quality treatment, approximately 52–80% of individuals recover from EDs [4]. However, there is a significant treatment gap between those who need treatment and those who are able to access the appropriate services [5]. Fewer than 20% of people with EDs receive specialized healthcare, and up to 49% of women, and 31% of men access support [6]. High costs of treatment, stigma surrounding EDs, and a lack of mental health literacy regarding warning signs and symptoms of EDs contribute to this gap in access to care [7]. Moreover, those who do not meet the stringent diagnostic criteria for an ED experience additional barriers to diagnosis and subsequent treatment pathways [8]. Designing programming that addresses these barriers (such as stigma, treatment cost, and poor mental health literacy) is of utmost importance to promote accessible treatment and support.

Psychological therapies, such as cognitive behavioral therapy-enhanced (CBT-E), are typically the first-line treatment to reduce ED symptoms, offered as structured, and often group-based, sessions in hospital-based treatment programs [9]. There is a need for continued support after discharge from intensive treatment programs, including relapse prevention programs and community support [10]. Virtually led programming and support has become increasingly popular due to COVID-19 and has been shown to be an accessible and effective way to deliver care for adolescents [11].

Though the definition of community-based programs is not widely agreed upon, Body Brave (described below) defines this as treatment and support services which are integrated within the community (versus in formal healthcare settings) to meet the diverse needs of clients who are at different points in their recovery journeys [9]. Community-based treatment and support for EDs does not necessitate access to hospital, though it can involve interdisciplinary collaboration between non-HCP

personal caregivers (e.g. family members), physicians, and other healthcare providers. This facilitates low-barrier and contextually tailored treatment and supports [12].

The involvement of lived experience within ED treatment and support can be valuable to participants and is encouraged as part of quality standards for ED care in Ontario, Canada (Ontario, 2023). There are several advantages of integrating lived experience in ED programming (i.e., peer leaders as part of co-design or co-delivery of services) including: fostering a sense of normality, comfort and reciprocity among clients, as well as reciprocity between clients and facilitators [13]. Trained peer leaders have successfully implemented ED prevention programs (e.g., the Body Project), both in-person [14], and online [15]. Although the inclusion of lived experiences can be valuable, some researchers have highlighted strategies to safeguard experiences (e.g., encouraging peer leaders to be trained in an allied health profession) [13].

Low barrier community-based support is in line with the stepped care model of mental health support which is an integrative approach that begins with low-barrier and accessible interventions and escalates to more intensive options as necessary [16]. Stepped care can be a cost-effective solution for health systems and can incorporate evidence-based strategies (i.e., CBT-E) and dialectical behavioral therapy (DBT) [17] to tackle mental health challenges such as EDs or disordered eating (DE) in a way that focuses on early intervention and preventing need for hospitalization [16]. Stepped care models can also help ensure continuity of care for folks with EDs and DE, as they can be stepped up or down based upon their needs [13]. Outpatient group-based programming can be tailored to meet the needs of people at different points in their recovery journey, which may foster the continuity of care that is needed when stepping down from higher intensity to lower intensity treatment. Community based services are one approach to bridge the gap between intensive care and prolonged recovery from an ED [10].

Body Brave is a nationally registered charitable organization (Charitable Organization No. 797943115 RR 0001) in Hamilton, Ontario, Canada that focuses on advocacy with and support for individuals with EDs or DE. Body Brave offers low intensity community-based group ED treatment and support led by healthcare professionals (including physicians, dietitians, social workers, etc.).

The stepped care model which Body Brave employs is depicted in Fig. 1: Adaptive Intensity of Care in Eating Disorder Treatment: The Stepped Care Model. Further, programs and services are provided at no cost, with the majority offered virtually, thereby providing accessible options relative to other local or provincial treatment programs. In 2017, Body Brave care providers developed On the Journey (OtJ), a healthcare provider (HCP)-facilitated support group, to continue helping clients who had completed structured treatment programs or initial support group offerings but needed continued follow-up through their recovery. The OtJ can act as a supplement to other supports at and in-between points of care modelled in Fig. 1 and can also be considered as community-based group programming within this model.

Body brave creating on the Journey

OtJ was developed as a closed group program for individuals in later stages of recovery who had previously attended treatment or support programs (offered at Body Brave or elsewhere). The OtJ program covers topics chosen by the clients for maximal relevance, and these are supplemented with evidence-based resources and psychoeducation such as CBT-E and DBT [9]. The Mental Health Commission of Canada emphasizes recovery as a journey which supports individuals living with mental health conditions to live a fulfilling, hopeful, and satisfying life [18]. In alignment with this practice, facilitators screen topics for OtJ to ensure the program fosters the

health and well-being of clients. For example, if clients request to talk about guilt and shame, the facilitator would ensure that this would be done in a way that honors evidence-based psychotherapy, whereas they would avoid talking about individual traumas as a main topic as that would not be appropriate in a group setting without a trauma therapist. The creators referred to the OtJ group as a “pod” in reference to a group of dolphins, a term used within existing ED research [19], as they swim alongside each other as they traverse their individual journeys. The creators felt that this was an inspiring metaphor and image of individuals connecting with others in community to travel on journeys together.

Below are details about the structure and evolution of the OtJ program:

1. Group size: Initially, groups had 4–8 people, which would maximize the sense of intimacy and community within the group. This initial group size was consistent with previous in-person programs successfully offered by Body Brave in terms of balancing client participation opportunities and fostering a supportive group environment. Group size expanded to 11–15 people meeting online during the COVID-19 pandemic to address increasing demand for services. All group offerings are closed versus drop-in and include the same participants for the entirety of the offering.

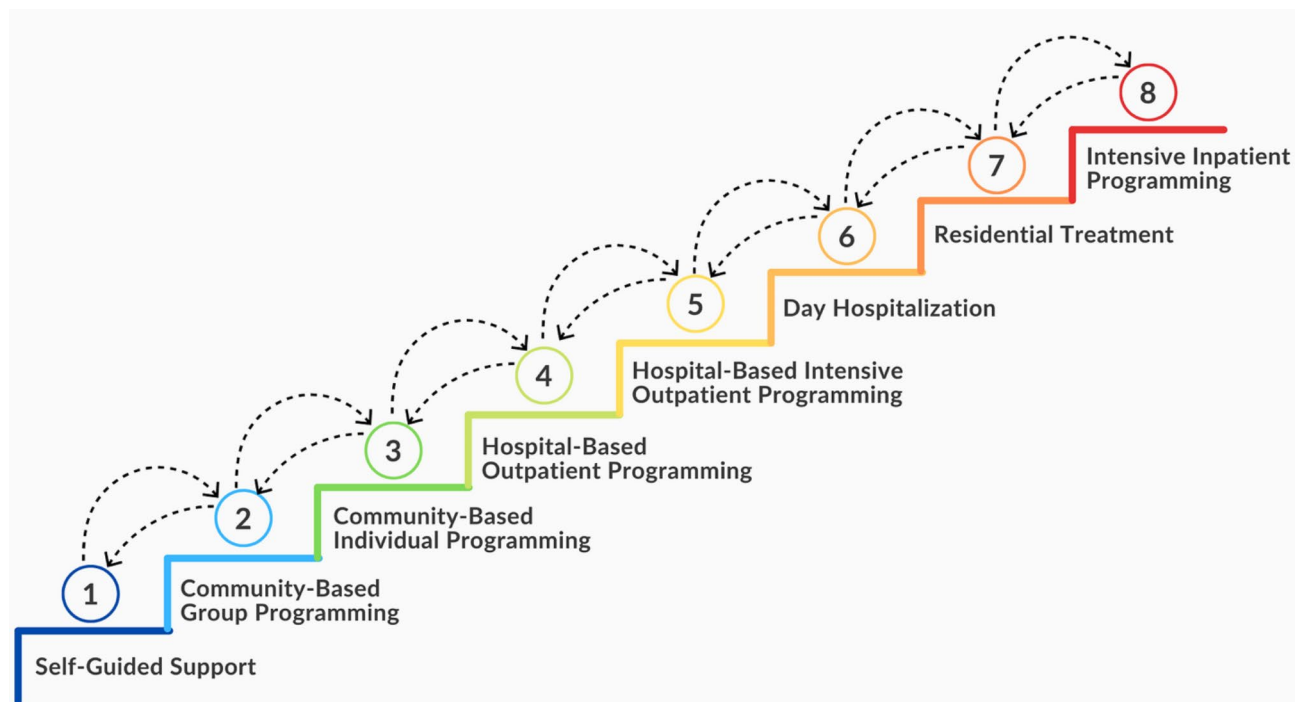


Fig. 1 Adaptive Intensity of Care in Eating Disorder Treatment: The Stepped Care Model

Table 1 OtJ session structure

Component	Description
Introduction (10–15 min)	· Group check in with facilitator. Clients can respond verbally or in chat or elect to pass.
Topic (1–15 min)	· Facilitator introduces weekly topic (as brainstormed by group during the first week). This topic is consistent and within the scope of the weekly facilitator. · Inclusion of brief prepared content from the weekly facilitator (e.g., handout, video-clip).
Discussion (20–30 min)	· Open discussion about the weekly topic. Conversations moderated by facilitator. Clients can participate verbally or using the chat.
Conclusion	· Wrap-up of session.

Table 2 Interview Guides for facilitators and Focus groups**Interview guide for facilitators**

(Guiding Question) How has your experience been with On the Journey?

1. When did you start working as a facilitator for the Body Brave on the Journey Pods?
2. What are the components of the pod sessions you have facilitated?
 - a. Have there been common themes that have emerged?
3. What were your expectations going into this position? Were those expectations met?
4. Can you tell us about the group dynamics?
 - a. Can you describe some successes you've observed in the group?
 - b. Were there challenges experienced in the dynamics of the group?
 - c. What improvements could be made to mitigate those challenges?
5. What types of strategies did you find helpful as a facilitator? What strategies did you try that were not helpful?
6. Do you believe that the training/information/support that you were given before and during facilitating the pods was enough to prepare you? Is there anything that you wish you would have known before starting as a facilitator?
7. Is there anything else you would like to tell us about your experience in facilitating the pods?

Client focus group guide

(Guiding Question) How has your participation in the On the Journey Pod affected your recovery? What do you see as the value of the pod approach?

Follow up questions:

1. Could you tell us how long you've dealt with your ED and when you started with On the Journey?
2. What were your hopes or expectations when joining OTJ/this program?
 - a. Were those met?
 - b. If not, can you tell us why you think they weren't?
3. What aspects of the program did you like?
4. What did you not like?
5. Did you have any concerns about the program? (prompts: as you prepared, during the program, or related to how it was delivered?)
6. What would you change?
7. How does this program compare to other programs you have taken part in (at Body Brave or elsewhere)?
8. Was there anything that you wish you had known before joining the program?
9. If another person were to consider joining this program, what would you tell them?
10. Is there anything else you would like to tell us about your experience?

2. Selection criteria: Reserved for individuals identified by a clinical team member based on completion of Living Body Brave (a manualized initial program offered at Body Brave) or a formal treatment program at regional hospitals, thereby including clients at similar stages of recovery, allowing for exploration of participant-relevant content.
3. Content: Discussion topics are derived from a brainstorming exercise during the first meeting to identify those most of interest to the current group. Group facilitators review the topics to ensure that the content remains pro-recovery and rooted in evidenced-based ED interventions. Content ranges from practical skills-based tools and interventions (e.g., cognitive restructuring, chain analyses, social integration, and cognitive remediation) to addressing difficult emotions such as shame and guilt. Facilitators organize topic and theme suggestions into a curriculum for the remaining weeks, identify evidence-based materials to include, and arrange for support from other Body Brave HCPs to facilitate relevant discussions as needed (e.g., registered dietician for nutrition-based topics). All groups have support from the chief medical officer at Body Brave.
4. Facilitation: During all sessions, there are two facilitators; both are registered HCPs (e.g., physician, dietician, psychotherapist) with clinical training. The group is client-centered, encourages discussion, and values the lived experience of clients. Details of the structure of the 1-hour sessions are provided in Table 1. The original components of the pod are included as supplemental materials.

Aims

The aims of this research were to:

1. Understand the origin, development, and evolution of the OtJ program model;
2. Describe the components of the OtJ model of care;
3. Understand client and facilitator perceptions and experiences of the OtJ program.

Methods**Study design**

We used a formative approach to investigate experiences with a community-based HCP-facilitated support group, OtJ, which included individual interviews with facilitators of the support group, as well as three focus groups with OtJ clients. Formative research involves the combination of data collection and analysis alongside program development, and aims to aid in the establishment of accessible, culturally and geographical relevant

interventions [20]. In the present study, integrated feedback from both the professionals facilitating the support groups, as well as from clients who participated in the OtJ program were analyzed by the research team, and, in turn, provided back to Body Brave to inform OtJ improvements. The research team did not include study participants (clients or facilitators). Ethics approval was received from the Hamilton Integrated Research Ethics Board (project #13445) prior to study recruitment.

Procedures

Recruitment

First, three active OtJ facilitators/creators (referred to as facilitators throughout) were invited via email by CL to individual semi-structured interviews; all three accepted and completed an interview. Following recruitment and data collection from facilitators, clients who had participated in OtJ during Spring 2022 were recruited. During OtJ sessions, the group facilitators asked clients if the principal investigator could contact them through email about a research study. Those who agreed to be contacted were sent an email that briefly described the study. Of 22 clients who were contacted, 12 expressed interest and participated in a focus group. Of the other clients contacted, six did not respond, two declined interest and two had scheduling conflicts.

Data collection

Clients and facilitators were given a copy of the informed consent form via email prior to participation, and they provided verbal consent at the beginning of the focus groups and semi-structured interviews. Interviews with facilitators ($n=3$) were conducted in July 2022 and focus groups with clients were conducted between October 2022 and January 2023. Semi-structured interview guides were developed by the research team for interviews with facilitators and focus groups with clients. The questions were generated by the research team and designed to be open-ended. The wording and flow of questions were rearranged during the creation of each interview guide. Semi-structured interview guides are presented in Table 2.

Focus group participants were offered to be entered into a draw for a gift card. All interviews and focus groups were conducted over Zoom, and facilitated by CL, the research director at Body Brave. For the interviews with facilitators, a member of the research team attended, took field notes, and asked additional questions. For the focus groups, at least one additional member of the research team was present to take field notes and ask additional questions if needed. All sessions were audio recorded and auto transcribed verbatim, and then cleaned. Numbers were assigned to participants to identify and anonymize the data which are presented in

participant quotes in the results (F=facilitator, FG=focus group number, P=client number).

Rigor

Throughout data collection and analysis, the research team included rapport building, reflexive journaling, and field notes for trustworthiness; keeping an audit trail for dependability; and the use of quotes for transferability. Triangulation across data (transcripts, journals, audio recordings) was incorporated into the analysis.

Data analysis

Data from interviews with facilitators and focus groups with clients were analyzed together. This decision was made during the coding process as initial codes generated from both participant types fit into similar subthemes which could be developed into meaningful themes that cohesively represented the data [21]. Interview and focus group transcripts were analyzed using Braun and Clarke's six-stage approach to reflexive thematic analysis [22, 23]. Reflexive thematic analysis was used given the focus on participants' subjective experiences with OtJ [24]. This process includes (a) data familiarization, (b) coding the data, (c) initial theme generation, (d) reviewing and developing themes, (e) refining, defining, and renaming themes, (f) producing the report [21]. The data were coded inductively, by assigning short phrases (or nodes) to data within each transcript using NVivo 12 (QRS International). NVivo was used solely for the organization of codes. Three authors first coded the transcripts independently. They then met to address and discuss codes and their individual biases. The authors met weekly to organize the codes into themes and subthemes. This approach is consistent with previous studies conducting group analyses of qualitative data via reflexive thematic analysis [25]. The research team met bi-weekly to generate initial themes by collating codes across all transcripts [23]. Two members of the research team acted as *critical friends* [26] which included challenging theme definitions and names. In congruence with the quality practice of reflexive thematic analysis [23, 27], themes and subthemes were created based on the unique and meaningful data generated from the transcripts. Final themes and subthemes were re-worked and renamed throughout the writing process. Members of the team engaged in reflexivity about their own connection to the research project and recognized how their own experiences with Body Brave may have influenced their interpretations of the results (See [supplemental file](#) – Author Reflexivity).

Content covered in OtJ

To provide context to OtJ discussions, we conducted a word frequency analysis and word cloud visualization of the most frequently covered topics within OtJ groups.

For each OtJ group offered between January 2020 and May 2022, weekly topics were extracted from group curricula documents and organized in a comprehensive master list. Repeating topics were documented in accordance with the number of times they were present. To depict the frequency of the topics discussed in OtJ groups, a word cloud was generated using Wordle [28], a software that creates word clouds from text provided by user and places more emphasis on words that occur with greater frequency.

Results

Three facilitators, two of whom co-created the program, were interviewed, and four focus groups that included 12 OtJ clients were completed. Across all transcripts (facilitators and clients), four overarching themes were generated: (1) Designing and Evolving OtJ, (2) Is OtJ a Treatment or Support Group? (3) Fostering a Safe Environment throughout Program Delivery and (4) The Power of Lived Experience.

Theme 1: Designing and Evolving OtJ

This theme encompasses how facilitators designed and evolved OtJ across multiple seasonal offerings and includes three subthemes: (a) *different from traditional treatment programs*, (b) *evolution and feedback loop: OtJ is constantly evolving* and (c) *Not a quick fix: repetition of the programming*.

Different from traditional treatment programs

Through their experience at Body Brave, facilitators identified gaps in current treatment offerings for clients with EDs and DE. All facilitators perceived that it was important to foster a sense of community for clients during their recovery, and the formatting of a new program to fill existing gaps. In addition to fostering a supportive environment, the facilitators expressed the importance of having a group for individuals who felt stuck in their recovery journey and who had experience with previous treatment programs. In addition, this program was designed to support people who had “fallen through the cracks” with their recovery. The facilitators discussed shortcomings of current programs, which inspired the creation of OtJ. Gaps in current programming included manualized programs, which were not helpful for all clients. One facilitator explained that OtJ was designed to offer something different, stating that:

“So, I think the idea was really like let’s create something different. We’ve got these curriculum-based groups and that’s great and there’s some people that don’t want that. They don’t need that anymore” [Facilitator (F) 3].

During the inception and development of OtJ, the facilitators recognized and respected participant autonomy and role in their own recovery, which was an integral component of the program. Clients taking part in the OtJ supported this approach. For example, one client greatly appreciated that OtJ was unique and unlike other programming available, stating that:

“The whole medical world is obsessed with CBT [cognitive behavioral therapy], like nobody wants to really give people space or... work with people in a way that’s relational or involves like choice or non-direction or is just supportive. I feel like there’s such a push always for everything to be manualized and so I actually really appreciate it [on the journey] that it’s not [manualized], because I really think that [manualized] it’s a real disservice, actually, to medicine and to psychotherapy and to treatment” [Focus Group (FG) 3, Participant (P) 3].

Evolution and feedback loop: OtJ is constantly evolving

Given its unstructured and un-manualized nature, OtJ has continued to be adapted since its inception to meet client needs within Body Brave’s capacity. Throughout the programs’ delivery, facilitators recognized the need to offer separate groups for restricting- and bingeing-related EDs. Although initially developed for individuals with previous treatment experience and individuals who felt “stuck”, the facilitators recognized that this stratification was too vague, as EDs vary widely.

“And so there’s a lot of stuff that’s similar about everyone with an ED, and there are some pretty significant differences as well... This is going to be the first time this summer that we’re going to split them and have On the Journey for bingeing and emotional eating and on the journey for restricting and purging”. [F3]

Another way that OtJ has evolved has been the expansion in group size to meet the demand for services. One facilitator identified this, stating that during the COVID-19 pandemic, it was no longer feasible to offer in-person group programming, and demand for services increased. Originally, OtJ was designed for a small group of individuals to foster cohesion. However, the program expanded to accommodate more clients due to increased demand. Despite this increase in group size, some facilitators indicated that the sense of connection and community remained strong. This was explained by one facilitator:

“We were thinking it would remain very small to preserve that sense of intimacy within the group”.

But, it's interesting that even though it is larger now [10–15 clients], people still seem to feel very much connected to each other" [F1].

Not a quick fix: repetition of the programming

Given that the OtJ program content is determined by clients in each group, no offerings are the same. Some clients said that this allowed them to choose their own destiny within the program. In addition, this resulted in clients being able to participate in multiple offerings of OtJ without redundancy. This was perceived as important to the clients and fostered a sense of support and options that are consistent with the long commitment required to recover (and maintain recovery) from an ED, opposed to "quick fixes." One client reflected on limitations of other programs, as she stated:

"Short-term interventions are [in]consistent with ED recovery, interventions [are] long and it must be necessarily long and committed. And, and I think that makes it difficult for programs and funding to come into existence and be sustainable – because these aren't short term interventions for ED recovery...so repeatability is important." [FG3, P1].

The client driven content of each offering allowed clients to repeat the program more than once, without information being completely the same each wave. This idea of repeated participation in the OtJ program was recognized as an asset by facilitators; one discussed this unique aspect as OtJ is seen as a safe space for clients to return to, rather than a failure to maintain recovery.

"It's similar individuals signing up you know, repeatedly for multiple rounds of on the journey, which I think is really cool, in that it shows that it's meaningful to them...Whereas in maybe another program, if someone kind of kept coming back, say to [hospital-based treatment program] – that may be an indication, like oh they're not doing well but for us seeing like all this person coming back to on the journey over and over... They're feeling maybe a sense of safety..." [F3].

Theme 2: is OtJ a treatment or support group?

Clients in the interviews and focus groups expressed uncertainty about whether OtJ would be considered a treatment or support group. This theme includes two subthemes: (a) *expectation mismatches* and (b) *tensions between censorship and support*.

Expectation mismatches

At times, throughout the evolution of OtJ, both clients and facilitators identified that their expectations were misaligned or mismatched. For example, during various offerings of OtJ, the facilitators perceived clients as wanting a space that fostered support and community. Through brainstorming topics of interest to curate content for each week of OtJ, the facilitators found that what they thought would be most pertinent and helpful for clients did not always align with what clients wanted to focus on. This was expressed by one facilitator:

"Initial assessment of what they wanted to work on and the topics they wanted to work on were quite different from what I imagined they would want to work on so they weren't interested in understanding more about what causes EDs, which was kind of expected, but they also weren't really very interested in working on, you know tools and techniques for overcoming the ED." [F1].

This contradicted what some clients thought of the program, expressing that they wished they had received more tools and treatment approaches. For example, though OtJ groups were considered supportive, some focus group clients expressed that material was redundant, and/or that it did not necessarily influence their recovery in terms of ED behaviors and symptomology.

It is important to recognize that perceptions regarding the lack of structure were not consistent across facilitators and clients. Although clients enjoyed, to some extent, the unstructured nature of OtJ, several also wanted more structure to the programming to address specific ED behaviors and symptoms. To better match their expectations, some clients recommended supplementing OtJ weekly meetings with additional activities and exercises to increase accountability with recovery-consistent behaviors including take-home activities, expressive art making and journaling.

Tensions between censorship and support

Some clients appreciated there were fewer rules within Body Brave's programming, including OtJ, compared with other treatment or support programs regarding what could be talked about. In this way, the groups sessions were more akin to a support group than a treatment group. For example, one client said:

"There seems to be some kind of, I don't know, gatekeeper system there [hospital treatment] that makes the environment a lot more sterile and so for that reason I do appreciate Body Brave that there's a comfort level of maybe a little bit more informality,

dare I say than other places, that's more inviting."
[FG 3, P1].

However, the rules set out about sharing experiences could also limit how freely they felt they could share. Although clients recognized the importance of keeping a safe environment, some mentioned that it was important for them to challenge their EDs by discussing sensitive topics that could be triggering. One client brought up the idea of "hyper fragility" saying: "I mean triggering is one very important thing to consider, but also leaning into the challenges that the ED presents is also important" [FG 3, P1]. Within other ED treatment programs and supports, clients expressed that strict rules around conversations conflicted with challenging ED thoughts and behaviors:

"It's really hard to actually talk in depth and like share openly about what's really going on and like actually challenge some of it, if you can't say that much...I don't know if it could have been like a more group negotiation." [FG 3, P1].

The brainstorming of topics allowed some clients to feel safer and more comfortable discussing more "taboo" topics. However, some clients recognized the dangers of self-selected topics. One client noted:

"I'm talking about that day with the topic was more about sexual kind of nature. I remember a participant at the very end had a very negative experience and I just feel like at the end when that came out there was this holy moly moment of why was this not caught ahead of time. Again, when you're dealing with things like rape or sex trafficking or big topics, you never know what someone is going through behind closed doors. And there was a sense of guilt, having talked so freely about the fun aspects. So again, I don't know if there's a way to screen it ahead of time." [FG 2, P2].

Theme 3: fostering a safe environment throughout program delivery

Theme three includes ways in which a safe and comfortable environment was fostered during OtJ. This includes three subthemes: (a) *the importance of facilitators*, (b) *advantages of the at-home online environment*, and (c) *fostering familiarity and community*.

The importance of the facilitators

The facilitators recognized the importance of their role in guiding client-driven content and moderating conversations and topics that were within their expertise and within the scope of OtJ. For example, one facilitator said:

"The topics that people want to cover are sometimes not necessarily appropriate for an online group, or sometimes...out of my scope. So, a lot of times people want to talk about trauma, which I'm not trained as a trauma therapist, and I also don't think like a zoom group necessarily is the place to go with that."
[F2].

Across focus groups, many clients expressed the importance of having qualified and experienced facilitators. Facilitators were perceived as key stakeholders in regard to maintaining client safety, which was demonstrated through the roles taken on by facilitators while delivering OtJ.

"I feel like I felt safer coming to group knowing that the facilitator is a professional and so that I knew that if things were going in a direction that was inappropriate that it would be stopped." [FG1, P3].

This sense of safety was expressed by most clients in relation to facilitators. However, the facilitators recognized struggles with the open-ended topics and less structured roles while leading online group sessions. One facilitator found it challenging to determine what topics may be more triggering than beneficial to clients. However, there were strategies (e.g., personal messaging online) that helped mitigate and address these concerns.

"I do find as well that it's hard to manage sometimes; if people are feeling triggered in the group often what we'll say is message the [second] facilitator who's not really talking right now and kind of to go with that and to be able to step out. You know, I think it's challenging because the things that we're talking about could be triggering in, are hard and at the same time like I think they're beneficial to people as well, like so." [F2].

Advantages of the online-at home environment

There were several benefits to the OtJ program being offered virtually. Initially, the switch to OtJ being delivered virtually via Zoom was due to COVID-19 social distancing policies that restricted in-person meetings. However, clients enjoyed the group being online as it reduced barriers to care – many of which exist beyond COVID restrictions — and fostered a supportive community. One common advantage noted by clients was the elimination of geographical and transportation barriers. Many clients lived beyond driving distance to Body Brave's physical location, but they were able to access the services.

“All of us here [are from] very different geographic locations and, yeah, EDs from a personal perspective, are so isolating and tend to make your life so small that being able to connect virtually from wherever is great” [FG1, P2].

This connection to others also helped foster community and support. The online environment seemed to mitigate body image concerns and facilitate recovery-related behaviors, as one client described:

“It’s easier to hide behind a camera. There are body image issues and self-confidence issues that if it was in person, I’d be worried that I was stressed. And I feel like I get more in my head. Of course, there’s pros to being in person too. I’m just. I’m sitting hiding on a camera right now and I feel a lot more comfortable with that.” [FG2, P1].

This increased safety was also perceived and echoed by the facilitators.

“I think it’s partly because they feel often a bit safer being in their own home environment, you know they can have their support animal right with them, and they can turn their camera off if they’re feeling stressed, and they can just choose not to participate if they’re having a bad day. So, in many ways it makes them feel a little safer I think being online.” [F1].

Beyond synchronous videoconferencing, Zoom allows for chats where clients and facilitators frequently shared supportive messages with the group. Zoom functions were set up so that clients could not message each other. The chat feature was perceived as beneficial by all clients, allowing them to participate in conversations and support others without having to verbalize. This was explained by one client:

“Being able to kind of look over it myself, or type something in if I didn’t feel like speaking out...I really appreciated that and just the fact that, like you know, we could use the little reactions and such, you know, just provide a little something else.” [FG2, P2]

Fostering familiarity and community

Community and familiarity led to positive perceptions of the OtJ program. Several factors that helped foster positive experiences were shared. Most clients said that they enjoyed, and recommended continued use of, the closed-group (the same clients each week versus drop-in group)

style for OtJ. This closed group helped foster community and comfort within the program.

“And I don’t really feel comfortable in a drop-in group. I understand their importance and like the reason why they’re there, but I kind of have a tendency to be vulnerable. Or, I have a tendency to want to be vulnerable and then I pull back really far if I don’t feel like I can [be vulnerable]. On the Journey helped me to recognize that like my pain and my struggle was worth examining and worth treating and that it’s possible to do that. So I really, I can’t overstate that, honestly.” [FG2, P2]

Feeling supported by like-minded individuals was perceived as beneficial and motivational in working towards recovery, and the online format fostered community and connectedness, which was important for clients as it allowed them to share experiences and broaden their perspectives. For example, one client said:

“There was this community feel of pulling resources together and being able to kind of share your own experiences at the same time pull from others as well, which I think the experience aspect was more powerful in this group as opposed to other groups where you’re learning more about ways to deal with things...” [FG2, P2].

Theme 4: the power of lived experience

An integral aspect in developing OtJ was promoting and recognizing client autonomy in their own care and that they guided the content covered in each offering of OtJ. Not only did the brainstorming process allow for a breadth of topics to be covered, but it also meant that each offering of OtJ was different. Figure 2 is the word cloud for the content covered across offerings of OtJ which depicts the breadth of topics discussed during OtJ. Some of the most common topics included body image, self-compassion, and communication.

Clients appreciated having programming reflect the needs of the group. For example, one client expressed: “what I appreciate about it is certainly...that we could set our own destiny within the program” [FG3, P1]. Clients recognized their own knowledge within their support services and recovery which resulted in positive perceptions of OtJ. In addition, clients enjoyed the flexibility of the program which they thought allowed for rich conversations and connections among each other:

“to have a more specific kind of participant-based programming, which was a very loose programming allowed for that kind of deeper conversation as opposed to having to cover material and then converse about the material, it allowed for that personal connection and kind of again deeper conver-



Fig. 2 Word frequency image based on topics covered across twelve offerings of OtJ. Larger font represents more frequent topics

sation and sharing about it and I think that’s what kind of puts On the Journey separate from the other programs offered.” [FG2, P2].

educational component or you kind of feel like everybody else has some of that same shared experience as you.” [FG1, P3].

In addition to facilitators, clients also recognized the redundancy of education-based programs, as well as their expertise in their own EDs. This was exemplified by one client, who said:

“I just think it’s so valuable to have a group that caters to people who already have experience with treatment or experience with - you know we’ve been around the block a few times already. Because then you’re not kind of wasting your time with all the

Overall, recognizing the expertise and experiences of clients was essential to OtJ, and was positively received by clients who participated in this HCP-facilitated support program.

Discussion

In this study, we set out to examine clients’ and facilitators’ experiences and perceptions with the OtJ program. This included describing the development and components of OtJ, and gaining an understanding of

participants' perceptions of the OtJ program and how participation affected their recovery. In addressing these aims, we were able to identify ways to adapt and improve OtJ. The results from the study emphasize the many strengths of the OtJ program in a community setting. Our findings highlight that OtJ allows clients, in general, to experience support that builds community, fosters client autonomy, and is accessible by being offered virtually and free of charge. These qualities were especially important during the COVID-19 pandemic when there was an increase in ED hospitalizations and ED symptoms, anxiety, depression, and body changes [29]. Access to ED care also decreased during COVID-19 due to lockdowns and scarce healthcare resources [29].

Fostering community and autonomy

Community is an important component of ED recovery and was a major theme expressed by OtJ facilitators and clients. A community-based study by Mitchison and colleagues [30] demonstrated that quality of life (QoL) is influenced by social support and encouragement and participants with higher QoL made positive progress in their recovery. Establishing a supportive, pro-recovery community, which is an integral component of the OtJ, thereby supports recovery.

Fostering client autonomy regarding the content of their care and valuing individual perspectives and worldviews are key components of the OtJ program and consistent with other studies that showed autonomy in treatment was associated with reductions in drop-out rates and improved therapeutic outcomes [31, 32]. Recognizing that each person is a “unique individual with the right to determine their own path towards mental health and well-being” is laid out in guidelines for recovery-oriented practice [18]. Though changes in ED symptoms and program retention rates were not measured in the current study, the positive experiences noted through analysis emphasize that autonomy integrated within ED support can foster positive client experiences.

The success of the OtJ also relies on qualified and skilled facilitators. Discussion topics were sourced from clients, however, facilitators reviewed these, curated evidence-based resources, and guided conversations to ensure the group remained pro-recovery. We highlight the value of working with clients, while also integrating expert knowledge, to ensure the selected content matches the needs and goals of the group [33]. From our findings, the skilled facilitators should:

- Make sure all group members are comfortable with the selected topics (e.g., sexuality) and anticipate those that may be challenging for some clients to ensure appropriate supports are in place.

- Recognizing their own scope of practice and knowledge is also important for facilitators to adequately provide resources or support on whatever may come up regarding the selected topics (e.g., trauma).

Having group-identified topics allows clients to repeat the OtJ program several times without redundancy, which serves as a supportive community as they continue their recovery journey.

Accessibility

Due to COVID-19, the group ran virtually via Zoom, which was widely regarded as a benefit because it eliminated some accessibility barriers and expanded group size. During the pandemic, many in-person ED treatment centers closed and access to outpatient or community-based treatment services was very limited [29]. As the length of waitlists for treatment programs grew, ED symptoms and hospitalizations were exacerbated for many individuals [29]. Providing OtJ, without pause in services related to the pandemic, was key during this time of need.

Virtual care also offers the benefit of reducing geographic and transportation barriers to accessing care. Barney and colleagues [34] reported that telemedicine was especially beneficial for emerging adults with EDs, who were frequently referred to treatment centers from a wider geographical range compared to patients seeking typical primary care. Likewise, OtJ clients benefitted from having access to support without the constraints of location. Healthcare providers in Canada have reported advantages of virtual ED treatment and support, including increased accessibility to care [35].

Opening conversations

The notion of “hyper fragility” experiences in current and previous ED treatment was discussed in one of the focus groups. Interestingly, clients perceived that group norms and rules (in OtJ as well as other support programs) often limit conversations within ED recovery. Cockell and colleagues [36] highlighted that reemergence into the “real world” (e.g., diet culture, negative self-talk) after residential ED treatment can trigger slips and relapses in ED behaviors. It is crucial to recognize that clients are often highly protected from societal triggers during treatment—which can result in relapses in ED behaviors when discharged. This concern was evident in the present study, with several participants expressing that being able to talk explicitly about ED-associated behaviors was necessary to make a full recovery. The idea of hyper-fragility in ED treatment and support should be further explored. For example, safeguarding conversations (e.g., forbidding words such as BMI, mention of weight) is common

and often viewed as an important aspect of peer-support programs [13]. Exposure therapy is a common cognitive behavioral approach used in EDs and body image interventions, often in the form of mirror exposure therapy and encounters with fear food [37]. It is possible that by forbidding conversations, individuals do not have the necessary skills to cope with such topics when they inevitably are exposed to them in the “real world”, compromising sustained recovery outside of treatment settings.

Implementing and improving the OtJ program

Our findings revealed several key components others may wish to consider when implementing a program like OtJ. First, selecting facilitators who have the required specialized knowledge and competencies is crucial for effectively guiding clients towards their goals. Facilitators who have both had formal health professional or social work training as well as experience with working in the area of EDs can better understand clients’ challenges and offer appropriate strategies or tools to support their journeys effectively. Having two facilitators allows for additional support during sessions. Balancing expectations between facilitators and clients is another consideration. Our study found that while facilitators aimed to foster a community, some clients expected they would gain practical tools that facilitate recovery. Finding a middle ground by integrating both elements can create a more effective and supportive environment for clients. Regular communication and feedback can also help ensure the program meets the diverse needs of the clients. Lastly, organizations must establish robust protocols and practices to safeguard clients’ emotional and physical well-being. These measures may include a closed-group format, pre-screening of sensitive topics, assuring confidentiality, and, in online groups, ensuring that the chat feature is monitored. Prioritizing these aspects can lead to successful implementation and impactful intervention, empowering clients in their personal recovery journeys.

Moving towards a future of valuing and incorporating lived-experience and client autonomy into healthcare services, the OtJ provides an example of how a community-centered and engaged approach can result in effective programming adjustments to suit the diverse and complex needs of those struggling with EDs or DE. As depicted in the word cloud (Fig. 2), the most discussed topics during OtJ for participants in this study included body image, self-compassion, and community. Identifying topics of discussion when implementing OtJ can assist HCP in preparing appropriate resources to complement weekly meetings.

Strengths

The strengths of this study are the inclusion of perspectives from program founders and facilitators, and clients

to give a more holistic view of program evolution. The similarity in what we heard from facilitators and clients highlights that the vision for the program and the experience within the program align. A strength of both the study and the OtJ program broadly include the attention to access in program design (i.e. virtual programming, reducing barriers to access, attention to the needs of clients), taking an approach which was centered around how clients view their own needs for programming through the co-creation of session curricula of the OtJ, and meeting the need for programming that suits the needs of folks who are in between, or at different levels based on a stepped care model. The study findings allow for client voices to identify ways to improve the program at Body Brave.

Limitations

The clients of this study were living in Canada and spoke English. Given the nature of OtJ, results and outcomes are not generalizable to all individuals living with EDs. Both OtJ and the focus groups were conducted virtually. It is likely that some individuals seeking support were unintentionally excluded as Wi-Fi and a device to use videoconferencing were required to participate. For this study, we did not collect demographic information about clients (e.g., age, gender identity, ethnicity), and thus were unable to comment on characteristics of the present sample. In addition, it is likely that individuals who completed OtJ and had positive perceptions with the program were more likely to participate in the study. Although data were treated with confidentiality, participation in focus groups was not confidential and may have influenced willingness to participate. Although focus groups can offer a comfortable environment for group discussion, some individuals may not have felt comfortable voicing unique opinions or experiences [38]. We did not share the interpretation of data back to participants (e.g., member reflections) [26] which could have strengthened the validity and trustworthiness of the analysis. In addition, data were collected in reference to OtJ programming that took place during COVID-19 restrictions; clients and facilitators in the present study may have had unique experiences that differ during non-pandemic times.

Future directions

Moving forward, Body Brave will continue to find innovative ways to ensure that the experiences and voices of individuals with EDs or DE are incorporated into research and services through routine program evaluation practices and the developing evidence-based support groups. To support access to care according to needs, the organization implemented a virtual recovery support program built on the stepped care model [39].

Ongoing research includes understanding the needs and experiences of diverse populations of people with EDs and considering adaptations to programming to better meet their needs.

Conclusion

The value of employing lived experience in medicine has been increasingly noted as beneficial in ED literature [40]. Specifically in mental health research, lived experience is known to provide unique perspectives of those who have struggled with illnesses themselves [41]. A key component that contributes to the success of OtJ has been the ability for clients to “choose their own destiny” in the program. Moving towards a future of valuing and incorporating lived-experience and client autonomy into healthcare services, the OtJ group provides an example of how enacting a community-centered and -engaged approach can result in effective programming adjustments to suit the diverse and complex needs of those struggling with EDs or DE.

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

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Author contributions

SG conceptualized, collected, and analysed data, co-drafted the manuscript and gave final approval of the version to be published. JD conceptualized, collected, and analysed data, co-drafted the manuscript and gave final approval of the version to be published. SCG analysed data, co-drafted the manuscript, and gave final approval of the version to be published. HH analysed data, co-drafted and edited the manuscript, and gave final approval of the version to be published. CL supervised, designed, and conceptualized the study, drafted the manuscript, and gave final approval of the version to be published.

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Data availability

The raw data analysed during the current study are not publicly available due to identifiable information in interview transcripts. The corresponding authors have access to all data.

Declarations

Ethics approval and consent to participate

Ethics approval was obtained through the local research ethics board at the Hamilton Integrated Research Ethics Board #13445.

Consent for publication

Not applicable.

Competing interests

CL was a member of the Board of Directors at Brody Brave at the time this study was completed but is no longer in this role.

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