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Peer support for eating disorders in Canada: program user perspectives

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Abstract

Evidence for the value of peer support for eating disorders (EDs) is growing. Peer support is not a replacement for treatment, but can provide hope for recovery, enhance motivation for treatment, and increase feelings of connectedness and belonging for those experiencing EDs. In this study, we explored peer mentees' experiences of peer support for EDs to better understand the impact of peer support and its role in the Canadian treatment and support continuum. We conducted semi-structured interviews with 20 people who had received peer support (group, one-on-one, or chat) and conducted a reflexive thematic analysis through a critical realist lens. We developed four themes. Participants described the importance of connecting with others who had "been there," which helped generate a sense of belonging and connectedness. They also highlighted aspects of the peer support "container" that needed to be in place, such as guidelines for groups and agreements for one-on-one mentoring. When peer support was delivered well, participants described how it helped them help themselves through increasing motivation, communication skills, and other coping skills. Finally, participants described the unique role of peer support within the treatment continuum, as a modality that was accessible, free, and delivered in a way that focused on the whole person. Together, our findings illustrate the value of peer support and considerations for enabling effective and safe peer support delivery.

Keywords Peer support, Peer mentorship, Eating disorders, Qualitative

Plain Language Summary

Peer support can provide hope for recovery, help people feel more motivated to engage in treatment, and generate a sense of belonging for those experiencing EDs. In this study, we sought to understand how peer mentees experienced peer support for EDs. We also wanted to know what role(s) they thought peer support served within the Canadian treatment and support continuum. We conducted semi-structured interviews with 20 people who had received peer support (group, one-on-one, or chat). We developed four themes using a qualitative analysis approach called reflexive thematic analysis. Participants described the importance of connecting with others who had "been there." This helped them feel less isolated and more connected to others with lived experience. They also described several things that needed to be in place for peer support to work, including guidelines for groups and agreements for one-on-one mentoring. If these things were in place, peer support could help people learn to help themselves; for instance, participants shared that they felt more motivated and developed stronger coping and communication skills. In terms of the role of peer support, participants shared that it was an accessible and free option, and one

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that made them feel seen as a whole person. Together, our findings illustrate the value of peer support and considerations for enabling effective and safe peer support delivery.

Introduction

Peer support, or the provision of support from those with lived experience of a similar life challenge [1], is increasingly recognized for its capacity to foster hope and facilitate both emotional and practical assistance for those experiencing mental health issues [2]. An emerging body of research has explored the value of peer support, sometimes referred to as peer mentorship, for EDs specifically (e.g., [3–5]). Quantitative studies exploring the use of peer support for people with EDs have highlighted its value for improving quality of life and attendance at treatment sessions [4], and reducing anxiety, depression, and body dissatisfaction, and ED behaviours [6]. Mixed methods studies have similarly revealed the potential for peer mentorship for EDs to improve hopefulness for recovery, reconnecting with the world beyond the ED, and reducing isolation [3, 4]. A recent study on the use of peer mentorship in the step down/transition from intensive treatment illustrated similar benefits, including hopefulness and a sense of reconnection with others and the world [7]. Systematic reviews of the use of lived experience support and peer support for EDs further emphasize the potential for insight to be shared in a way that provides inspiration [8] and a sense of belonging [9] for people experiencing EDs.

Peer support programs for EDs vary in their construction. Some move through a structured set of phases from initiation to redefinition of the peer support relationship (e.g., [4]). Others have a set number of weeks for their programming and base their model on a particular definition of ED recovery (e.g., [6]). Peer support may also be delivered in one-on-one and group formats [5], and/or be accompanied by pre-recorded recovery narratives and text-based guidance [10]. Co-development of plans for peer support is common (e.g., [3]), aligning with a focus on self-determination within peer support more broadly [11]. Eating disorder peer support may include discussions about managing ED thoughts and behaviours, motivation and commitment to recovery, relapse prevention or management, setting goals for and working toward recovery, and dealing with triggers [4]. In addition to peer support for people with EDs, interest in peer support for parents and caregivers of those with EDs is growing [12, 13].

Despite the potential benefits of peer support for EDs, there has been some apprehension and resistance to the inclusion of peer support as a modality for EDs given fears about the potential for comparisons or iatrogenesis

[8]. Hearing recovery stories can be helpful for some, while for others there is a risk of feeling triggered [14]. Given these concerns, proponents of peer support for EDs have emphasized the importance of supervision for peer supporters, training in co-developing boundaries, and ensuring that those giving and receiving peer support are ready to engage in the peer support relationship [3]. Navigating boundaries in the unique peer support relationship has been noted as particularly challenging to manage [7].

Existing studies on peer support have illustrated potential benefits when used in the context of EDs and have raised important points that warrant further investigation. Among them, they invite further exploration of the specific role(s) of peer support within the ED support continuum, particularly in resource-strapped healthcare landscapes. They also invite us to continue to dig deeply into specific aspects of peer support people find helpful, and what needs to be in place to facilitate effective peer support delivery for EDs. In this study, we explored the experiences of young people (ages 14–29) in Canada who were receiving peer support. We sought to answer the research questions: 1. How do those who have received peer support (one-on-one, group, or chat) for an ED describe their experiences? And 2. What role(s) do program users describe peer support serving in the ED support continuum in Canada?

To ground the results, we have provided Supplementary Materials that provides a brief outline of the treatment and support continuum and peer support delivery modalities.

Methods

We received ethics approval for this study through the University of Calgary Conjoint Faculties Research Ethics Board. Participants were recruited upon registration to take part in peer support programming via the online platform (Careteam) or through a flyer sent out to one-on-one and group participants. Eligibility criteria were communicated with participants; these included being between the ages of 14 and 29, living in Canada, and having received peer support (chat, group, or one-on-one) through one of the partner organizations (EDNS, Silver Linings Foundation, Body Brave). All interview participants received a \$35 Amazon gift card to thank them for their participation.

Primary author AL conducted semi-structured interviews (for full interview guide see Appendix 1) with

20 individuals who had received peer support for an ED via Zoom; AL conducted all interviews between July and December 2023. Participants reviewed and signed a consent form prior to the interview and re-affirmed consent verbally prior to commencing the recording. The interview guide was reviewed by the project's youth advisory committee and scientific advisory committee. Interviews ranged from approximately 20–55 min (average approximately 30 min) and focused on participants' experiences of peer support, including their journey to peer support, what they found helpful and less helpful about peer support, challenges, and recommendations. While the decision to stop interviewing was partly pragmatic (i.e., no further participants were expressing interest), the data could be considered to have adequate information power [15] given the high degree of specificity of responses to the questions and participants' shared expert positioning as individuals who had sought and received peer support. AL completed a reflexive memo after each interview, noting key moments, reflections on the interview process and emotions or thoughts arising, and anything that she felt would be important to remember in the analysis process. She then transcribed each interview with the assistance of Aiko (an on-computer transcription software) and reviewed each transcript for accuracy.

We analyzed the data using reflexive thematic analysis [16, 17], taking a critical realist epistemological orientation. From this frame, we assumed that we do not have unmediated access to participants' feelings about peer support but propose that their experiences are "real" in their consequences in terms of enhancing our collective understanding of peer support for EDs. Following transcription, AL read through the transcript a second time, noting observations in a Word document (data familiarization phase). Next, she created a master Word document with a table for each transcript, in which she did a first pass code. She coded inductively or "from the ground up," grouping sentences under provisional labels. Next, she explored codes for duplication and overlap, reducing the overall number of codes and increasing their specificity, returning to the data to confirm changes. From this reduced list, she began to sort codes into candidate themes, looking across content categories for shared *meaning* in relation to the research questions. Throughout this process, she explored quotes in relation to candidate themes, rearranging and reconsidering themes several times before generating the final list of candidate themes. This list was shared with the rest of the research team; we then met as a research team to discuss and refine themes, a process that continued through asynchronous communication until a final set of themes was established.

In exploring the data, AL was attuned to her embeddedness within the organization providing peer support, where she occupied an insider–outsider role; she was conducting the research with the organization, but not as an employee of the organization. She had not personally experienced peer support for EDs but does have lived experience of an ED and recovery that gave her shared grounding in experiences some participants shared, including the ED treatment system in Ontario. However, her lived experience of this system is from more than 13 years ago. She also brought her lens of socio-culturally and systemically-oriented research on EDs to the data; she typically works with critical feminist and social justice informed theoretical orientations in analysis. The context of this research should also be considered as it likely informed both lines of questioning (through the interview guide and semi-structured prompts, following participants' expressed lines of thought)—the a priori study indicators included hopefulness, self-compassion, wellbeing, sense of belonging, and knowledge and use of coping skills. She rarely probed directly for these indicators; however, she was attuned to their presence within what participants shared. Coauthors brought varied lenses to continued analysis, including research and/or clinical lenses from inside the EDs and mental health fields. Some (e.g., SJ, SK) were also involved in developing the peer support programming.

Findings

Participants ranged in age from 14 to 28 years (average 21.7). Most participants used she/her pronouns. Additional demographic information is not provided in order to maintain participant confidentiality. Names reported in the findings section are pseudonyms. Twelve participants had experienced one-on-one peer support and 11 had tried peer support groups (not mutually exclusive). Four participants had tried peer support chat. We did not collect diagnostic information or require official diagnosis for eligibility. Participants spoke about a range of ED experiences, including restriction, bingeing, and compensatory behaviours. Some, but not all, participants described engaging in therapy (either ED specific or general mental health) concurrently with peer support. Others reported engaging with peer support *following* treatment or while waiting for treatment.

We developed four themes in relation to our research questions. The first encompasses participants' articulation of how peer support made them feel seen and heard; engaging with others with lived experience afforded a feeling of connection and sense of belonging. The second is focused on the factors that enable peer support to feel supportive—the processes and elements of programming that carve out peer support as a container for holding

challenging experiences. The third highlights the specific value of peer support as a modality that helps people help themselves, including through helping them cultivate self-compassion and self-trust, alongside other coping skills. A subtheme of this theme hones in on the ways in which peer support could contribute to increased motivation for recovery and changed perspectives amongst mentees. Lastly, the fourth theme enfoldes the ways in which peer support serves a specific role within the Canadian treatment continuum; for many participants, peer support was a consistent touchpoint that was accessible to them along several points in their journeys. We describe these themes in detail in this section (see Fig. 1 for a thematic map).

Theme 1: feeling connected to others with lived experience through peer support

Overwhelmingly, participants described the opportunity to connect with others with lived experience as a core benefit of peer support. While many participants described supportive others in their lives as empathetic and helpful, they also articulated the unique value of being in the presence of others with lived ED experience. Often, seeking this kind of perspective was what drew participants to peer support, as was the case for Lindsey:

I think it's really important to have that connection [...] I was really looking for someone with lived

experience. And that's why I didn't connect with my therapist, because she just didn't really know what I was going through. So I just really wanted to talk to someone that had that experience. And then when I met my supporter, I just felt [...] like someone could understand me. (Lindsey)

Feeling understood and a sense of connection is often a highly meaningful aspect of peer support [3,6]. Lindsey and others described peer supporters as those who could understand them or offer a form of support that others—including both formal and informal supporters—could not necessarily provide. This is not to say that others in their lives were actively *unhelpful*; however, peer supporters had unique insight into the specificities of living with an ED and working toward recovery.

Isolation is common amongst those with EDs and was exacerbated by the COVID-19 pandemic [18,19]. Connecting to oneself and to others can be a core part of the recovery process [20,21], for many in this study, peer support provided a bridge to that kind of reconnection. Many participants reported that peer support not only made them feel less alone, but it also served to reduce feelings of isolation, which they contrasted to how they felt during their ED.

... my experience with disordered eating is it is like the most isolating, it can be the most isolating feeling where you're just like, I am craaa-zy. And nobody

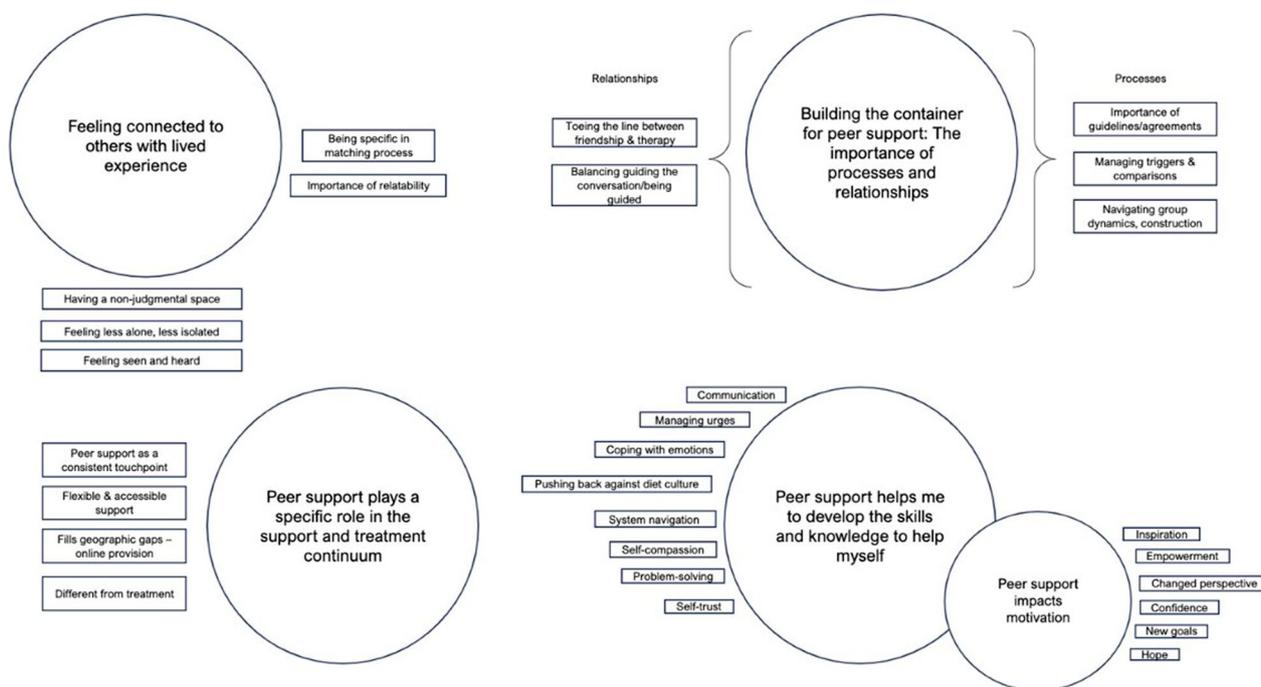


Fig. 1 Thematic map

else feels this way. And I am just like, unable to even process how crazy I am, let alone talk about it. And you talk about it with someone, and they're like, you're not crazy, or you are but it's fine because we're all crazy in this way. [...] it's not like a nihilistic view of things but it's like, this is a big world, we are very complicated people in this very big world. [...] under that hood, it makes sense [...] it felt like everything was more approachable with that, like everything was maybe not like easier to deal with, but it took the pressure off of having to deal with it. [A: Yeah] knowing that I wasn't like trying to like fix some like huge mistake I was just like a human being who needed to sort through some stuff. (Robin)

Robin described the importance of having an approachable peer mentor who was able to understand her in her complexity. Rather than feeling “craaa-zy” being a bad thing, working with a peer mentor enabled her to feel connection *in* difference, where difference could be framed as affirmative rather than a problem [22]. The idea of feeling less alone echoed throughout participants' narratives, anchoring their experiences in a sense of connectedness and belonging.

For many participants, this feeling of connectedness was enhanced when peer support was provided by supporters similar in age to them. Sloan shared how this enabled a sense of groundedness in context:

... I felt like it was important that I wanted someone to understand what factors kind of led into my eating disorder. [...] I feel like a lot of it can definitely be universal. [...] Like societal expectations and pressures like media and things like that... but having someone who understood like how it portrays on Instagram and how it portrays to me through like the celebrities I had seen growing up, that was something that made it a lot... I don't know, made it much more relatable (Sloan)

Like many others, Sloan specified during the matching process that she wished to be connected with a mentor similar in age. Preferring an age-matched peer mentor was not a universal experience, and several participants reflected on the benefits of working with an older mentor who could offer perspective from hindsight. However, being able to connect with someone similar in age was highly valued by many. Emerging adulthood has been noted to be a particularly fraught time for many with eating disorders [23,24]. Being able to connect with others with lived experience during this time was important to many participants in both one-on-one and group contexts. Some participants also shared how they specified other similarities in the matching process, including

wanting to be matched with a mentor with similar ED and/or treatment experiences, body size, sexual orientation, and gender identity. Working with peer supporters with similar experiences could help participants feel like they could fully be themselves in peer support contexts.

Participants used words like community, safety, and belonging to describe what it felt like to be engaged in peer support—both in one-on-one and group contexts.

... when I think of community, I think of a sense of belonging. I think of somewhere you can feel safe. I think of having people to relate to, you know, like even with your group of friends or your own little community, you're all people who relate to one another and chose to be with one another. And I feel like that's what this is. We all chose to be here and, you know, we're all going through something similar and we're accepting one another and of one another's journeys. And I think communities to always try and challenge people to grow. And that's definitely what we're doing on a group and individualistic basis, I suppose. (Brooklyn)

As Brooklyn described, peer support groups were not without challenges; however, going through challenges alongside others who “chose to be here” and who were experiencing similar things enabled a sense of safety and belonging.

Theme 2: building the container for peer support: the importance of process and relationships

Participants overwhelmingly described peer support as a positive experience. They also acknowledged that there were several things that needed to be in place in order for this space to feel like one where they could fully connect with others with lived experience. A concern noted within the literature on peer support for EDs is the potential for triggers to arise for either peer mentors or mentees [3,8,14]. These concerns are often grounded in a reflection on the potential for people with EDs to engage in comparisons [25]. Several participants noted the potential for comparisons to arise, noting that the creation of a space completely free of triggers would be impossible: “I guess eating disorders are very competitive. So like, no matter what someone says, it could still be triggering. So I feel like it's almost impossible to make like a triggering free space” (Chandler). Participants described the potential for triggers to arise as a potential deterrent from engaging in peer support—often due to their concerns about being the one to trigger others.

Despite concerns about the *potential* for triggers to arise, most participants did not report having been triggered in peer support contexts. They described several

processes and elements of peer support services that helped them to feel comfortable. In the context of one-on-one support, the establishment of boundaries and norms through agreements completed in the first session with a mentor was described as particularly helpful.

[... the] mutual agreement form. We did discuss what things are like triggers for both of us, which actually ended up being the same thing. So it worked out. Because we knew that both of us wouldn't cross that boundary. Because it's a common ground of concern. And like, for me personally, I get very like, "I'm sorry, like I don't want to affect you" kind of thing. So I would say something and [...] before I'd say it, I mean, I would say, are you comfortable with me saying this or that? [...] we have that relationship. And she'd go, yeah, of course. (Quinn)

In this extract, Quinn explained that she was mindful of not wanting to inadvertently trigger her mentor. Given that mentors *may* experience triggers in the mentor–mentee relationship [3], establishing agreements and discussing boundaries seems to have been helpful for many in knowing how to navigate sensitive conversations. As Quinn explained, this was established in the agreements, but also navigated on a case-by-case basis, as the relationship grew. Thus, rather than seeing the agreements as a one-and-done approach to boundary-making, boundaries were often envisioned as dynamic and evolving. This dynamicism is an important consideration given that peer support relationships shift and change as rapport builds and the role of peer support in someone's life develops [4].

Participants in group peer support noted that guidelines were important for setting the stage for helpful interactions. They noted that it was important for guidelines to be clear and understandable. Participants varied substantially in their prior involvement with ED treatment services. For some who were newer to groups about EDs, some of the language (e.g. “anti-diet”) was unfamiliar and feeling out the guidelines took a bit more time. Rey noted that figuring out the language of the groups was an adjustment: “I think they called it a non-diet culture or a... there was a few phrases [...] it was like way over my head that I would say that one out of all of them was like way over my head.”

Group facilitators played an important role in helping steer conversations when they veered into territory that breached guidelines; participants largely reported that facilitators were skillful in doing this. Some participants reflected on moments where they did feel activated in groups and wished that the facilitator had checked in with them after the fact. However, many acknowledged the difficulty of balancing facilitation with checking in

with individual participants, as well as the fine balance between guidelines that are so stringent as to restrict any specificity and guidelines that are too loose and may lead to triggers arising. As Harper noted, “the line is like, this big [gestures a small amount] [...] because everyone's so different and responds in different ways.” Indeed, some participants noted that having guidelines that enabled a certain amount of specificity could enable deeper conversations to occur:

And my previous experience in groups have been very much like, you can talk about it, but you can't really talk about it because it might be too triggering or you can't use certain words or describe certain things. And everybody here was just really respectful of that to the point like where we could actually talk about it at a deeper level, which was awesome. (Sidney)

This extract from Sidney illustrates the fine line Harper alluded to; to have meaningful, supportive conversations, the “container” of peer support needed to be carefully built in a way that facilitated mutual respect and sensitivity. For some participants, the ability to co-determine topics and focus felt *less* potentially triggering than how they experienced content in some clinical sessions, wherein the sole focus on the ED could sometimes lead to feeling worse. For instance, Quinn described:

When that [therapy...] it had like checkpoints, like it was, it was a lot of pressure. [A: Yeah.] P96: That was an uncomfortable time for me to go to there. I felt... like very depressed going there. Like, I had got into like a depression because I was feeling judged. And then I was also kind of getting out of my ED, which was like... loud, right? (Quinn)

This participant and several others reflected on how feeling pressure in medicalized treatment settings or therapy did not always make them feel good about themselves, but that it felt quite different in the peer support setting. While this could be at least partially related to the challenge of addressing symptoms head-on it reflects the potential for *any* encounter around an ED to be triggering, not just peer support encounters.

Across peer support delivery modalities, participants shared that they appreciated the ability to lead the conversation. However, in some cases participants expressed a desire for peer supporters to prompt them more often, including in moments where they wished to be challenged to a greater degree to address their ED. Once again, a fine line needed to be established here. Participants often expressed appreciation for the wide-ranging nature of peer support conversations, which extended beyond the ED itself. Micah explained:

I think that's also the great thing about the mentorship was that there was no there was no pressure to like focus on eating the whole time, which is a difference with [... therapy setting]. That was all the time for that one hour we had to talk about the eating. But this it was kind of like we could talk about life and get to know each other and talk about our interests and our hobbies. And, yeah, that was definitely a huge difference for me and something that I really valued because it's confronting to talk about it for a whole hour. (Micah)

Talking about the ED for the entire session could be “confronting” and the opportunity to discuss other parts of life—which, as many expressed, were often linked to how they were doing with their ED—was important. At times, however, participants wished to be prompted to dig a bit deeper into the ED, as Jody described:

I don't know if this is too much to ask but if I'm like grasping at straws for something, because it's so wonderful but [...] basically like a little bit more training with, with regard to how to how to keep the conversation going. [...] I find sometimes it will like... peter out like, like halfway through and I don't know how to how to reinitiate the conversation. [...] I don't know if everybody would need it. [...] maybe some more specific on, like motivational coaching and stuff like that but I don't know if that's within their scope (Jody)

As Jody alluded to, peer support fills a very specific role within the support continuum, being neither friendship nor therapy [2]; this role will be discussed in more detail in theme 4. In relation to this theme, however, we might hone in on the aspects of this excerpt that invite us to consider the specificity of the peer support *relationship*. Jody's comments aligned with those of others who suggest that having prompts or more guidance on topics of conversation might be helpful in peer support. This might also be helpful in defining the peer support relationship as something different than friendship. While participants largely noted that peer supporters were skilled at maintaining boundaries and avoiding drift into the friendship role, some suggested that having even more clarity might be helpful in this regard.

Theme 3: peer support helped me develop the skills, knowledge, and motivation to help myself

Participants often described peer support as helpful in assisting them to build knowledge and skills that helped them in their recovery. Peer support did not necessarily have a direct impact on participants' eating behaviour.

Instead, it was often described as helping participants develop skills such as problem solving, communication, self-advocacy, system navigation, and more. Additionally, they described how peer support helped to build self-compassion and self-trust.

Rather than being a therapy intervention designed to impact ED behaviours, peer support was often described as more of a “helping hand.” Sage articulated how:

I would say helping hand. It really... and the reason why I say that is it really was like in all of our sessions, [mentor] would just put her hand out for me there. And [...] it wasn't like she would ever, you know, be like the person to save me, but she would just, she would just lend a hand every time. (Sage)

For Sage and others, peer support was described as *assisting* them rather than *saving them*; often, participants engaged in peer support alongside other therapeutic activities (see theme 4). However, above and beyond peer support as adjunct to *treatment*, the way participants described peer support often positioned it as an adjunct to the personal work they were doing to figure out how to live in recovery. Recovery is often described as a non-linear journey (e.g., [26]), as a process of identity exploration (e.g., [27,28]), and as layered with individual, relational, and social contexts (e.g., [29]). Working through recovery, then, involves more than overcoming symptoms. Social support is also important for recovery [20,21,26,30]; for many participants, peer support added a layer to “social” support, providing a space that felt similar to friendship but with an added layer of shared experience and nonjudgmental, non-contingent support.

Participants also reflected on how peer support helped them to orient more compassionately toward themselves. Self-compassion can be challenging for people with EDs to access but can help to moderate feelings of self-disgust and drive for thinness that can maintain EDs [31] or act as a protective mechanism against ED symptomatology [32]. Participants did not necessarily find self-compassion easy to enact, but described how peer support could be helpful in cultivating a greater degree of self-acceptance:

I have a hard time feeling compassion to myself. Um, but I sometimes like when the facilitators or the group members kind of show that as like strength or just sharing and yeah. So I find sometimes it can help remind me that, yeah, showing up is good or it's a sign of strength or it can just remind me of that. But I mean, in general, self-compassion is something that I have a hard time accessing a lot of the time, but it is nice. And I do try to feel good towards myself if I do show up and participate in however way I can. (Devin)

As this extract illustrates, the flexibility of peer support also played into this participant's ability to feel good toward herself. As she was able to "participate in however way I can" (i.e., speaking or not, sharing in the chat, etc.), showing up to peer support was made easier. In turn, participating could in and of itself be a helpful, self-compassionate action.

Subtheme: peer support impacts motivation

Participants varied in their motivation for recovery when they began peer support. Some noted that it was helpful to begin peer support when already on the path to recovery; however, others found peer support to be a helpful entry point to recovery. For instance, Sloan shared:

No, I actually, no, I, I initially had told her like, I don't want to change right now. Like I'm like, I just kind of want to hear about your story. Like, have you, how you found recovery? [...] I think it's been over half a year that we've been talking and we've gotten a lot more comfortable and she's like, you should start thinking about goals and what things you want to do. And then it was like a slow approach getting there. And once we started off with like the first, like, why don't you try achieving one of your goals? She's been like, okay, what's next? Let's keep going. (Sloan)

In this extract, Sloan reflected on the process of change she experienced in peer support; she went from preferring to primarily hearing about her mentor's experiences to setting her own goals. Having peer support as a consistent touchpoint, and one that many participants described as less pressure-filled than formal treatment, afforded this participant and others the opportunity to ease into changing their perspectives. Rory described how engaging in peer support helped her to remember that her goals were important:

I usually forget or like just have like low motivation [...] you know, the eating disorder kind of like convinces me that like, oh, you know, your goals aren't that important or something like that. And then it just like prioritizes other things that aren't necessarily as healthy. [...] when I talk to the peer mentor, it definitely like helps me like kind of revamp and [...] be like, yeah, you can do this and stuff like that. And it kind of gives you tricks and tips to cope with that. (Rory)

This participant drew on an externalizing perspective on the ED, reflecting on the ED as convincing her that her goals were unimportant. Peer support, then, helped to provide another perspective to counter this voice. For several participants, this perspective-changing function

of peer support was helpful for enabling motivation for recovery.

Peer mentors can act as role models for recovery [6], enhancing hope for recovery [3,7]. This role modeling could assist not only in the skill-building described in the larger theme, but also specifically in enabling motivation and hope for recovery.

her being like nothing you say can trigger me like that type of thing. I'm like, damn, that's possible? Like to get to that point, like that's so wild and that's like so cool. And I'm like, we're the same age. Like I could be you eventually, you know what I mean? [...] being able to see that and kind of have her as this like... end goal, is also very nice. Like I feel like whenever I come back from seeing her [...] I feel a little bit more optimistic. (Briar)

As Briar reflected, even the process of establishing boundaries with her mentor served to provide a sense of hope or motivation for recovery. Meeting with her mentor, then, enabled her to feel more optimistic about her own recovery. The context of shared experience, therefore, both enabled a feeling of being seen and heard—and a sense of potential for the future.

Theme 4: peer support occupies a specific role in the treatment and support continuum

Participants reflected on how peer support served a unique role within the treatment and support system in Canada. Peer support can be engaged at different points in support and treatment seeking, including as an adjunct to treatment (e.g., [6]) and transition from treatment (e.g., [7]). It can also contribute to enhanced engagement in treatment (e.g., [4]). As noted in theme 3, participants also described how peer support could be helpful for supporting positive change and skill building. Further, participants described the unique and helpful context of being seen and heard in peer support (theme 1) and the boundaries that could be put in place to facilitate effective peer support (theme 2). Another important facet of peer support raised by participants was its capacity to fill several noted gaps in the treatment continuum, including geographic gaps, financial gaps, and the need for different people to serve different roles in the recovery team.

Several participants reflected on the importance of the availability of *virtual* peer support for enabling them to access services. This was often positioned in relation to the geographic gaps in accessing ED services across the country; specialist services in particular tend to be centralized in more populous provinces and in urban settings. As Sloan noted, this centralization could lead to challenges in accessing any kind of support: "I just really had trouble like finding any sort of support in the

beginning [...] Like at the time I was in [remote area] which is a lot more remote with a lot less resources.” Similarly, Harper shared that she appreciated “the option to always have like kind of that reminder that, oh my gosh, that the resource is here for me online, especially because I live in a town where there’s nothing.”

While many participants appreciated peer support being online to enable it to fill geographic gaps, this could also introduce challenges. For instance, if participants lived with others who did not know about their ED, they were sometimes inclined to share less openly in peer support. As Parker explained:

“just privacy wise, I’m always worried that they’ll overhear something if I do decide to share. So that definitely plays into it a little bit. At least for virtual groups. I’d rather have a physical space that I can go to that’s removed from any listening ears.” (Parker)

Thus, while online provision of peer support enabled it to fill a geographic gap, some participants did express a preference for in-person support in a dedicated, private space.

In addition to filling a geographic gap, peer support could also fill a financial gap for participants, many of whom reflected on the fact that the program was free as highly important. For some, this enabled them to have a consistent touchpoint that was more predictably available to them, versus private therapy in particular, which could wax and wane depending on financial circumstances.

Treatment was so expensive and it was always so unpredictable. Like I would join one dietitian or I would join one psychotherapist for a month and then [...] we don’t have enough funds and I would have to stop. So I was never really consistent with my treatment but the [groups] and the peer mentoring were both things that would actually be consistent for me. (Sage)

As Sage and others noted, being able to access free support enabled a kind of consistency they were unable to have when relying on services not funded by provincial healthcare. Given the limitations of publicly funded services in terms of wait lists, stringent criteria for admission, and time in program, having a free form of support without a specific time limit felt important for many. It should be noted that several participants shared that they worried they were taking up too many resources by continuing on with peer support for quite some time.

I’ve just felt like an internal like... guilt I think about around using the service too because I know it’s free [...] and I was like, I don’t want to take up your time, like I don’t want to just expect that

there’s someone who’s like, going to be on the end of the phone every couple months [...] I felt like... guilty about that for some reason. (Robin)

At times, participants’ guilt about continuing to use the service was assuaged by peer supporters, who reiterated that all people deserve help and support when dealing with an ED. However, in the context of a resource-strapped system and within a system of managed care that often frames ED treatment and recovery as time-limited [33], it is perhaps unsurprising that some participants worried that they were taking up limited resources. Equally, this could be related to a feeling of self-silencing in the context of EDs [34].

Many participants were engaged in other forms of support in addition to peer support. Often, they described peer support as filling a different role in the recovery team. For instance, some participants were engaged in therapy for co-occurring conditions and sought peer support to address the ED specific concerns they had. For others, one-on-one support was helpful for undertaking specific treatment protocols, whereas peer support groups fulfilled a desire for connection with others with lived experience.

I do like one on one on my own, like separately with my own therapist. So it’s, I don’t typically feel like I need that as a resource, but groups was harder to find because [...] I wasn’t sure where I was going or what to look for exactly or how to get there. [...] it definitely it does offer you something different from just like the one on one where it feels a lot more kind of like community based. And it’s, I like that it’s not all about me the whole time, because that can be kind of nerve wracking. Like you get to speak and be heard and sometimes people bounce off what you say or reply to what you say. And then you get to, you know, talk about the next person or check in with the next person. And I really like that. I like that it’s more of a back and forth. (Brooklyn)

As Brooklyn described, having group-based peer support enabled less of a spotlight on her experiences and more of a back and forth between group members. Having peer support, then, complemented ongoing one-on-one work while serving more of a community role. Other participants similarly remarked upon the differences between peer support and treatment, referring to peer support as a less formal space where they could be themselves, speak in terms familiar to them, and even interject humour and casual anecdotes into the support relationship. This was often particularly

valued by participants who had not experienced more formalized treatment settings as particularly helpful.

Discussion

In this study, we sought to understand participants' experiences of peer support for EDs and the role of peer support in the support and treatment continuum. Participants expressed how they valued peer support for its ability to enable connections with others with lived experience, provide a flexible but bounded space, and help them learn to help themselves. Peer support served a specific role within the treatment and support continuum, including filling geographic and financial gaps. Participants differentiated between peer support and other forms of support and treatment, reflecting on the uniqueness of a free, accessible space that enabled self-determination and less pressure in meeting particular milestones at particular moments in time. While peer support was not without the potential for triggers and comparisons, and some would have preferred in-person opportunities, participants were largely positive about the role peer support had played in their recovery journeys.

Overwhelmingly, participants reflected on the importance of connection and community within the peer support space. Connecting with oneself and others can be a core part of ED recovery [20,21]. Given the isolation associated with EDs for many, particularly during COVID-19 [18,19], being able to connect with others who share lived experiences can contribute to a sense of being less alone and more hopeful for recovery. Peer mentorship can enable people actively struggling to see the potential for recovery [3–6]. At the same time, peer support seemed to provide a space where there was less *pressure* for recovery—and for a particular kind of recovery. People with lived experience often express a preference for a non-linear recovery that does not impose stringent criteria or expect “perfection” [26]. Peer support seemed to enable this more flexible orientation to recovery, enabling a focus on participant-directed preferences for the focus of sessions and the kinds of goals they wished to achieve.

A recovery model orientation for EDs has the potential to enable a reconceptualization of who gets to determine what ED recovery looks like [35,36]. Peer support, in its focus on building community and focusing less on a deficit-based model of recovery, offers the opportunity to engage with different orientations to recovery [37]. This orientation toward recovery is not about “settling for less”; indeed, participants reported feeling challenged to address their ED in peer support settings, and hopeful for a life beyond the ED. For many, addressing challenges in peer support included addressing the intersections between the ED and the rest of their lives. Many have argued that moving beyond a siloed approach to recovery

with a primary sole focus on symptom remission and weight and nutritional stabilization is helpful [26,29]. As participants reflected, engaging in peer support tended to encourage a focus on how ED recovery is entangled with the “rest of life”—focusing less on the symptoms and more on developing skills and changing one's perspective on what is possible. Recovery can be difficult to imagine when one is reduced to their symptoms and their identity subsumed into their ED [36]; peer support offers an opportunity to be *seen and heard* in one's struggle, without this struggle being the *sole focus*. Indeed, as participants reported, the flexibility of peer support often led to feeling less pressure to perform recovery in a particular way. Given that people with EDs are not always trusted to be “experts on their own experiences” [38], this represents a major step toward re-envisioning what trust and relationship might look like in ED support systems.

While not everyone who experiences an ED will engage in comparisons, the potential for comparisons and triggers to arise has been noted as a concern amongst those exploring lived experience involvement in treatment and peer support [8,14]. Training and supervision for peer mentors can assist in mitigating the potential for iatrogenic harms from peer support [3] as can focusing on the establishment of appropriate boundaries [7]. Participants' descriptions of their peer support experiences highlight additional pieces of the peer support “container” that help to maintain the safety and recovery orientation of peer support. These included the co-development of agreements for one-on-one support and guidelines for groups. Realizing the possibility of peer support, thus, seemed to hinge at least in part on effective implementation—for instance, through strong mentor training, a template for agreements, and, ideally, guidelines for peer supporters to use when conversation would lull or there was a need for redirection. Interestingly, some participants reported feeling more activated in clinical settings versus peer support, which they tended to relate to the opportunity to *not* just talk about the ED. The focus on *connection* and skill-building for general wellbeing (e.g., development of self-compassion, communication skills) were often described favourably by participants.

Limitations

While this study illustrates the promise of peer support for people aged 14–29 living in Canada and highlights several important considerations for peer support's role in the treatment continuum, it also has several limitations. Firstly, the “dose–effect” and unique contribution of each type of peer support (e.g., one-on-one, group, chat) is unable to be determined on the basis of this data. While about half of the sample had experienced group support and half had experienced one-on-one, we did not

design this study to directly compare between groups. Some had done both group and one-on-one peer support and some had also engaged in peer support chat options. We did not gather information about how many sessions of any of the forms of support participants had received, though some participants volunteered this information. Given that participants were reflecting on their experiences of peer support broadly, they were not necessarily reflecting on the unique contribution of each type of peer support to their overall wellbeing. Additionally, that we have limited demographic information about our sample is also a limitation. While reporting minimal demographic data is helpful for maintaining participant confidentiality, we are unable to comment on the extent to which peer support may be more or less helpful for people with different demographic characteristics.

Future researchers may wish to explore the potential impact of peer support for specific groups, for instance trans and gender non-conforming individuals, racialized individuals, or those experiencing food insecurity, to nuance the broader arguments put forward in support of peer support for eating disorders. While participants' ages ranged widely within the broader category of "youth," we did not specifically explore differences in experiences based on age. Understanding the unique needs and preferences of those seeking peer support at different ages may reveal further recommendations for implementing peer support across the lifespan. Further, given that we did not collect diagnostic information, we were unable to specifically analyze the impact of different symptomatology and diagnoses (or lack thereof) on access to treatment and support. Given that access to treatment can vary per diagnosis [39], future researchers might specifically explore the relationship between peer support use and different ED experiences. Additionally, it would be interesting to assess the potential for peer support across different ED symptom clusters or diagnoses to tease out any differences regarding the design and delivery of peer support.

Implications

Since the advent of COVID-19, low-barrier support for EDs has been more in-demand than ever [40]. Peer support, as a form of low-barrier support for those with EDs, may be considered as a helpful part of the treatment and support continuum that, when done well, specifically enables connection and community to be built. This study contributes to the building body of evidence supporting the use of peer support for EDs (e.g., [3–5]).

There are also several implications that stem from this study. Conducting qualitative research with those using

peer support programming enabled us to gain rich insight into the "container" for peer support, which could aid in continuous quality improvement for peer support programming. The degree to which participants emphasized the importance of guideline clarity supports the need for lived experience-led guideline development and review to ensure that guidelines are understandable to as many people as possible. Further, participants emphasized the importance of the matching process, which suggests that those delivering peer support should start or continue to take time to consider the traits and preferences participants express, when possible. In terms of clinical implications, engagement with peer support as an adjunct to treatment seemed to be helpful for participants. Whereas clinical treatment can engage directly with protocols for symptom management and clinical cognitive and behavioural strategies, peer support can provide a more informal space for exploring how the ED impacts one's life. Participants' stories also point to the importance of providing peer support for free, with trained mentors who can skillfully navigate sensitive conversations. Just as peer support for family members has been suggested to be an important part of the treatment and support continuum [41], peer support for those with EDs might also be considered. Sustainable funding would help to enable peer support to continue to act as a consistent touchpoint for those experiencing EDs at different points in their recovery journeys.

Appendix 1: Interview guide

1. To help us get oriented, I'd love to hear a bit about your story and what brought you to the program.
 - a. It would be helpful to know what language you use to describe your experiences — some people prefer disordered eating, others use the term eating disorder, or some other term; what words do you prefer?
 - b. [using this language] could you tell me a bit about your [disordered eating/eating disorder]?
 - c. [possible prompt: when did you decide you wanted to get involved in the program? Which program(s) did you try? Why?]
 - d. [possible prompt: Were there any other services/programs/helping professionals you considered or tried?]
 - e. [explore journey through program(s) what made the participant want to continue, if participant

- made any changes to what they participated in throughout the course of involvement; if they switched what they were doing, ask about why]
2. What have you found to be most helpful about [this/these program/programs]?
 - f. [possible prompts: was there anything you liked? Was there anything you found made you think differently about your [eating disorder/disordered eating]? If participant brings up hope, self-efficacy, self-compassion, etc. follow this thread to tease out how/why]
 3. Is there anything that you have found less helpful? If so, what?
 - g. Was there anything that you found particularly challenging? In a good way? A bad way?
 - h. Is there anything that could be changed to make this aspect/these aspects better?
 4. How would you describe where you are at now with your [eating disorder/disordered eating]?
 5. Has your involvement with these services influenced your [eating disorder/disordered eating]? If so, how?
 6. [If participant has used groups, peer support, chat] As you know, a lot of the programming involves interacting with other people who have shared experiences of disordered eating/eating disorders. What has that been like for you?
 - i. [possible prompts] what has been helpful? Challenging? New? Different?
 7. What do you think is next for you [in your recovery/journey/movement through your [disordered eating/eating disorder]?—use language participant has used around DE/ED/recovery]
 - j. How confident are you feeling about your ability to do this?
 - k. What kinds of things do you need to help you get there?
 8. [If person used peer support specifically] If you could describe peer support in one word, what word would you use?
 - l. Why did you choose that word?
 - m. What kind of feelings does that word bring up for you?
 9. Are there any recommendations you would make about the program(s) you are involved in or have been involved in to make them better?
 10. Is there anything else about your experience that you would like to share?

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s40337-024-01068-y>.

Supplementary information 1.

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Author contributions

AL: protocol development; interview guide development, interviewing, formal analysis, writing, reviewing/editing. JC: reviewing/editing protocol and study instruments, commenting on analysis, reviewing/editing manuscript; GD: reviewing/editing protocol and study instruments, commenting on analysis, reviewing/editing manuscript; SJ: protocol and study instrument development, reviewing/editing manuscript; SK: reviewing/editing protocol and study instruments; reviewing/editing manuscript; NO: reviewing/editing protocol and study instruments, commenting on analysis, reviewing/editing manuscript; LW: reviewing/editing protocol and study instruments, commenting on analysis, reviewing/editing manuscript.

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Availability of data and materials

The datasets associated with this study are not publicly available as consent to publish full datasets was not sought and obtained from participants.

Declarations

Ethics approval and consent to participate

This study received approval from the University of Calgary Conjoint Faculties Research Ethics Board (REB22-1590). This approval was also accepted by the Children's Hospital of Eastern Ontario (CHEO) Research Institute. Participants reviewed and signed a consent form prior to being interviewed.

Consent for publication

Study participants completed informed consent prior to participation, which included permission to publish de-identified excerpts/quotes.

Competing interests

Shaleen Jones is Executive Director of Eating Disorders Nova Scotia (EDNS), through whom the peer support described in this article was provided. Sonia Kumar is CEO of Body Brave, who are partners in the provision of peer support. Neither SJ nor SK directly analyzed study data.

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