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**Member Perceptions of an Online Community-Based Program for Adults with Brain
Injury**

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MEMBER PERCEPTIONS OF AN ONLINE COMMUNITY-BASED PROGRAM

Abstract

The purpose of this study was to document member perceptions of an online community-based program that rapidly transitioned from an in-person format during the COVID-19 pandemic. To accomplish this, a sample of 24 adults living with brain injury who are members of the community program completed a survey, and a subsample of 11 of these participants were interviewed. Both quantitative and qualitative data were analyzed using a mixed-methods approach. Results from both methods coalesced around similar themes that indicated the importance of the program in increasing members' quality of life. Survey results indicated that the majority of members prefer in-person programming to online, however the majority are also likely to attend online programming in the future and would like to have both options available. Themes from the interview included (1) The Program Fulfills Members' Needs, (2) The Online Format Improves Accessibility, (3) Members' Thoughts on the Transition, (4) Downsides Associated with the Online Format, and (5) Suggestions for the Future. Discussion includes analysis of benefits and downsides to an online program and the potential utility of this information towards the development and improvement of similar programs.

Keywords: brain injury, quality of life, online, community-based program

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Introduction

Brain injuries affect all domains of human function, including physical, cognitive, and social-emotional. An acquired brain injury (ABI) is defined as any injury to the head that results from either external (e.g. traumatic brain injury from a motor vehicle accident) or internal causes (e.g. cerebral vascular accident [stroke], tumor, etc. (Brain Injury Association of America, 2012). The CDC estimates that over two million individuals in the US sustain an ABI each year with yearly health care costs estimated at \$34 billion (Centers for Disease Control and Prevention, 2014). While the severity of brain injury differs widely among individuals, the impacts on daily living and overall perceived quality of life once they return home are undeniably similar regardless of the etiology of the injury (Williams et al., 2014). Physical impairments impact the ability to navigate environments and engage independently within the community in work and leisure activities. Impairments in cognitive function often result in memory deficits and reduced ability to reason or solve problems. In addition, the behavioral changes associated with cognitive and social-emotional functioning, such as reduced awareness of others, personal insight, mood changes and swings, may hinder the ability to engage in meaningful social interactions (Brain Injury Basics, 2020). As a result, most individuals returning to the community following a brain injury typically have limited social connections and reduced participation in community activities, including work.

Lifelong disabilities represented by chronic brain injury result in considerable needs for long term, community-based support, which often are unmet (Corrigan et al., 2004). For example, Pickelsimer et al. (2007) reported that the unmet needs of persons with ABI included isolation and reduced social access. Community-based programs with the focus of facilitating the return of adults with brain injuries to productive, healthy lives through community-building

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opportunities and social/emotional support groups have been shown to be beneficial in improving quality of life and reducing life stress (White et al., 2016). Further, facilitation of social/emotional support groups for people with brain injuries have been shown to reduce social isolation and improve access to social and vocational opportunities (Hawley & Newman, 2010).

Krempels Center in Portsmouth, NH is a non-profit organization “dedicated to improving the lives of people living with brain injury” (Krempels Center, n.d.). Krempels Center offers an environment that allows for social connection-making and community support within several of its daily program offerings. Members come voluntarily for social connection and to develop skills in areas of perceived need. In three separate studies, staff at Krempels Center, in collaboration with their university research partner, documented the effectiveness of the program, while also revealing some of the elements in the program that made it meaningful to members (White et al., 2016; White et al., 2018; White et al., 2020). This research provides a solid description of how and why the program works in its in-person format.

Unfortunately, the outbreak of COVID-19 caused this community center to temporarily shut down; all in-person programs were suddenly suspended. Recognizing the devastating impact of the shut-down on its membership, staff swiftly transitioned to offering online programming in order to help reduce the effects of isolation and to provide continued opportunities for skill attainment and progress towards goals.

This study proposed to document member and staff perceptions during an extraordinary time in the history of Krempels Center when in-person programming suddenly moved to the online environment during the Covid-19 pandemic, and to explore the effectiveness of offering a sustainable online program in the future. It is framed as a program evaluation applying a mixed methods approach by collecting quantitative and qualitative data. Both online surveys and online

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personal interviews were employed to gather information from members about their impressions of the transition to online programming, including how it was accomplished as well as impressions of how effective the program has been at meeting member needs. Results were then analyzed by two researchers.

Method

Two methods were applied for this program evaluation study. These included an anonymous survey which all participating Krempels Center members were invited to complete and a follow-up interview for a willing subsample of the survey participants.

Participants

Participants were recruited to take the survey through the use of an email asking for volunteers to take part in the research study. This email was sent out to all Krempels Center members, including both members who are their own guardians and members with guardians. 24 members participated in the survey and either consented or their guardians assented prior to answering the first question. 21 members who took the survey were their own guardians. Three participants in the survey were not attending online programming at Krempels Center. At least one participant who was also interviewed was an online member who had never attended Krempels Center in person. In addition to recruiting survey participants through an email, the primary researcher attended an online community meeting and introduced the study as well as asked for volunteers to participate in a semi-structured interview. From there, emails were sent out to the members who demonstrated interest and both consent from members and assent from guardians were obtained through the use of electronic forms. Within the survey, participants were asked if they were willing to be interviewed to more deeply understand their experiences; of the 24 participants, 11 Interviews were set up via Zoom with the members who volunteered

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and were conducted over the span of three weeks during the summer. Descriptive information about the interview participants can be found in Table 1. This is a subsample of survey participants as all interview participants also participated in the survey. Ten of the interview participants were able to express themselves verbally, however one participant had significant aphasia and communicated with me through typing out their responses in the Zoom chat. All participants are relatively local and over half live in NH, with a few members from both Maine and Massachusetts. All participants were given a pseudonym and procedures for the study were approved by a university-based institutional review board (IRB) for ethical conduct in research methods.

Table 1*Interview Participants*

Name	Gender	Type of Brain Injury	Years Post Injury
Alex	Male	TBI	1
Chris	Male	TBI	19
Jane	Female	CVA	6
John	Male	TBI	16
Karen	Female	CVA	7
Kyle	Male	Congenital deformity	Unknown
Mary	Female	TBI	23

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Max	Male	CVA	7
Sam	Male	Brain tumor	13
Susan	Female	TBI	35
Tom	Male	TBI	14

Note 1. This is a subsample of survey participants.

Note 2. TBI = traumatic brain injury; CVA = cerebrovascular accident.

Procedures and Data Analysis

This study applied both a quantitative and qualitative approach to program evaluation, in which the member perceptions of Krempels Center's online programming were assessed using two different methods. By using two methods to collect data on the same topic, triangulation was established to assure validity of the research study (Abowitz & Toole, 2010). The first method used was a survey taken by Krempels Center members. This survey was created using a tool called Qualtrics. Members were given the option to state their name at the end of the survey, however most participants remained anonymous. The purpose of this survey was to establish a baseline understanding of member perceptions regarding the online program at Krempels Center. Survey questions coalesced around what members like and dislike about the online program, as well as how it affects their quality of life and stress (see Table 2). A ten-point Likert scale was used for the questions in which members were asked to rank their stress perception, the program's effect on their quality of life, and their social connectedness to other members. In order to analyze these results, the scale was divided into thirds (1-3, 4-7, and 8-10) and responses were grouped and labeled accordingly (see Figures 4, 5, and 6). All responses were then

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categorized and analyzed to help to determine the overall consensus about the program's effectiveness and whether it should remain an option in the future.

In order to gain a deeper understanding of the benefits and drawbacks of the online program, virtual interviews were conducted via Zoom with 11 participants who volunteered to elaborate on their survey responses. Each participant was interviewed using the same guiding questions (see Table 3) that were intended to elicit unique responses centered around whether the online program is working well or not. Questions were open-ended in order to facilitate a conversation around the pros and cons of the online program, and each interview lasted about 20-40 minutes. All the interviews were video-recorded and transcribed verbatim. Trustworthiness and dependability were established by first having the principal researcher who conducted the interviews analyze the transcripts and identify recurring themes that emerged based on the questions posed. The second researcher read the original transcripts without reviewing the primary researcher's analysis and also came up with themes and major points that stood out to her. Once all the transcripts were read and analyzed by both researchers, notes were compared and discussed between the two and a consensus of the final five major points was developed. Through using this method, confidence was also obtained among the two data analyzers.

Table 2

Sample Survey Questions

- Do you participate in online programming at Krempels Center?
- What device do you use to access Krempels Center online?
- How often do you attend online programming?
- Which format do you prefer, online or in-person? - Please share your reasons.

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- How likely are you to attend the online program in the future?
- Please write the top three challenges of attending Krempels Center online.
- How much does the online Krempels Center program influence your quality of life?
- Reflecting on the past two weeks, how much daily stress have you felt?
- Reflecting on the past two weeks, how socially connected have you felt to other members at Krempels Center?

Table 3

Sample Interview Questions

- Can you tell me what it is like to be at Krempels Center online?
- What online groups do you attend the most?
- What aspects do you like most about online programming?
- What was it like to transition from in-person to online?
- Have the staff been helpful during the transition?
- Is there anything you dislike or would like to be improved in regard to online programming?
- Would you continue to attend online programming if it is still offered later on?
- Is there anything else about the online program that you would like to tell me that I have not asked?

Results

Survey

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Table 4*Attendance characteristics of participants (n=24)*

Online participation	Attendance frequency >2 times per week	Not attending online program
21	15	3

Of the three members who indicated that they do not attend online programming, two shared that they either did not have a camera or microphone on their desktop computer or they felt that they needed instruction in how to use Zoom and create backdrops to maintain personal privacy of their home environment.

Most participants agreed that they were able to access programming more often or the same amount as they used to attend in-person. More specifically, nine of the members who participated in online programming can attend more frequently now that it is online, and ten report that it does not matter whether it is online or in-person, they can attend the same amount either way. Only one member, however, reported that they cannot attend the online program as much as they used to attend the in-person program.

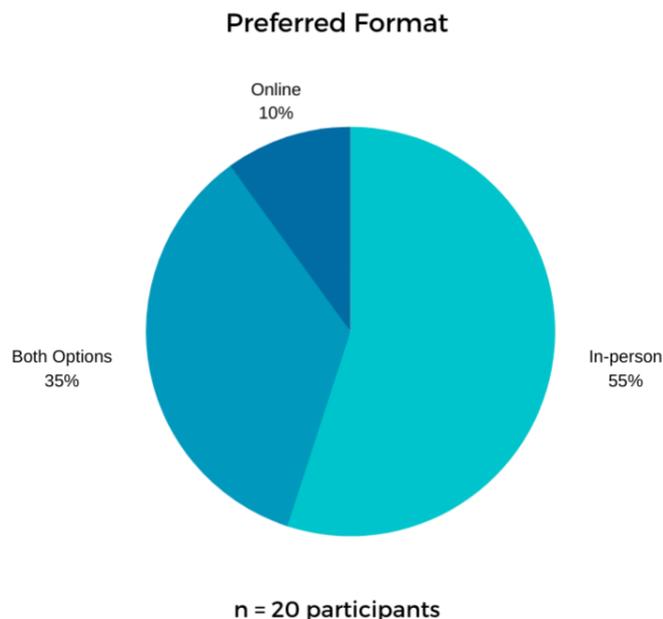
The majority of participants noted that they preferred in-person programming (Figure 1). However, a significant number (35%) stated that they would attend a hybrid version if offered. Reasons for their responses varied. A majority of those who preferred the in-person option stated that they enjoy the personal connections and face-to-face interactions that the center allows. One member mentioned that the program was “beneficial in eluding house arrest” and others agreed that it gave them somewhere to go during the day. Overall, members who preferred in-person programming liked the “social atmosphere” that is supported by the in-person format.

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Those who would prefer to have access to both options reported that the in-person option was great for personal and face-to-face connections, but attendance was sometimes hard and could be “time consuming.” Some expressed that having access to both would allow for greater participation for those who could only attend in-person once or twice a week. Difficulties in attending in-person programming included a long drive and driving expenses.

Lastly, those who prefer the online option reported that it is easier to attend classes online and that it allows them to be more independent and less reliant on others to drive them to the center. Members also reported that it is “less stressful” and gives them more free time.

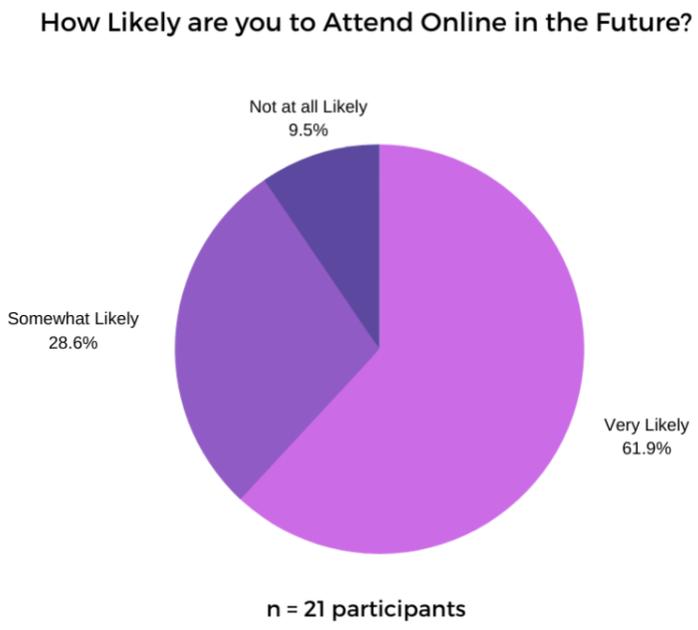
Figure 1



When asked about future attendance, participants responded favorably to attending online as part of a hybrid program (Figure 2).

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Figure 2



Survey participants responded that the staff have been helpful in the transition from in-person to online programming. Members reported that staff were helpful by sending out reminders and links to Zoom meetings, as well as fixing technological problems that arose.

Members were asked to list their top three challenges in regard to attending Krempels Center online. Common responses included: technology/internet problems, sitting all day, staring at a screen for so long, distractions, having to be at home, lack of personal connections, inability to engage, feeling disconnected, and lack of assistance from others.

Of 23 members who participated in the survey, about 75% rated their quality of life as “very good” or “good” (Figure 3). A majority of participants further indicated that the online program has a great effect on their positive quality of life (Figure 4).

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Figure 3

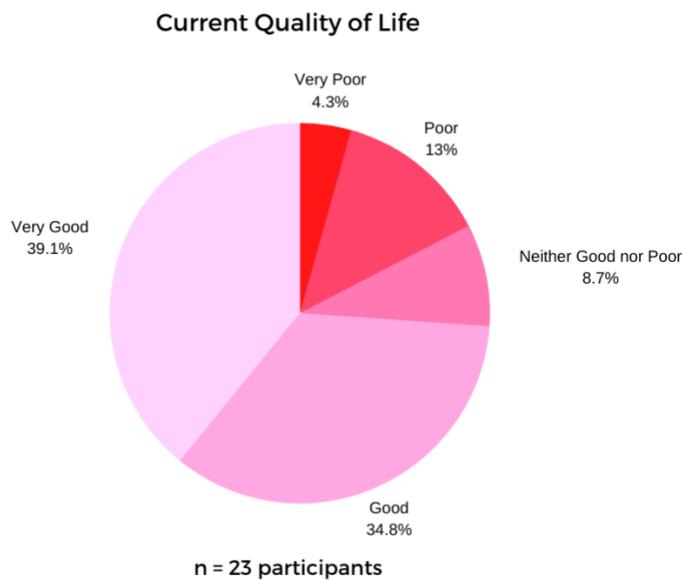
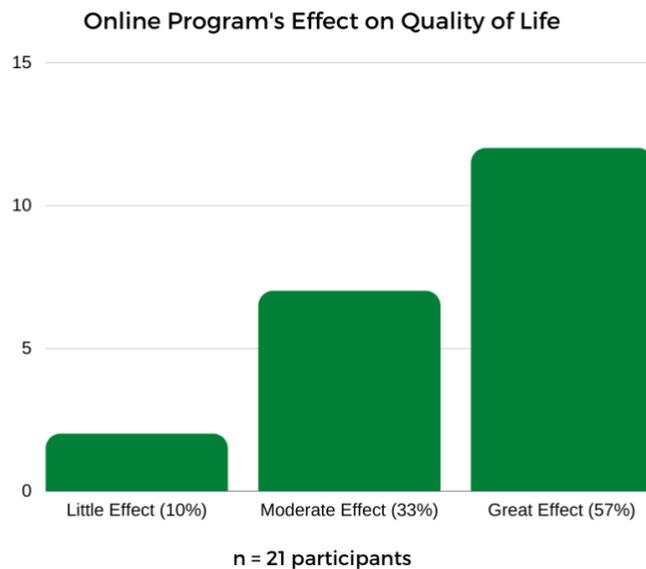


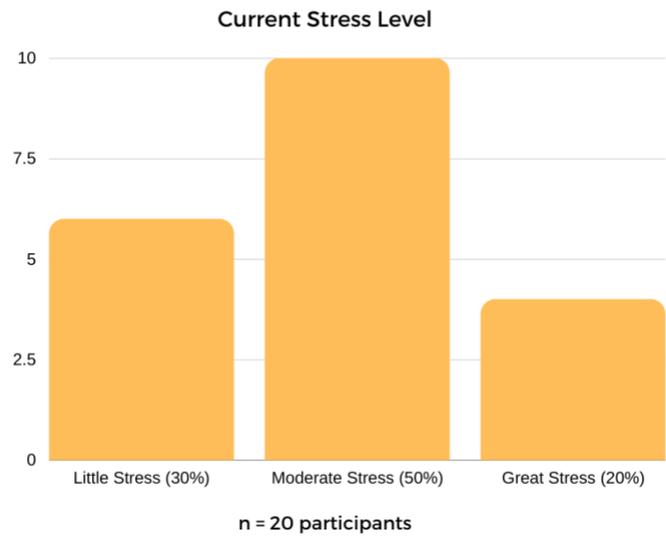
Figure 4



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According to 20 participants, the majority experience a moderate amount of daily stress (Figure 5).

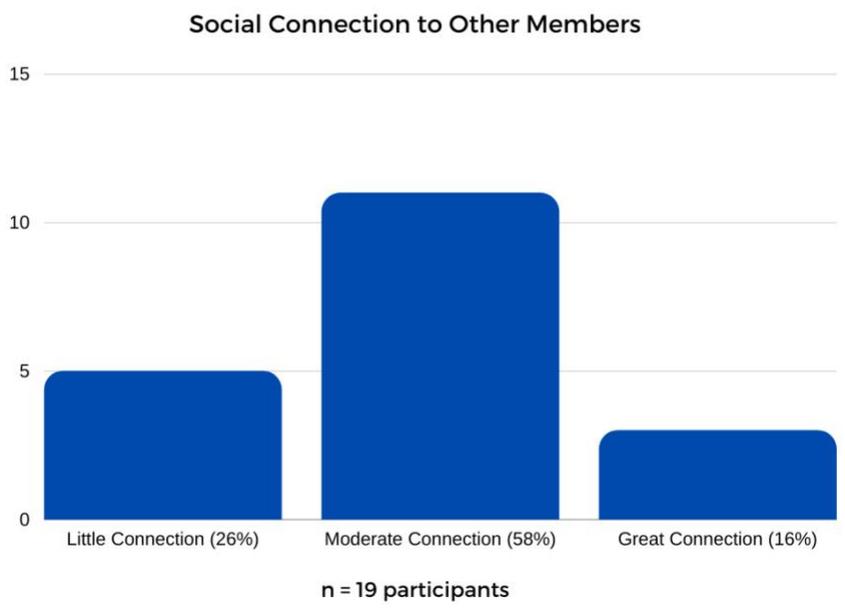
Figure 5



Lastly, the majority of participants indicated that they feel moderately connected to other members at Krempels Center in the online format (Figure 6):

Figure 6

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Interviews

After transcribing all 11 interviews, several key points emerged based on the questions posed. Responses were organized around five common themes and principles including (1) The Program Fulfills Members’ Needs, (2) The Online Format Improves Accessibility, (3) Members’ Thoughts on the Transition, (4) Downsides Associated with the Online Format, and (5) Suggestions for the Future. These groupings all coalesced around how the online program is currently meeting members’ needs and are summarized below.

The Program Fulfills Members’ Needs

The most evident theme among the 11 interviews is that the online program fulfills members’ needs in some way. Topics discussed that fall under this theme include increased socialization, less isolation and depression, improved communication skills, and that the program gives members something to do with their day. Overall, responses indicate that the program increases the quality of members’ lives.

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Many participants spoke about how the online program brings people together, thus reducing social isolation and depression that many brain injury survivors experience. It also promotes feelings of connectedness with others. This is captured by Tom's comment:

"I think the key is to still feel connected... When you have a brain injury you feel like you're the only person, it's you against the world sometimes, but knowing like at least a few times a week I am able to plug in and be in the community. It was really challenging to not be in the community beforehand and now I feel an overwhelming sense of belonging and support when I'm at Krempels and see all the faces and I get that same kind of supportive feeling when I'm online as well... Even though it's different, I can't imagine going through times like this without having that connection" (Tom).

Chris also made a noteworthy statement on this topic:

"Me and a few other members, we communicate with each other several times a day to help each other from getting depressed... Overall for me it's great because I get to see people, I get to interact. I'm not sitting on my couch trying to figure out what I'm gonna do... It greatly improves the quality of brain injury survivors' lives" (Chris).

Several participants also made comments related to the program giving members something to do during the pandemic when there are not many social opportunities. Kyle mentioned that his family leaves for work in the morning every day and he is usually alone. However he shared that the program "... definitely keeps me from making me bored or out of my mind on the Mondays, Wednesdays and Fridays so I am just trying to stay busy on the other days that KC is not open" (Kyle).

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Other participants made it clear that the program is a welcoming space and a “judgement free zone.” This further helps members feel more included and open to having conversations with fellow members. Max shared his experience which captures this well:

“It’s nice not being judged because everyone has been through similar things than you and everyone is very welcoming and understanding. Comforting is the word I would use to describe it... It’s nice being able to talk with the other men at Krempels and share problems and you know help other people get through things. It’s just nice conversations and good people” (Max).

The Online Format Improves Accessibility

The second theme includes comments related to the benefits of the online program over the in-person program in that it is more accessible. This is because there is no transportation needed to participate, the schedule is flexible, it allows people from further away to attend, and contributes to less fatigue in members who are able to take breaks and naps in between if needed. Karen shared that she is now able to attend the program more often now that it is online. She stated:

“For me it’s helpful because before COVID I only went to KC on Mondays because of rides and availability reasons, but now that it is online I do it 3 days a week because I ain’t got anything else to do. I like that I can do it anywhere” (Karen).

Susan also shared that as a result of her brain injury, she has very poor vision and one of her eyes is permanently shut. As a result, she is unable to drive, which is a problem other member face as well. She mentioned that “Getting places is my biggest challenge... I like it all [the online program] because I live an hour and ten minutes away so my dad would have to drive me and now I get to attend all the time and have something to do all the time” (Susan).

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Sam shared that what he likes most about the online program is the “ease of access, I mean I just go to my computer, turn it on and boom no troubles” (Sam).

Chris explained that he struggles with neurofatigue as a result of his TBI, thus it used to be hard for him to get through a day at the center without getting too tired. He said that the drive would “drain his battery” and would need to take a nap right when he got home and couldn’t spend time with his daughter. He commented: “Now that it is virtual, I don’t have that fatigue, I can participate more in the groups” (Chris).

Members’ Thoughts on the Transition

This theme is more of a grouping of responses that related to member perceptions of how well the switch from in-person to online programming went, rather than a key takeaway as represented by the first two themes. Members’ thoughts on the transition include that the staff were helpful with technology issues and incorporated each members’ unique needs. In addition, the transition was effective in that it created little to no stress, technology was easy for the most part, and the format was familiar, so it did not take long for members to get used to. John stated that the transition was

“As good as it could get. I don’t think it was that hard. Obviously, there are some differences and getting used to this and that... I was talking with another intern and we worked on some things, as far as you know technique and tips and tricks about the social aspects of being online” (John).

Chris also believed that the transition went smoothly since the online format was so similar to the in-person one and the technology aspect was easy to learn. He explained that:

“You know it’s great that they kept the same format, the same schedule, morning meeting, morning group, lunch and afternoon group so that familiarity was key to making

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the transition easier... The staff is incredible, and I don't know where they get these interns, but everybody, whether it's virtual or in-person this gives credit to the interns, the students themselves and the professors, it's mind blowing to me" (Chris).

Downsides Associated with the Online Format

While a majority of responses were positive, there were a few negative remarks made about the online program. Common trends around this topic that were brought up include the lack of face to face interaction and lack of one on one time with members. Jane summarized these remarks well by saying

"It feels like I'm talking through a window so it always feels a little amiss... you can't sit down and have a conversation with people, you know, you can go to a break out room but that reminds me of going to a timeout room. I'm sorry but it is just strange to me. But when you don't have that kind of comfort type thing happening that's hard" (Jane).

John also expressed his frustration with the inability to communicate with just one member over Zoom. He explained that everything he says is broadcasted to the whole group and going into breakout room is a "big ordeal:"

"The thing I find most annoying online is that you can't say something to someone directly or you know, show them a picture of something you did last weekend or ask a question to someone or such. There is no opportunity for that period. You know you can ask a question to the group leader, but it's kind of hard. It's hard to say hey I want to chat with you afterwards, hold on a minute. It's hard to single out someone like that" (John).

Suggestions for the Future

The downsides to the online program mentioned by participants point to areas they perceived could be improved. Fortunately, many members offered suggestions on things they

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believe could be done better and techniques that can be used to improve the online format.

Suggestions include having more group options, groups every day of the week rather than just three, more breakout rooms, and a hybrid option (both online and in-person).

As a result of some members preferring the online format over the in-person format and others preferring the in-person format to online format, many members suggested the idea that both options should be available. This would likely increase the amount of people who are able to access it and reap its benefits. Karen shared her thoughts on this:

“I think I would prefer it to be in person, but I was only able to go one day a week because of rides and other stuff so I think it would be nice if they also have the online option in addition to in person. That way I could go in person on Mondays with my mother in law who took me before and do a little bit online if I can as well” (Karen).

During John’s interview, he was adamant about wanting more opportunities to speak to one or a few members individually. He dislikes that there are not many opportunities for breakout rooms and social opportunities besides groups. He suggested that

“One thing I would want to do would be more breakouts, more lunch or you know, more social things. Something along the lines that is more open to communicating with people... Actually, you could probably go into break rooms 1, 2 3, or 4 and maybe join that room and see if anyone else is interested in such. Just have the option so if so and so wants to talk to John, they can be like hey I’ll meet you in this room so they can talk details about you know where would you go for a camping trip, that kind of thing instead of having someone interject where you don’t want them their opinion” (John).

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Discussion/Conclusion

This study sought to explore member perceptions of Krempels Center's transition from in-person to online programming, as well as overall program effectiveness. Results from both methods coalesced around similar themes and the survey data can be used to uphold the major points taken away from the interviews. It is evident, according to both the survey and interview data, that Krempels Center (online and in-person) drastically influences members' lives in a positive manner. The program brings people with unique brain injuries together in a place that fosters social connectedness, feelings of belonging, and encouragement from members and staff. The major points that emerged from this study are notably similar to those that were referenced in a prior study on Krempels Center (White, 2020). The commonalities between the two studies reinforced the sense of community and acceptance that Krempels Center fosters.

Although members commented that the in-person format is irreplaceable in that face to face interactions and personal connections cannot be replicated over Zoom, it is clear that the swift transition from in-person to online is just as important to most members. While a majority of members prefer the in-person format (55%), there is an overwhelming amount of members who are likely to attend the online program in the future (90%). Further, many members stated either in the survey or in an interview that they would like to have the option of both formats in the future.

Those interested in developing similar online programs or transitioning from an in-person to online format may find this study helpful as it provides insight into what aspects of programming members found to be beneficial, as well as certain aspects that could be improved. Participants of this study agreed that the online program promotes an accepting environment for brain injury survivors to share their experiences and it gives them something enjoyable to do

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during the day. A majority stated that staff were encouraging and helpful when technical problems arose, or brain injury related challenges emerged during groups. Participants also made note of staff members' efforts to create groups that are inclusive of all members, regardless of their needs. In addition, participants shared that they enjoy the ease of access that is supported by the online program and are appreciative of the seamless transition from in-person to online. Noteworthy elements of this transition included keeping the daily schedule the same as the in-person one, embedding Zoom links into each group title so that they are easy to access, and the creativity of the staff and interns when leading online groups. All these elements that lead to Krempels Center's successful online program can be taken into consideration by others looking to create or improve their online program.

In addition to the positive remarks made about the online program, some downsides of the program were addressed, and suggestions were made about ways that the program could be improved. Negative comments included lack of opportunity to form personal connections and face-to-face interactions, as well as the inability to speak to one or a few members rather than the whole group. Suggestions offered to mitigate these problems included adding more breakout rooms, creating new groups, having staff give instruction on the use of a backdrop on Zoom, and making programming five days a week rather than three. These remarks and suggestions may be helpful in avoiding similar problems or to become aware of the downsides associated with an online program in general.

Limitations of this study include the small sample size, potential bias among members who chose to participate in the study, and the possibility that participants did not feel fully comfortable sharing their opinions with the researcher. The main limitation of this study is that the sample was taken from a small group of adults with brain injury, all located in close

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proximity to Krempels Center in Portsmouth, NH. All participants were above 25 years old, making it difficult to generalize the results to younger populations. Also, given that the population consisted only of brain injury survivors, this may limit generalizability to populations with different diagnoses who have similar online programs. Another potential limitation is that the members who volunteered to be interviewed and take the survey were biased and whose opinions were not reflective of all the members' viewpoints. Since members were given the choice to take the survey and be interviewed as opposed to being randomly selected, there is a chance that those who volunteered did so because they wanted to share all the good aspects of the online program. It is possible that those who did not volunteer to be interviewed made that decision because they did not want to risk speaking poorly about the program. Fortunately, there was a good mixture of positive comments on the program as well as some negative remarks and suggestions for improvement. A final possible limitation is that the participants did not know the interviewer very well. The interviewer only attended one online programming day, and introduced the study in another, yet did not get to know members on an individual level. This may have resulted in members withholding information about the program when being interviewed. Fortunately, none of the participants appeared at all uncomfortable and were willing to be open and honest about the programming. We also ensured members that any information they shared would remain confidential and that we would use pseudonyms instead of real names.

Overall, results of this study emphasize the importance of community-based programs for adults with brain injury and both the benefits and limitations of a virtual format. Findings from this study offer suggestions on how to improve the online program at Krempels Center, which may help lay the groundwork for similar programs. The findings also provide examples of elements that worked well during the transition from in-person to virtual, as well as the negative

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aspects of the online format. Given the current pandemic and the advancements in recent technology and telehealth, there is a need for increased awareness and knowledge in regard to the benefits of online, community-based programs, such as the one at Krempels Center.

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