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Peer-to-peer connections: Perceptions of a social support app designed for young adults with cancer

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Abstract

Objective: Social support is a critical, yet frequently unmet, need among young adults (YAs) with cancer. YAs desire age-appropriate resources to connect with peers. Peer-to-peer mobile apps are promising interventions to provide social support. Peer-to-peer apps will be more effective if development incorporates users' input for whether app designs (look and function) afford meaningful connections.

Methods: We interviewed 22 YAs to assess perceptions of a peer-to-peer app at a YA cancer convention in April 2017.

Results: Participants were an average age of 29, mostly female (77%), white (73%), and well educated (68% with 4-year college degree or higher). Most participants expressed interested in using an app to connect with YAs, but preferences varied by prevalence or rarity of one's cancer diagnosis. YAs shared trade-offs for profile anonymity versus profiles with more personal information, requests for filter options to connect for varying support needs, and desires for tailored messaging and chat room features (eg, topic-specific and search capabilities).

Conclusion: Findings demonstrate the promise of apps to fulfill YA cancer survivors' unmet peer support needs and provide guidance for app optimization.

Clinical implications: Peer-to-peer support apps should be designed so users can control their identity and customize features for meaningful connections.

KEYWORDS

cancer, eHealth, interactive design, mobile app intervention, oncology, social networking, social support, user experience, user interface

1 | INTRODUCTION

Approximately 70 000 adolescents and young adults with cancer (ages 15-39) are diagnosed annually, and over 1 000 000 survivors live in the United States.[1] Yet the large population of YAs with cancer (ages 18-39) remains underserved with few age-appropriate resources for their unique psychosocial needs.[2] Unmet social support is a prominent issue YAs face.[3,4] YAs struggle to find peers with diagnoses and suffer from social isolation, compounded by extended absences from school and work.[3,4] Lack of social support is associated with poorer physiological functioning, increased sensitivity to stressors, decreased physical functioning, and worse overall quality of life among YAs [5, 6].

Mobile apps may be an optimal platform for increasing social support through connection with peers affected by YA cancer.[5,6] Mobile apps—as electronic health (eHealth) interventions—are feasible, acceptable, and potentially efficacious for health behavior change,[7,8] medication adherence,[9,10] and condition self-management among youth with chronic illnesses.[11] Over 92% of YAs in the United States

own a smartphone,[12] and apps can leverage social networks for personalized social support not available in some physical environments.[13] Moreover, YAs report cancer support should be convenient, preferring technology over face-to-face and from peers with similar cancer-related experiences.[14]

Peer-to-peer apps meet these YA eHealth preferences. Connecting with peers who have shared experiences (without strong attachments of one's core network) can provide critical support through cognitive empathy without adding emotional burden.[15] Given the lack of age-appropriate resources and YAs desire to connect, we hypothesized that YAs will have positive perceptions of apps designed for peer connections to deliver social support. However, little is known about what designs and interactive features—critical for positive user experiences—may encourage engagement.

For peer-to-peer apps to be effective, they must be designed so YAs with cancer can meaningfully connect with peers. While many free apps are available for cancer prevention, detection, and management,[13,16] less than 1% of apps have social support features (ie, cancer survivor stories, member locators, and communication tools), and there is no evidence for how these features influence online support, whether potentially through increases in social connectedness[17,18] emotional support, friendship, or reductions in loneliness and perceived rejection.[19] App development should be directly informed by users (ie, user-centered design) and evidence-based theories.[20] According to social presence theory, the design and functionality of interactive features influence whether users feel immersed and connected with others via media.[21] This feeling of being with peers (ie, social presence) is an important motivator for seeking and sharing support online.[22] To our knowledge, there is no evidence for how YA cancer apps could be optimized to increase feelings of being with peers and reliable access to social support that facilitates engagement to meet YAs changing needs.[21-23]

The study aimed to gain insights for YAs' perceptions of and willingness to use peer support apps. We elicited reactions to one app, the Stupid Cancer app, developed for YA (ages 18-39) and available to anyone in the YA cancer community, where users can connect based on similar demographics or cancer characteristics (eg, age, gender, and disease type/stage) in private, one-to-one messaging or group chats. Perceptions of the app from the YAs with cancer are critical for eHealth development to foster authentic engagement and, in turn, improve social support and well-being.[24]

2 | METHODS

This study was conducted during a YA cancer convention, CancerCon, in April 2017. The University of North Carolina's Institutional Review Board approved all procedures (17-0922).

2.1 | App stimuli

Participants interacted with an app developed by Gryt Health for Stupid Cancer—a YA cancer advocacy organization (https://grythealth.com/the-app).[25] The app is designed to give YAs control over whom they connect however they feel comfortable (private messages vs group chats).

In the app, users view introduction screens explaining the features and app purpose before setting up a profile (eg, demographics and cancer diagnosis) with an avatar (Figure 1). Users customize the skin tone and hairstyle of the avatar, including options with or without hair, headscarves, and hats. The discover tab shows a list of possible peer connections, populated by an algorithm. Users can use the "say hello" button for the messaging feature, similar to sending a text message. Users can also enter the chat room for group conversations.
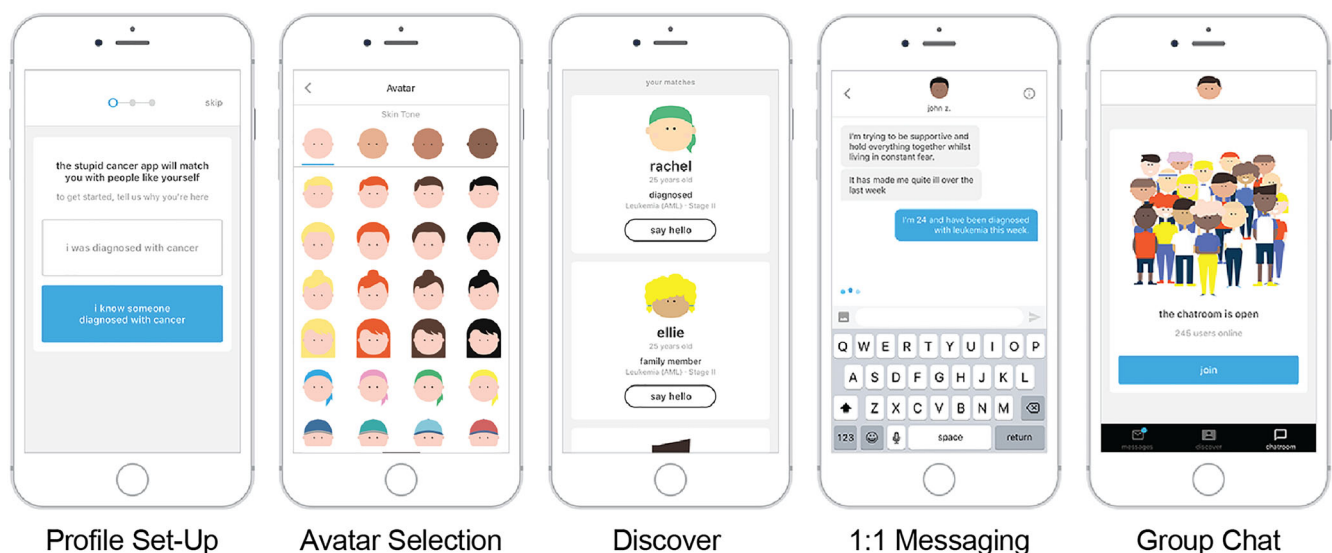

| Profile Set-Up | Avatar Selection | Discover | 1:1 Messaging | Group Chat |

FIGURE 1 Peer-to-peer app features

2.2 | Study participants and procedures

All CancerCon registered attendees (n = 329) were invited via email to share opinions about the peer-to-peer app. Follow-up emails for interviews were sent to all eligible participants (over 18 years old; diagnosis as a child, adolescent, or YA). Among those interested (n = 34; 10.3%), 27 attendees scheduled interviews (8.2%). Five interviews were with caregivers and excluded. Participants were given $25 gift cards.

Following informed consent, half-hour, semi-structured interviews were conducted with researchers (A.J.L. and A.J.S.) in private locations at the convention. All participants, previously unknown to the researchers, were informed this research was conducted independent of Stupid Cancer to understand peer-to-peer app perceptions. The interviews began with requests to audio record. Each participant then completed a survey with demographic and cancer-related (diagnosis and treatment status) items and was given a phone with a beta version of the Stupid Cancer app. Participants viewed the introduction as if they downloaded the app. When prompted for personal information, a test account was used. Participants were given time to explore app features at their own pace. Participants were asked their overall impressions, including likes and dislikes, and their willingness to use the peer-to-peer app. Next, participants were asked these questions (ie, overall impressions, likes, dislikes, and willingness to use) about each feature and asked if they would share the app. Individual interviews with YAs, and in one case in the presence of a caregiver, were conducted until saturation of themes was reached.

2.3 | Data analysis

Audio files were transcribed verbatim. Notes were taken (A.J.L.) and reviewed (A.J.S.) for the one interviewee who declined to be recorded. We used manual, open coding with an inductive analysis approach to identify emergent themes in the interview transcripts (and notes).[26] Two researchers (A.J.L. and L.H.) analyzed transcripts to develop a codebook for themes and subthemes. One researcher then coded all transcripts (L.H.); a random subset was parallel coded by the second researcher (A.J.L.). Lastly, the two researchers reviewed all coding, discussed until agreement was reached, and interpreted all coding into broader themes.

3 | RESULTS

Participants included YAs with a prior cancer diagnosis (n = 22; Table 1). The average age was 29 (SD = 5.09); most were female (77%), non-Hispanic (96%), and White (73%). Primary diagnoses included leukemia (27%) and Hodgkin lymphoma (23%), among others. Participants were "in treatment" (14%), "on-going therapies" (14%), "chronic disease" (18%), or "completed treatment" (55%). Themes are below and in Appendix A.

3.1 | Peer-to-peer app reception

YAs with cancer expressed interest in using a peer-to-peer cancer support app. One participant stated, "I think this could be a really cool outlet to be able to make some [peer connections] or even keep connections." Others were more tempered, desiring more features or benefits to drive use. As one participant stated, "I would [use a peer-to-peer app], provided it has ... interactivity and the social media and stuff."

A few users expressed cautious enthusiasm, stating they had been excited about social apps before but quickly lost interest after discovering few people actively engaged. As one participant explained, "if a lot of people are using it I think a lot of people will use it." Despite concerns, most participants stated they would download the app and share it.

3.2 | Peer-to-peer connection preferences

Participants differed in the ways they wanted to connect with peers. Some YAs wanted connections with at least one commonality; others preferred matching on multiple characteristics.

Connection preferences notably varied by prevalence or rarity of their diagnoses. Those with more prevalent diagnoses desired connecting to peers who shared multiple characteristics (eg, diagnosis, location, age, and gender), whereas YAs with rarer cancers feared algorithms would yield too few matches and sought to connect based on a single criterion for specific needs. Users with rare diagnoses shared that they would look for different connections to provide informational support (eg, shared treatment) versus social support (eg, shared location and life status). One YA described, "... there are a lot of rare cancers ... I know for sure I am never going to find anybody with my type of cancer on this app or maybe in the world ... similar type of treatment or like same hospital will be really great."

Participants desired search features to tailor connections for issue-specific support needs, beyond algorithm-based options. One participant stated, "I would love to have suggestions right off the bat that are prepopulated for me, but I would also like the ability to go through and be like I am having some girl related issues so I would like to find girls my age ... But if I am having a treatment related issue then I would want to see people with my type of cancer." Some participants expressed interest in building a mentor/mentee relationship to connect with survivors for advice and to share their experiences. Additionally, participants—often those with more prevalent diagnoses—indicated a desire to use the app to make in-person social connections, to complement the virtual environment.

3.3 | Profile representations in peer-to-peer apps

Participants differed in how they wanted to represent themselves within peer-to-peer apps, highlighting a profile paradox—the desire to balance privacy and anonymity with developing more intimate connections. Participants desired control over their identity expression,

TABLE 1 Participant demographics

	% (n)
Gender	
Female	77 (17)
Male	23 (5)
Hispanic	
No, not Hispanic or Latino	96 (21)
Yes, Hispanic or Latino	5 (1)
Race	
American Indian/Alaska Native	5 (1)
Asian	14 (3)
Black	9 (2)
White	73 (16)
Currently enrolled in school	
No	82 (18)
Second year undergraduate	5 (1)
Third year undergraduate	5 (1)
Graduate or professional school	9 (2)
Education (not enrolled)	
Some college or technical schooling	5 (1)
2-year college degree	9 (2)
4-year college degree	41 (9)
More than 4-year college degree (eg, graduate degree)	27 (6)
Living environment	
Rural	5 (1)
Suburban	64 (14)
Urban	32 (7)
Employment	
I am employed full-time	64 (14)
I am employed part-time	14 (3)
I am not employed	23 (5)
Diagnoses[a]	
Brain tumor	9 (2)
Breast	5 (1)
Epithelioid hemangioendothelioma	5 (1)
Hodgkin lymphoma	23 (5)
Leukemia	27 (6)
Liver	9 (2)
Neurofibrosarcoma	5 (1)
Non-Hodgkin lymphoma	5 (1)
Sarcoma	14 (3)
Treatment status	
In treatment	14 (3)
On-going therapies (hormonal, immunotherapy, etc)	14 (3)
Chronic disease (in/out of treatment)	18 (4)
Completed treatment	55 (12)

Note. n = 22. Verbatim response options are shown.

[a]Diagnoses include additional open-ended responses.

but differed for options they would use to do so. A little over half of the participants liked an avatar for their profile, although many wanted to personalize avatars with facial expressions, jewelry, and facial hair to add detail and convey emotion. Participants from racial minorities needed more representative skin tones and hair options. Without these options, minorities may be discouraged from using these cancer support resources; one African American participant stated, "I am not a fan at all … The black people skin tones are definitely off."

Participants appreciated the privacy and anonymity afforded by avatars rather than photographs for their profiles. One participant stated, "I think just the anonymity of it. Not having any biases towards people because of how they look … Like you have this diagnosis, you are this age, and it is not like a judgmental thing, but more of a scientific, fact-based thing." Another participant noted the appropriateness of avatars to avoid physical appearance disclosure during treatment, "I don't have to worry about taking a picture of myself that is cute, which is important for a lot of people, especially if you are sick and you are not happy about your bald head or swollen cheeks." When participants shared concerns about security, anonymity, or asking intimate questions, they often preferred using avatars; maintaining and/or protecting their identity was paramount to connections with other, unidentified users.

Conversely, participants desired to "know" whom they are interacting with; for a "connection" or a "relationship" via the app, they wanted a photo, most notably, of the other user and for some, of themselves. Participants felt more assured of the authenticity of connections with photographs than avatars. Participants also felt pictures would facilitate more personal relationships, through feelings afforded when putting a face with the user. Many participants acknowledged that photographs come at the expense of one's anonymity and preferences could differ for private and public chat features; "I think when you are trying to connect on a personal level, a face and a name are good to go together. I like face and name connections … I think for the chat room I would much prefer an avatar."

Some participants suggested linking to other social media accounts in profiles would increase their trust in other users, despite privacy trade-offs. Opinions were mixed; some viewed links to other social media accounts as a security measure, while a few participants wanted to keep their cancer profile separate from other accounts. If separate, some suggested these apps could serve as safe, unique environments for the YA cancer community. One participant said, "I don't know if I necessarily do want it to be integrated. I think people, even though they want to connect to other people that are affected by this, they [aren't] necessarily ready to go public in certain other respects … I think if you add [other social media] onto it then it kind of takes away that safe space."

3.4 | Interacting within peer-to-peer apps

Participants expressed excitement about using apps with private and public chat features. Several participants offered suggestions to enhance users' experiences.

3.4.1 | Chat rooms

Participants were mixed on how frequently the chat room should be open. Some preferred specific, announced times to minimize chances of someone posting a comment or question that goes unanswered. Others said having specific times would pose scheduling conflicts. Participants also desired chat rooms for specific topics, rather than a general chat room open to all users/comments; "… it would be awesome to have an all-girls chat room." With a mind toward privacy, participants also desired control over their identity in chat rooms; one participant shared, "I think it would be nice to have the option of making [your account] public and/or private [e.g., private for some features]. I think there are like women out there who have infertility and just issues about intimacy or whatever relationships … if there is an option of making it private it might be something they want to discuss in a chat room." Female participants were more likely to desire gender-specific chats for potentially sensitive topics.

Some participants desired organized chat rooms for user-suggested topics or chats with medical professionals to answer questions. Participants suggested public-facing chats include search options so users could quickly find information and use these apps as reference, not just for real-time connections.

3.4.2 | Private one-to-one messaging

Participants were eager to connect via private messages and appreciated features similar to traditional texts in a secure cancer support environment. Most respondents endorsed that users should be limited to sending only a few texts to a new connection to restrict unreciprocated contact; read receipts and blocking options were also desired to control interactions. Beyond individual connections, most people also wanted the option to connect with multiple people through private group messages that could allow users to develop relationships, share information, and potentially coordinate meet-ups.

4 | DISCUSSION

Social support is one of the primary unmet needs of YA cancer survivors.[3,4,27] Given nearly ubiquitous increases in the use of smartphones and desire for convenient technology-based interventions, mobile apps can be tools to address this need.[6,13,28] However, for any technology intervention to be effective, early development must include patients' input for features they desire to use.[24] Our findings indicate that YAs are eager to use apps to access peer support, with varied feature preferences. Peer-to-peer app development should be mindful of how YAs want to connect, interact, and reveal themselves to balance privacy with social support needs.

The app was perceived as a potential outlet to learn about cancer-related experiences and address psychosocial concerns, reflecting how YAs with cancer use online support groups for informational support, to cope with emotions, and to define their self-identity throughout the cancer continuum.[29] Yet participants envisioned using the app

differently; some (generally with more prevalent diagnoses) saw the app as an opportunity to connect with peers with many similar characteristics, while others with rare diagnoses desired to connect with individuals based on one shared characteristic (eg, treatment and marital status) to leverage a larger network to meet their information and emotional social support needs. Enthusiasm for the app was tempered by skepticism of whether enough users would join the community to provide ample connections. Research validates this hesitation; the more users that join a support group or network, the greater the benefits to all users.[6,30]

A prevalent theme that emerged was the juxtaposition of desires for anonymity versus more personal connections—disclosing more or less about one's identity through photographs or linking to other social media accounts. As YAs grapple with their cancer identity, online environments can uniquely afford anonymity to minimize sociodemographic differences, allow YAs to present themselves however they wish, and facilitate discussion of sensitive topics.[6,31] Using an avatar would provide participants anonymity to discuss personal information and seek support in a way they could not face-to-face, or if they had a profile picture. Conversely, over half of the participants were willing to trade anonymity for more personal connections with other users through profile pictures, where photographs—as cues for the evidence of a real person—increase a sense of authenticity and potentially intimacy of the connection.[21] Overall, users consistently desired control over their profile and security settings, with abilities to confirm other users' identities, to facilitate intimate social connections.

While some YAs wanted to link the app with their mainstream social media (eg, Facebook) accounts, others desired a separate network for cancer support. Feeling emotionally isolated from existing networks is common among YAs,[6,32] and whether current social media help or exacerbate negative feelings is highly debated. Critics of social media note that spending more time with online social networks is associated with negative physiological well-being, including loneliness and depression.[33] Proponents of social media have shown that online social support (eg, via Facebook) can uniquely contribute to well-being and social connectedness,[17,34] especially among those who more readily express their true self online[35] and those unable to receive face-to-face support.[36] While this study focused on perceptions of a unique platform for peer-to-peer support, further investigation should ensure online support for YAs meets both their identity and connection needs. While users of standalone support apps may benefit from having greater control over their unique cancer identity and interactions, features nested within mainstream social media (eg, private Facebook group) provide other beneficial opportunities, such as potentially reaching a larger network—a notable adoption concern of participants was too few users—and allowing users to more easily integrate cancer in their broader identity, if desired.

Participants had mixed desires for complementing app relationships with in-person meetings. Online social support has unique challenges stemming from a lack of nonverbal communication cues, discomfort with expressing emotions in written word, and over-reliance on the online community, all of which may be overcome by in-person connections.[6,31,37] However, YAs—especially those with rare diagnoses—were not concerned with in-person connections; they were more interested in meeting others with their diagnosis and acknowledged online apps offer access to larger communities with shared experiences.[38] Overall, users desire connecting with real people to give and receive support for the many unique challenges of cancer on their terms, controlling their identity and not solely through algorithm-based connections or prescribed chat times and topics.

4.1 | Study limitations

All participants were recruited from CancerCon, a convention for YAs with cancer. Participants may systematically differ from those who chose not to attend. Attendees could have an increased desire for social support, indicated by their convention attendance, and a higher socioeconomic status, indicated by the ability to afford travel. Thus, results may not be transferrable to YAs with cancer broadly. On the other hand, recruiting CancerCon participants provided opportunity to reach YAs who may not respond to standard research recruitment or hospital-based studies. Future app optimization research should survey a broader network of YAs.

4.2 | Clinical implications

Despite the promise of cancer-focused apps, too many well-intentioned intervention apps are unused, and very few are developed with specific YA community needs in mind.[13,16] Optimizing the design of peer-to-peer apps to increase authentic feelings of being with others (eg, customizable profiles) and seeking and sharing in the app (eg, tailored connections) is important step to increase user participation[21-23] and the likelihood of meaningful connections in the app. While tech-based interventions are often touted as cost-effective, there is limited economic evidence for developing customizable platforms to improve health outcomes.[39] Future economic and behavioral evaluations are critical to fully assess the scalability, sustainability, and, most importantly, ability for peer-to-peer apps to deliver social support to YAs who need it the most. Improving peer-to-peer apps based on user feedback is a critical first step to improve engagement among the YA community and, in turn, facilitate access to social support after a cancer diagnosis to improve health outcomes.[24]

5 | CONCLUSION

YAs with cancer desire peer-based social support and welcome eHealth designed specifically for their cancer community. Peer-to-peer apps should be designed to balance connection and intimacy with security concerns and include customizable features to meet individual needs (eg, profile options, search features, and private group messaging). Using evidence-based recommendations to optimize user experiences has promise to enhance connections in peer-to-peer apps and, potentially in turn, facilitate social support to alleviate a critical psychosocial concern of an underserved YA cancer population.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

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APPENDIX

PERCEPTIONS OF A PEER-TO-PEER APP FOR SOCIAL SUPPORT

Themes	Quotes
App Reception: An app could serve as a positive alternative to other support options	"Yeah [I would use the app], I don't want a group session where we are all talking about how we feel. I tried that, didn't work. "I was going to a pediatric clinic so most of the people that I saw were 2 years old or, you know, 10 and I was 20. Or on the flipside, I started out in an adult oncology ward and the people around me were 60 and 70, and so there is kind of that feeling like there wasn't anyone else my age that was going through it, and so like I was able to find some support groups online through Facebook, but I think if I had had an app to use that I would have."
Connection Preferences: An app could facilitate connections for similar experiences, non-cancer conversations (with those who "get" it), and mentorship	"I feel like everyone is in a different stage of life as a young adult too which is really interesting thing about being so young and so even I don't know how you would be able to do this but just like me being a patient as a student is really different from like late 20's being professional, losing their job, just a very different stage of life even though we might be like 5 years apart." "Regardless of what we are going through personally, as a person who has terminal cancer, I still want to focus on normal stuff as much as possible... We are not sitting there talking about how long do you have and what are you not able to do. It is more like here is this gal who loves to go kayaking and now she is involved with this nonprofit that does kayaking for cancer survivors and here is me who works as a ropes course facilitator trainer and trains people in high ropes courses even though I am dealing with this ..." "I think [a mentorship feature] could be really powerful in the app ... I just know a lot of people do find a lot of peace through online forums and being able to see someone say, like, oh my gosh I have been through that too. I know people find their social support through that."
Profile Representation: Avatars provide anonymity, but photos facilitate connection	XI think avatars are better for [a place where you can anonymously talk] but if it is the kind of place where you are wanting to connect with other people that are like you and build some sort of support group I feel like maybe pictures are better for that." " think it would be easier to connect with people if you could see like who you are talking to.wasn "I like that if you are the person in treatment that you have [avatars] that have little scarves and hats, so that in case you don't have hair, because I have been there."
Feature Interactions: Customization of interaction features allows users to find others based on specific needs	"I guess in my head when I think about the issues that I want to talk about with other survivors or caregivers or whatever like I kind of compartmentalized them with diagnosis and then gender and age related. So I would think of chatrooms kind of like that." "I like that you can use messages and chat with people [in one app] ... because I really hate the Facebook has a second messenger app." "Like say 30 people come to my meetup and I don't want to give 30 people my phone number because I don't really quite know them, but hey, lets connect in this app and we can all message under this one group."