

Developing Social Enhancements for an Online, Positive Emotion Intervention for Alzheimer's Caregivers: Qualitative Study of Focus Groups and Interviews

Ian Kwok, Emily Gardiner Lattie, Dershung Yang, Amanda Summers, Paul Cotten, Caroline Alina Leong, Judith Tedlie Moskowitz

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Ian Kwok¹ MSc; Emily Gardiner Lattie¹ PhD; Dershung Yang² PhD; Amanda Summers¹ MA; Paul Cotten³; Caroline Alina Leong¹; Judith Tedlie Moskowitz¹ PhD, MPH

¹Northwestern University, Feinberg School of Medicine Chicago US

²BrightOutcome Buffalo Grove US

³University of California San Francisco San Francisco US

Corresponding Author:

Ian Kwok MSc

Northwestern University, Feinberg School of Medicine

420 E Superior St

Chicago

US

Abstract

Background: Alzheimer's disease (AD) is a degenerative neurological condition that requires long-term care. The cost of these responsibilities is often borne by informal caregivers, who experience an elevated risk of negative physical and psychological outcomes. Previously, we designed a positive emotion regulation intervention that was shown to improve well-being among dementia caregivers when delivered through one-on-one videoconferencing lessons with a trained facilitator. However, the format required significant resources in terms of logistics and facilitator time. To broaden the reach of the intervention, we aim to develop SAGE LEAF, an iteration of the intervention in a self-guided, online format with enhanced opportunities for social connection.

Objective: The aim of the present study was to gather feedback to inform the design of social features for the SAGE LEAF intervention. In the absence of a facilitator, our goal with the self-guided SAGE LEAF was to integrate various social features (e.g. discussion board, automated support, profiles, etc.) to maximize engagement among participants.

Methods: Qualitative data were collected from 26 individuals through 1) interviews with participants who completed a previous version of the intervention via videoconferencing with a facilitator, 2) focus groups with dementia caregivers who had not previously experienced the intervention, and 3) focus groups with AD clinical care providers. We conducted a qualitative, thematic analysis to identify which social features would be most helpful and how they could be implemented in a way that would be best received by caregivers.

Results: Interview and focus group feedback indicated participants generally liked the potential features suggested in the interviews and focus groups, including the discussion boards, multimedia content, and informational support. They had valuable suggestions for optimal implementation. For example, participants liked the idea of a buddy system where caregivers would be matched up with another for the duration of the study. However, they expressed concern about differing expectations among caregivers and the possibility of matched caregivers not getting along. Participants also expressed interest in giving caregivers access to a podcast on the skills, which would allow them to review additional content when they wished.

Conclusions: Taken together, the discussions with caregivers and providers offered unique insight into the types of social features that may be integrated into the SAGE LEAF intervention, as well as implementation suggestions to improve acceptability of the features among caregivers. These insights will allow us to design social features for the intervention that are optimally engaging and helpful for caregivers.

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Original Manuscript

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Conclusions: Taken together, the discussions with caregivers and providers offered unique insight into the types of social features that may be integrated into the SAGE LEAF intervention, as well as implementation suggestions to improve acceptability of the features among caregivers. These insights will allow us to design social features for the intervention that are optimally engaging and helpful for caregivers.

Keywords: Alzheimer's disease, dementia, caregiving, eHealth, online interventions, positive emotion, stress, coping.

Introduction

The impact of Alzheimer's disease (AD) continues to broaden as the global average life expectancy grows.¹⁻² Consequently, the number of individuals who will assume the role of a primary caregiver of a friend or family member with AD is expected to rise, with estimates indicating that informal care accounts for 40% of the total cost of care.³ In the US alone, this amounts to an estimated annual total of 18.6 billion hours of unpaid care.⁴

At the individual level, the protracted nature of AD results in an extended caregiving role that intensifies as the care recipient's health gradually declines.⁵ For example, initial caregiving responsibilities may include assisting with activities of daily living like providing transportation, preparing meals, and helping with chores.⁶ However, in more advanced stages of the disease, caregivers often have to cope with agitation, aggression, and wandering⁷– while shouldering an increasing logistical and financial burden of coordinating care.⁸⁻⁹

The weight of these responsibilities comes at a cost to caregivers, who experience adverse mental health outcomes, like increased depression, anxiety, and suicidality;¹⁰⁻¹³ as well as negative consequences for physical health, demonstrated by increased sleep disturbance, fatigue, and undernutrition.¹⁴⁻¹⁵ This, in turn, may lead to a decline in the quality of care and subsequently, poorer outcomes for the care recipient.⁵

In light of the growing recognition of the stress of AD caregiving, researchers are developing targeted interventions that offer a combination of psychoeducation, social support, and / or psychological support for caregivers.¹⁶⁻¹⁷ Of note, researchers are increasingly using eHealth technologies that leverage electronic information and communication (e.g. telehealth, mobile apps, and web-based apps) to broaden dissemination of these resources.¹⁸⁻¹⁹ Since the onset of the COVID-19 pandemic, eHealth technologies have found renewed significance when in-person AD support services were suspended, necessitating a rapid shift to telehealth offerings.²⁰

The present study was the first step in the adaptation of an existing caregiver intervention into a socially enhanced online intervention – SAGE LEAF (Social Augmentation of self-Guided Electronic delivery of the Life Enhancing Activities for Family caregivers). SAGE LEAF will comprise a positive emotion regulation curriculum that has been shown to be helpful for individuals experiencing significant life stress, including those with type-2 diabetes, metastatic breast cancer, HIV, and depression.²¹⁻²⁴ In a prior study, the intervention was also tailored specifically for dementia caregivers, and delivered through videoconferencing by trained facilitators.²⁵ The intervention was effective at reducing symptoms of depression, while improving self-reported physical health and positive emotion outcomes. However, the one-on-one facilitation that was provided for participants required a significant commitment of resources in terms of recruiting and training facilitators, as well as an estimated 6-8 individual contact hours per participant over the course of 6 weeks. Hence, our goal is to tailor the self-guided, online version of the intervention for caregivers, while incorporating unique *social features* that may help foster engagement among participants.

Specifically, our aim was to enhance *social presence*, defined by computer-human interaction researchers as the perception of others in an online environment.²⁶⁻²⁸ The construct has been shown to be associated with enhanced perceived learning and satisfaction in e-learning

environments.²⁹ But to identify potential social features that may be helpful for Alzheimer's caregivers, it is also necessary to first understand how they currently utilize social technologies to support their caregiving activities and emotional well-being. For example, caregivers may utilize discussion boards hosted by the Alzheimer's Association,³⁰ or those on social platforms like Facebook or Reddit.³¹ Furthermore, in the context of the COVID-19 pandemic, caregivers are now increasingly reliant on these social technologies with the rapid shift from in-person to virtual support resources, which include videoconferencing support groups for caregivers.³²

Hence, to examine the preferences and requirements of Alzheimer's caregivers, the present study aimed to solicit feedback about a set of potential social features for the SAGE LEAF intervention. These were identified from a review that we conducted on social features that were being implemented on research-focused and commercial eHealth apps,³³ in consultation with study team members and developers who were involved in the design of previous versions of the intervention (Table 1).

Table 1. List of Social Features

Social Feature	Description
peer groups / cohort	Enrolling caregivers in groups so that they have a "cohort" of peers that progress together in the program. This allows group participation to occur synchronously in a "live" online setting or asynchronously in a manner that allows patients to engage with the intervention at their own pace in the context of an assigned cohort. ³⁴⁻³⁶
profiles	A profile page that may be shared with others. Examples of profile content include being able to choose an avatar and answering some questions about themselves. Such features involve varying levels of self-disclosure, data management, and personalization that may enhance the sense of the presence of others in the intervention. ³⁷⁻³⁹
private messaging	Participants are able to send each other private messages. Some examples include messaging through SMS, ⁴⁰⁻⁴¹ commercially available apps like Facebook, Whatsapp ⁴² or built into the eHealth intervention. ⁴³⁻⁴⁴
buddy system / matching	Pairing participants who are going through the study at the same time. Some examples include matching participants who are going through the intervention at the same time, with someone who has previously completed the program as a "peer mentor" each other, or enrolling a partner the participant has an existing relationship with. ⁴⁵⁻⁴⁷
videoconferencing group	A facilitated group with participants through videoconference. Similar formats include support group and education / training videoconferencing sessions. ⁴⁸⁻⁴⁹
discussion board	An online discussion board on the content of the lessons. Possible discussion board enhancements, include notifications when other users like or comment on their

	posts. ⁵⁰⁻⁵²
automated support	May include reminders / notifications for participants who are not logging in or feedback collected at the end of lessons. Such features have been shown to enhance adherence in eHealth interventions. ⁵³⁻⁵⁴
multimedia / videos / podcasts	These forms of multimedia are commonly used to disseminate educational material in a way that engages participants, thereby promoting literacy and enhancing health-related outcomes. ⁵⁵ This might include testimonials and quotes from previous participants, or messages from the study team.
informational support	FAQs or other information about how to connect with caregiver organizations, online support groups, and mental health providers. Such resources may enhance a participant's sense of perceived support and information competence. ⁵⁶

We collected feedback through 1) individual interviews with caregivers who completed the prior version of the intervention,²⁵ 2) focus groups with dementia caregivers who had not yet been exposed to the intervention, 3) focus groups with clinical providers of people with AD. The findings will inform the types of social features to be included into the SAGE LEAF intervention, and how they can be implemented in a way that is most beneficial for caregivers.

Methods

Design

A combination of focus groups and interviews were conducted to solicit feedback on the short list of potential social features for the SAGE LEAF intervention. Subsequently, a qualitative analysis was conducted on the transcripts to identify gather feedback about each feature.

Sample and Sampling

Three groups of participants were recruited:

- 1) Individual interviews: Dementia caregivers who participated in a previous version of the intervention.⁵⁷ We emailed individuals who had previously provided consent for recontact and provided them with information about the interviews. If they wished to participate, they completed a screener survey to determine if they met the following eligibility criteria: 1) currently identify as the primary family caregiver of a person with dementia, 2) speak and read English, 3) have access to high-speed internet, and 4) have access to a webcam for videoconferencing. The interviews were conducted by the lead author (I.K.), who adhered to a semi-structured interview protocol to guide the discussions. They lasted approximately 45-60 minutes, and topics included 1) the types of social connection technologies that participants use in their everyday life, 2) reactions to potential social features that may be implemented for SAGE LEAF (e.g. private messaging, discussion board, virtual profiles etc.), and 3) solicitation of suggestions for other additional social features not previously mentioned.

- 2) Caregiver Focus Groups: Dementia caregivers from Northwestern Memorial Hospital's Cognitive Neurology and Alzheimer's Disease Center (CNADC) were recruited for 2 focus groups comprising 5 caregivers each. We emailed caregivers who had previously provided consent to be contacted for research purposes through the CNADC and provided them with information about the focus groups. If they wished to participate, they were asked to complete an online screener survey to determine if they met the following eligibility criteria: 1) currently identify as the primary family caregiver of a person with dementia, 2) speak and read English, 3) have access to high-speed internet, and 4) have access to a webcam for videoconferencing. The focus groups lasted approximately 90-120 minutes, and was similar in content to the interviews. 2 focus groups were conducted, comprising 5 caregivers each (N=10)
- 3) Clinician Focus Groups: We contacted clinicians who provided care for people with AD or their family/informal caregivers (e.g. physicians, nurses, social workers, etc.) through email from the CNADC and the University of California, San Francisco's (UCSF) Memory and Aging Center. Both are comprehensive research and care centers that treat Alzheimer's disease, hence clinicians are involved in a broad range of AD programs that integrate patient care, training, and research. Interested clinicians completed a screener survey where they could indicate their professional experience to determine if they met the following criteria: 1) current employment as a clinician for AD patients and their caregivers (e.g. physicians, nurses, social workers, etc.), 2) access to high-speed internet, and 3) access to a webcam for videoconferencing. 1 focus group was conducted for AD providers (N=6)

Table 2. Caregiver Participant Characteristics.

Caregiver Characteristics	Interviews (N=10)	Focus Groups (N=10)	All Caregivers (N=20)
	%	%	%
Gender			
Female	80	70	75
Male	20	30	25
Race			
White	100	90	95
Black or African-American	0	10	5
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>
Age	70.20(9.48)	63.40(6.52)	66.80(8.65)
Years of Caregiving	7.50(2.50)	4.80(3.19)	6.15(3.17)

Table 3. Provider Participant Characteristics.

Provider Characteristics	Focus Groups (N=6)
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	%
Gender	
Female	100
Occupation	
Nursing	50
Social Work	50
Years in Practice	17.67(11.33)
% of Patients with AD	77.67(31.89)

Data Extraction Procedure

We conducted a qualitative, thematic analysis to identify 1) positive and negative feedback, and implementation suggestions on each of the potential social features, as well as 2) additional social features suggested by participants.

The interview and focus group recordings were transcribed and uploaded to the Dedoose qualitative and mixed methods research application in preparation for thematic analysis. Because the interviews and focus groups followed a similar structure, with questions asked about the same set of features, all transcripts were collated and analyzed together. 2 independent coders performed the coding (I.K. and C.L.). First, they conducted an open-ended coding of a test transcript to extract a preliminary list of codes. The coders met to discuss their observations, resolve differences in these observations, and to refine the list of codes. An additional study team member (J.M.) was involved in reviewing the list to ensure that it captured the potential range of feedback. Next, to ensure a high level of agreement, the coders performed an interrater reliability (IRR) test on 3 transcripts. While there is debate about the applicability of IRR in interpretive, qualitative research, its measurement allows for greater transparency, and motivates adherence to the established coding guidelines.⁵⁸ During the test, a Cohen's Kappa of .68 was achieved, which is regarded as a substantial level of agreement.⁵⁹ Subsequently, the coders met to resolve the discrepancies highlighted by the test and refined the codebook once again.

Next, the coders proceeded with a first round of independent coding that comprised 5 transcripts. They randomly selected one of the transcripts to be double-coded, and met to discuss any discrepancies in their coding. Finally, they proceeded with a second round of independent coding of the 5 remaining transcripts.

The codes were organized based on the type of social feature that they reference. For *each* social feature, sub-codes were created for 1) positive feedback, 2) negative feedback / barriers, and 3) implementation suggestions. Additional codes were created for other social technologies mentioned (e.g. Whatsapp, Facebook, etc.) online resources, and additional ideas suggested by participants (See Appendix C for a table of codes and code count). In the following section, the results are categorized by social feature type. Quotes from participants are presented with the identifiers 1) "PX" to denote participants who have completed a prior version of the intervention, 2) "CR" to denote caregivers who participated in the focus groups,

and 3) “PR” to denote providers who participated in the focus groups. Due to the personal nature of the interviews and focus groups, the full transcripts are not made publicly available.

Ethical Considerations

The protocol for the present study was approved by the university’s Institutional Review Board prior to conducting the study. Eligible participants were sent an electronic consent form through email delineating the risks and benefits of participation, at which point they could confirm their preference to participate or decline participation in the study. Data collected from REDCap surveys were stored on a secure, HIPAA-compliant, and password-protected server at the university. The data were de-identified, with no identifying information linked with their feedback. Participants were paid \$25 for attending the virtual focus group and interview. Providers were not reimbursed for their participation.

Results

Peer Groups / Cohort

Participants generally liked the idea of being in a peer group, and caregivers drew comparisons to their previous participation in caregiving support groups. However, they expressed concern as to how they would be matched into groups.

CR2: *I think if you want to have peers, you do need to match them up closely. By the progression of disease maybe.*

CR3: *I think that you have to be careful as to who’s in the peer group ... I’ve been in other support groups where [caregivers were caring for] somebody had dementia, somebody with Alzheimer’s, and [another caregiver was caring for someone with] PPA (primary progressive aphasia). And they’ve got similarities, but they’re so drastically different.”*

Furthermore, participants had varying opinions about how caregivers should be grouped together. Some suggestions include grouping by age, relationship to caregiver, or type of dementia. One participant also suggested that it may be helpful to group individuals based on their recreational interests instead of their caregiving status.

CR1: *I think it’s also good to have in a peer group ... And I don’t think gender or anything like that matters whatsoever, it’s more about where they are and what they’re doing at the time, with the same type of diagnosis.*

PX1: *Well, I think that general background is so important ... You know, educational—the number of degrees you get isn’t as important as interests. Are you interested in art? Are you interested in gardening? ... It’s one way that certainly people get together.*

Hence, type of dementia or progression of disease were the most preferred methods of

grouping individuals. Participants in the focus groups and interviews were able to readily articulate their grouping preferences by tapping into their own experience of caregiving, and their specific needs based on their care recipient's diagnosis. This underscores the utility of segmenting future participants by type of dementia diagnosis.

Profiles

There is a high degree of variability in how user profiles are utilized in eHealth platforms, ranging from toggling basic settings, to more extensive social features like managing invites, notifications, and social groups. Our proposed enhanced user profiles would allow participants to customize the way that they present themselves in the virtual space, and would help lay the groundwork for future social interaction on the SAGE LEAF platform. Such user profiles might include being able to select an avatar, or allow participants to display their name and other personal information if they chose to do so.

Similar to the feedback about the peer groups, focus group and interview participants were primarily interested in caregiving-related characteristics of other users such as the relationship between caregiver and care recipient and type of dementia diagnosis.

PR1: *Family relationship. If they're the adult child or spouse/partner. I've also—if it's the younger onset versus later onset.*

PR3: *I think people would be interested in knowing the diagnosis of the person the other caregivers are caring for. So, if someone is an adult child caring for their parent with Alzheimer's, I feel like they would be interested in meeting other people in similar situations.*

PR4: *I think age is a big factor. I've had a lot of people who are younger, like maybe family caregivers, who are more interested in talking with somebody their own age. Or around—near their own age.*

Taken together, this feedback suggests that the information that is shared in the profiles may be similar to the variables in which participants might be grouped together. This emphasizes the synergy between these features and how they may foster a sense of shared identity among participants.

Private Messaging

A private messaging function would allow participants to contact each other individually on their own, and would function similar to social network platforms, like Facebook and Instagram, that allow for direct messaging. Overall, feedback was positive, but one clinician articulated their concerns about privacy and security.

PR5: *... in my support group there are people who request, you know, to be connected to each other. And I think I always try to make sure that I ask both parties before I connect them ... So maybe the option to stay private or to be public.*

Contrary to our expectations that caregivers may share similar concerns about security and privacy about being contacted online, the feedback suggests that caregivers were open to the idea of being able to send and receive messages, and expressed minimal hesitation towards the private messaging feature.

PX10: *Oh, I think that would be fine. You know, I see nothing wrong with that. I think, you know, friendships could be formed out of that. And private support and like-minded thinking people...I see absolutely nothing wrong with that.*

PX12: *I think that's fine. I think that would be good because you're going to have to find a way to build trust, and then it's also somebody who is in a similar circumstance than yourself. So, yeah, so that's how I would look at it.*

Hence, feedback was generally positive about the ability to connect with other caregivers through a private messaging feature. Participants emphasized that their potential willingness to use this feature was based on the assumption that other participants would be in a similar caregiving situation as them. For instance, participants indicated that the similarity of the diagnosis of their care recipient, or whether they were also spousal or other family caregivers were important attributes that might influence their use of this feature.

Buddy System / Matching

To maximize the sense of social presence that future participants might experience, we initially proposed a buddy system where participants would be paired up with a peer or "buddy"; either with someone who was going through the program at the same time as them, or with participants who had previously completed the intervention. This social feature would complement the peer groups in that participants would be able to feel like they were part of a group while being able to connect individually with other participants. Alternatively, this could be deployed as a standalone feature in the event that there were not enough participants to form a cohort. Overall, we received mixed feedback from caregivers and clinicians about the concept of a buddy system.

In their feedback, caregivers expressed interest in this idea because it would provide accountability for progressing through the program to their potential buddies, and enhance their motivation to engage with the content.

CR3: *Oh, it totally would (be helpful). Because I would be more concerned about disappointing the other person. "Oh, they need me! I have to check my email", or "I have to check that text. I don't want to disappoint them."*

PX7: *I think it's a great idea. You know, it would have been nice, if I had had one, but I was just flying by the skin of my teeth and sometimes I crash landed.*

In contrast, clinicians expressed significant concerns about implementation about a buddy system. They described past experiences with similar efforts where the matching was unsuccessful or burdensome and lead to a disappointing experience for the caregivers involved.

PR5: *I've tried connecting caregivers that I work with, and unless they really hit it off naturally in most cases it doesn't work out.*

PR2: *I think there can be a problem in the two caregivers having really different expectations about what the relationship is going to be ... I think it would add a level of burden to caregivers too ...*

Hence, while caregivers expressed enthusiasm for this idea, clinicians spoke from their own past experiences and were strongly against the idea of matching because they found it

challenging to establish shared expectations and to anticipate whether caregivers who were matched would get along well. Therefore, it is unclear whether the benefits of the buddy system may be outweighed by potential complications that arise out of these unanticipated social dynamics.

Videoconferencing Group

At present, support groups form a crucial resource for Alzheimer's caregivers, as demonstrated by the wide range of group programming in both online and in-person formats.^{17; 60} Hence, another possible feature was a video conferencing group where participants would be able to log in at a given time during the week to connect with other caregivers with the specific focus on discussing the skills being taught in the program.

The onset of the COVID-19 pandemic has hastened the transition of in-person support groups to online video conferencing groups. This transition was demonstrated in the readiness that caregivers expressed in adopting these video conferencing technologies. It is notable that all the interviews and focus groups took place during the start of the pandemic.

PX1: *I have been surprised that the Zoom meetings—I've gone to many of them ... I should point out I'm 83 years old, okay? ... via online, that sort of thing, would be very good for a person like me.*

In terms of implementation suggestions, one participant highlighted that these videoconferencing groups would be a good addition to the program, as long as participation was optional. This underscores the importance of building flexibility into the social features being offered since caregivers have competing demands, or may simply prefer different features.

PX10: *I think if you could make it as an offering but not a requirement ... But I think you have to be understanding of the fact that not everybody's going to be able to do that at the same time ... it's hard for me to commit weekly to a certain time.*

One concern that was expressed by both caregivers and clinicians, was the importance of making sure that the videoconferencing group discussions stayed on topic. Caregivers articulated various past experiences where their time was not spent efficiently because other participants deviated from the focus of the discussions.

PX11: *... I would go and check out other groups, and that was always a real disappointment. And I would not go back to those when, you know, somebody would just insist on eating up the entire hour with their issues. And so that's a problem ...*

CR5a: *I would gravitate towards anything where there was some real-time moderation or facilitation, just to help keep the learning on track.*

The feedback suggests that videoconferencing groups can be helpful for caregivers. However, there was concern about the efficiency of these meetings which could be addressed by having a facilitator who is able to moderate and guide the discussions. A facilitated group would allow participants to discuss the topics freely, while ensuring that the time be directed towards the

topics and skills included in the program. Participants also liked the idea of having a portion of the video conferencing group sessions that were not necessarily related to caregiving or the positive emotion skills presented in the program, with several participants expressing interest in an informal happy hour where they could connect with each other casually.

Discussion Group

Caregivers often seek information online about their care recipient's diagnosis, behaviors, and symptoms. Hence, many already participate in AD-specific discussion groups that are associated with the Alzheimer's Association or informal groups that proliferate on social media platforms like Facebook and Reddit. In line with our expectations, participants were generally open to the idea of using the discussion board. One clinician suggested that there may be some overlap with these existing platforms which could present a barrier to participants using the discussion board.

PR2: *... some of the feedback we get from caregivers is that, "You're asking me to do something I already have a mechanism for doing that. So, I already have a way to share photos with people that I'm close to, it's called Facebook or whatever. But you're asking me to sort of do it in this different venue." So that's been a negative when you're asking somebody to do something, that they already have a way to do that.*

Furthermore, both participants and providers emphasized that the utilization of the discussion board would be contingent on how the benefits of engaging with the discussion board were conveyed to participants. Some of their suggestions included highlighting how the discussion board could amplify their practice of the skills or to allow them to feel more connected with other participants in the study.

PR3: *I think there are some advantages, and that if you really say the discussion board is to really talk about the skills or share examples of where you use the skills ... And if you framed it so that—I could even see it as being a way to amplify the skills.*

PX12: *... to encourage people and say, "Hey, look at, you know, it's normal for you to feel isolated and trying to get questions answered. It's worth it to try and work with these tools.*

This feedback suggests that caregivers may be open to using the discussion boards, yet there were concerns about how these discussion boards might duplicate their existing online practices. Thus, it is essential to highlight the benefits of engaging with the discussion board associated with the positive emotion skills program to encourage their use. This may be in the form of prompts or reminders to participants about these benefits.

Automated Support

As described in Table 1, automated support would comprise notifications or reminders that are sent out based on certain triggers; for example, if a participant did not log on to the platform for a certain number of days, or if they endorsed poor mood for an extended period of time. With automated support, the intention is to provide caregivers with a sense that their participation is valued and that we would be responsive to their level of engagement. Similar to

the feedback collected in prior versions of the intervention, participants found the concept of reminders helpful, but expressed the need for these messages to be framed in a way that was supportive and encouraging.

PR5: *I guess that's where I would give them points, and like, more like entice them rather than nag them.*

CR3: *Because when you first said it (automated support), it was totally irritating to me. I thought, "I'm doing this to take care of myself, and now you're making me accountable?! I don't have time today!" And then after you talked a little more, then I felt better about it ... I think it's how you frame it. Or how I frame it for myself.*

PR2: *You could try to be really empathetic and kind of understand why they didn't get to it, versus the risk that if someone got an automated message that might just add to their sense of everything negative about why they haven't done the skills.*

Across the board, providers and caregivers reiterated the importance of supportive and encouraging messaging when implementing the automated support features. This underscores the importance of emphasizing the *rewarding* aspects of participation – instead of reprimanding or penalizing caregivers for not using the various features. Furthermore, it may be helpful for this supportive language to be integrated not only into the automated support features, but throughout the intervention as well – for example, using the registration emails, videos, podcasts, etc. as opportunities for cheerleading and supporting participants.

Multimedia / Videos / Podcasts

Multimedia content like videos and podcasts may help enhance the perception that there are study staff members behind the program and other caregivers who are involved in the study. In prior versions of the intervention, caregivers worked one-on-one with a facilitator to learn the skills. In order to compensate for a lack of face time in the present self-guided format, we proposed the addition of multimedia content to make the skill-building lessons more engaging by hearing directly from the team members involved in the development of the study. In their feedback, participants unanimously liked the idea of including this multimedia content.

PX1: *I think that would be good. I mean, again, it takes the program out of being a program and puts it into a dialogue with someone. And I think it's always good to see the face of the people who are running the program.*

PX14: *It might be encouraging for them to hear and see that they're not alone, that others have gone through it and have come out on the other side.*

Some participants suggested the idea of including a podcast as part of the program. This would allow caregivers to review the material at a time that is most convenient for them. This is consistent with feedback about other social features in which participants suggested that flexibility may be helpful for caregivers who are busy.

CR1: *And I like the idea of the podcast, so that you can do it on your time and when it's convenient for you ... ten, less than ten minutes here and there throughout the week ...*

CR4: *I participate in a 30-day class right now ... It is a five-minute podcast that she sends, along with a list of daily activities and a curriculum has been provided in*

advance. So, you know that the five-minute podcast is five minutes out of your day, and you can do that, it's pretty easy to find five minutes.

The overwhelmingly positive feedback about the proposed multimedia social features demonstrates that participants are interested in sharing more about insights from the study team as well as from previous participants. In the absence of live communication, their feedback suggests that such multimedia features may be central to developing a sense of social presence.

Informational Support

Caregivers often utilize the web-based resources to seek information about providing care for their loved ones with dementia. While participants felt that informational support could be helpful, their feedback suggests that it was important that it was targeted and provided specific information that was useful for caregivers.

PX6: *But be real specific ... the specific information is way more helpful.*

PX10: *my husband's diagnosis is not specifically Alzheimer's ... a lot of the things that have to do with the Alzheimer's Association don't apply to him ...*

CR5a: *the referral ... You know, a piece of paper with 20 different organizations on it were not helpful.*

Their feedback also suggests that many caregivers are discerning about such resources and sophisticated in their information search methods. Hence, the informational support provided by the study should be thorough and specific in order for it to be meaningful for participants. For example, participants indicated that it would be helpful if such resources were organized by geographic location or if they could be sorted in a way that would make it easy for participants to find the resources that are most helpful to them. Another approach would be to provide additional resources that relate specifically to the skills that are being taught.

Other Social Features

We also collected feedback about other social features that might be helpful for caregivers. One participant suggested that the study team solicit participants' input throughout the program to foster a sense of involvement. This feedback draws some similarities with the brief survey that we will provide at the end of each lesson asking participants to rate how they felt about the lesson on a scale from one to five stars. While this feature was not previously considered a social feature, the act of soliciting feedback provides participants an opportunity to express their thoughts about the program and reinforces the sense that there is a study team who is collecting the feedback and trying to improve the intervention for the benefit of caregivers.

PX1: *I think asking for opinions ... getting involved in just what you're doing and asking what I think. "Okay, what do you think of the program?" It's certainly one way to get involved, as long as it's done in such a way that it's meaningful.*

Participants also mentioned how the use of other platforms like Instagram or Facebook may complement the intervention. The feedback suggests that creating a parallel dialogue on these already-used platforms could foster an enhanced sense of social connection. One benefit to using these platforms is that participants would be able to connect with each other around the

positive emotion skills across multiple platforms, which may enhance their learning. Participants also mentioned how the COVID-19 pandemic had heightened their sense of social isolation, hence the integration of these popular social media social network platforms may help caregivers feel more connected as they complete the study.

PX10: *I think if you had something that allowed people to respond to one another, whether it was a chat room ... they create a Facebook group that is specific to that course ... And that those people during that course can talk to each other, and every now and then the instructor chimes in if she feels that there's something that she can add to it or some guidance. But I think something where people could connect would be nice.*

PR5: *I was thinking along the same lines of connecting on a specific theme, you mentioned gardening or cooking, I think those are the kinds of things that people do on Instagram or Facebook. But the WhatsApp group can be more private, so it can be formed just with the people who meet each other, and then they can share ...*

Discussion

In the present study we collected feedback about social features that may be implemented for an online, positive emotion skills intervention for Alzheimer's and other dementia caregivers. Through 1) individual interviews with participants who completed a prior version of the intervention, 2) focus groups with dementia caregivers, and 3) focus groups with AD clinicians, we collected information about the specific needs and preferences of caregivers in the implementation of these social features. Participants provided a number of insights about how to implement these features in a way that may be best received by caregivers.

Overall, participants provided extensive feedback about the proposed features and how they could be best implemented. However, they had fewer suggestions for additional features that might enhance a sense of social connection. This may be because we asked participants open-ended questions about additional features towards the end of the interviews and focus groups, at which point they may have exhausted their ideas or there may have been overlap with our proposed features. Nonetheless, participants were engaged throughout the discussions and provided unique insight into how we could refine our feature set.

Participants generally liked the proposed social features and provided valuable suggestions about how the features could be improved. One such example is the multimedia content proposed for the study, for which participants suggested a podcast format to allow caregivers to review this additional material at their convenience. This is similar to other exploratory eHealth interventions that have utilized this delivery format to enhance health literacy,⁶¹ weight loss,⁶² and self-compassion.⁶³

Other feedback included the automated support features, which participants emphasized the importance of providing encouragement to caregivers instead of shaming them for nonadherence. In a study on a physical activity intervention for older adults, it was found that when the messaging was positively framed (i.e. described in terms of the rewards and benefits of exercise, as opposed to the costs of inactivity), participants' pedometer readings indicated that they had walked more compared to those who received negative or neutral messaging.⁶⁴ Therefore, we could incorporate this positive framing, for example, if participants have not

logged into the website for several days, and send personalized email messages letting them know their participation is missed; while recognizing that caregivers have busy schedules, and reminding them that they might receive a boost in positive emotion by spending just a couple of minutes completing the home practice activities.

There were certain instances where caregivers and clinicians differed in their feedback. For example, caregiver participants were generally open to the idea of being paired up with a buddy in the program. However, clinicians who had implemented similar programs were able to speak from their own experiences with attempts to match participants that weren't feasible based on differences in life experiences and expectations for engage with a buddy program. Thus, although caregivers thought they would enjoy a buddy feature, clinicians noted significant barriers to implementation of this feature. Another example of disagreement between caregivers and clinicians was the private messaging feature, where one clinician highlighted concerns about privacy and security that caregivers did not report. Across eHealth interventions, researchers have far more information about how these platforms work and the accompanying benefits and risks compared to their participants.⁶⁵ Hence, researchers have an ethical responsibility to convey this information to participants. Recognizing these differing perspectives underscores the importance of integrating feedback from both caregivers and clinicians in refining these social features.

Participants were asked for additional suggestions for features that would enhance social connection or sense of social presence. Their suggestions included soliciting feedback from caregivers as they progress through the program and utilizing existing social media platforms to foster a sense of social connection beyond the SAGE LEAF.

Further Research and Implications

The feedback collected from the focus groups and interviews will be used to inform the development of the social features for the SAGE LEAF intervention. This will include developing a list of "trigger events" for the automated support features, and wording the notifications or reminders in a way that would be supportive to participants. We will also include enhanced user profiles where participants can toggle how they would like to receive notifications, and share more detailed information about their caregiving status to other users if they wish to. We will also include videos and podcasts, where study team members will introduce each positive emotion skill and suggest methods for mastering the skill.

The feedback from the focus groups and interviews also helped clarify which social features may be potentially challenging to implement, such as the buddy system. In future versions of the intervention, a study team member could facilitate a matching process among participants. However, this may require additional resources to implement.

The feedback made clear that informational resources were extremely helpful for caregivers. However, it was apparent that caregivers already seek these resources through online groups or informational websites hosted by caregiver organizations. Furthermore, it appeared that this information is most helpful when it was specific and tailored for the caregiver and care recipient. Recognizing that the primary aim of the intervention was to deliver the positive emotion skills and not more general caregiving skills per se, while acknowledging it would take significant resources to successfully implement these informational support features, this feature is less likely to be prioritized for inclusion in future iterations of SAGE LEAF.

While the present study focuses on all of the potential social feature enhancements (i.e. discussion boards, podcasts, automated notifications, etc.) intended for SAGE LEAF, future versions of the intervention could explore which enhancements are most effective by using a factorial design, where participants are randomly assigned to different combinations of the features to determine which can be most helpful or may best enhance a sense of social connection. In a randomized control trial of a prior version of the intervention designed for individuals with depressive symptoms,⁵¹ we randomly assigned participants to different combinations of enhancements and found that facilitator contact in combination with virtual badges yielded the highest participant engagement. Given that SAGE LEAF will be entirely self-guided, future research should explore which features, individually and in combination, lead to the biggest impact on caregiver engagement and well-being. For example, user profiles may help caregivers disclose more information about themselves and their caregiving circumstances, which may then enhance the quality of interactions that take place on the discussion boards. Additional research may also involve measuring the extent to which these combinations of features lead to measureable increases in *social presence* – which is hypothesized to mediate the relationship between the application of these social features and desired intervention outcomes.

Strengths and Limitations

The feedback collected from caregivers and providers offered valuable perspectives not only on features that may be helpful and engaging, but also ways in which they may be implemented to best benefit caregivers. Additionally, the combination of interview and focus group formats allowed for both individual feedback and group discussions to aid in the generation of ideas.

However, the semi-structured interview format of the interviews and focus groups potentially limited the range of feedback collected. With our questions focusing primarily on the proposed features, this may have constrained the participants' ability to provide novel ideas for new social features.

Another limitation to our study is the lack of ethnic diversity in our caregiver sample, which consisted of primarily White participants. To achieve a more diverse sample and perspectives in future studies, future research should oversample for underrepresented ethnic groups if needed.

Conclusion

The present study involved a qualitative analysis of focus groups and interviews with caregivers and clinicians to determine which social features might be most helpful in tailoring a self-guided positive emotion intervention for Alzheimer's caregivers. The feedback collected suggests that the participants were mostly open and receptive to the innovative social features we proposed. However, their lived and professional experience provided unique insights into how best to implement these features in a way that would be helpful and engaging for caregivers participating in future versions of SAGE LEAF.

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