Improvements on a Mobilized Stress Management Program (Pep-Pal) for Caregivers of Oncology Patients

Abstract

Background: Caregivers of patients with advanced diseases are a highly-distressed population. Recent research has focused on recognizing caregivers in need of psychosocial support to help them manage their distress. Evidenced-based technological interventions have the potential to aid caregivers in managing distress.

Objective: To describe caregiver perceptions of the usability, acceptability, and future adaptations of a mobilized psychoeducation and skills-based intervention.

Methods: This study is a part of a larger trial of a mobilized psychoeducation and skills-based intervention (Pep-Pal) for caregivers of patients with advanced illness. The current substudy utilized mixed methods analysis from quantitative data from all 26 intervention participants and qualitative data from 14 intervention caregivers who completed the Pep-Pal intervention. The qualitative semi-structured individual interviews, which were conducted within the first four weeks of completing the intervention, assessed the helpfulness and utility of Pep-Pal. Applied thematic analysis was conducted via independent review of transcripts to extract salient themes.

Results: Overall, Pep-Pal was deemed acceptable for caregivers of patients with advanced cancer in all web-based sessions except for Improving Intimacy. Caregivers perceived the program to be of use across the areas they needed and in others that they had not anticipated. Caregiver recommendations of key changes for the program were: to include more variety in caregiver actors in sessions, change the title of Improving Intimacy to Improving Relationships, provide an audio only option in addition to video, and to change the format of the mobilized website program to a stand-alone mobile application.

Conclusions: The valuable feedback in key areas from individual interviews will be integrated into the final version of Pep-Pal that will be tested in a fully powered randomized clinical trial.

Trial Registration:
Clinicaltrials.gov NCT03002896; https://clinicaltrials.gov/ct2/show/NCT03002896

Keywords: advanced cancer caregivers, psychoeducation, mHealth, cancer, BMT, Phase I, qualitative research, Internet, randomized controlled trials
Introduction

Background

There are over 40 million caregivers in the United States and this number will only increase over time. Caregivers provide uncompensated support for loved ones at a value of over $450 billion/year and lost income equivalent to over $300,000 per lifetime. Over half of caregivers report feeling overwhelmed by their responsibilities. Caregivers have been termed “silent patients”, neglecting to seek treatment for themselves in lieu of taking care of their loved ones. Caregivers of patients receiving hematopoietic stem cell transplant (HSCT), patients enrolled in phase I oncology clinical trials, and patients with advanced cancer experience significant distress. Besides the transplant process, patients who undergo HSCT commonly suffer from sexual dysfunction, which can also contribute to caregiver suffering.

Caregivers are reluctant to participate in support services because of extra burden. There are barriers to accessing treatment, and consequently there is strong support for developing novel and convenient behavioral health interventions to support caregivers in coping with caretaking responsibilities and reducing depression and anxiety. Use of technology to deliver innovative and convenient behavioral health interventions to support cancer caregivers can improve coping and reduce depression and anxiety without the added burden of having to attend a face-to-face session. According to the National Alliance for Caregivers, a large majority of family caregivers believed that using technologies such as video phone systems and a caregiving coordination system would be personally beneficial, save them time, make caregiving easier logistically, increase self-efficacy, and reduce stress. In particular, mobile technologies (e.g., telehealth) have been effectively implemented in family caregiver populations without face-to-face interactions and may help to overcome some logistical and geographical barriers to garnering support.

Telehealth is a mode of delivering health care services through telecommunication and is commonly used to deliver educational interventions, consultation services and behavioral interventions. It can be used as a means of improving social support, collecting care management data, symptom monitoring, and clinical care delivery. In a review assessing telehealth tools and support to family caregivers, more than 95% of the 65 studies reported significant improvement in psychosocial outcomes. Telehealth studies conducted on rural family caregivers as well as telehealth studies conducted in a home setting found significant improvements in psychological health and quality of life of family caregivers. Additionally, family caregivers reported high levels of satisfaction and comfort with using telehealth. These findings suggest family caregivers who provide round the clock care and symptom monitoring can utilize telehealth interventions for efficient care while reducing burdens of traveling to medical clinics.

While evidence on effects of telehealth interventions on family caregivers is encouraging, further attention is needed to identify the most effective technologies for family caregivers of cancer patients. Furthermore, because high rates of mobile phone usage are among socioeconomically disadvantaged populations, mobile technologies present an optimal intervention strategy for targeting caregivers with financial limitations and other barriers to accessing in-person care. As technologies continue to emerge, engaging caregivers still remains a significant challenge. There are no evidence-based interventions to help caregivers manage their distress using technological platforms that can be disseminated.

Evidence-Based Intervention

Recent studies show that brief interventions can be effective in reducing caregiver distress who are caring for allogeneic HSCT patients. Providing strategies to improve communication and intimacy after transplant may help caregivers better adjust to relationship changes. To advance the state of science and overcome limitations of available caregivers resources, an RCT of an in-person skills-based intervention was completed with caregivers of allogeneic hematopoietic stem cell transplants (allo-HSCT). The brief intervention,
PsychoEducation and Paced Respiration and Relaxation (PEPRR), was shown to reduce perceived stress in caregivers (primary outcome) with reductions in depression and anxiety as secondary outcomes. We have adapted PEPRR and enhanced it for a mobile-based platform (Pep-Pal). Based on focus groups and feedback we have found that Pep-Pal is feasible and usable in caregivers of patients receiving auto HSCT. The present study builds upon the formative feasibility and usability study and tested the mobilized intervention, Pep-Pal, in a pilot randomized controlled trial (RCT) with caregivers of Auto-HSCT patients, caregivers of patients enrolled in phase I oncology trials, and caregivers of patients with advanced cancer.

Objective
The purpose of this study was to continue to establish Pep-Pal as an evidence-based intervention for reducing distress in caregivers of patients with advanced illness by further assessing acceptability and usability of Pep-Pal through qualitative interviews and self-report assessments. The aims of this study were to assess acceptability of Pep-Pal by caregivers based on mean self-reported helpfulness scores, and usability based on the majority of caregivers ratings’ as above average on the usability questionnaire. Acceptability and usability of Pep-Pal was evaluated through semi-structured qualitative interviews. In addition, we explored ways to improve Pep-Pal based on caregiver feedback via post-intervention questionnaires administered to all intervention participants and through qualitative interviews. Feedback about improvements to Pep-Pal will be integrated into a final version to be tested in a fully powered RCT.

Methods
Participants were randomized to Pep-Pal or treatment as usual. Treatment as usual (TAU) was any support or resources caregivers sought out themselves. Quantitative assessments were administered at baseline before randomization and at three months post-baseline. Semi-structured, in-person interviews were conducted within one month of completing Pep-Pal with 14 intervention condition participants.

Setting
This study was conducted at the University of Colorado Comprehensive Cancer Center.

Participants
Participants were eligible to enroll if they identified as a primary caregiver of a patient who was either receiving a HSCT, enrolled in a phase I oncology clinical trial, or diagnosed with advanced cancer (stage IV, solid tumor). For the purposes of this study, primary caregiver was defined as the person in the patient’s life who is primarily responsible for care decisions, emotionally invested in patient’s care, and provides instrumental care such as transportation. Additional inclusion criteria included, 1) participants over the age of 18, 2) ability to read and speak English, 3) absence of cognitive or psychiatric conditions prohibiting participation (e.g., significant developmental or intellectual disability), 4) endorsed a moderate level of anxiety (e.g., greater than or equal to 8 on the Hospital Anxiety and Depression Scale (HADS-A)), and, 5) had access to a computer, laptop, smartphone, or tablet with internet access. Rationale for the screening cut off score of 8 or above on the HADS-A is based on clinically significant anxiety symptoms in medical populations. There were no other inclusion/exclusion criteria.

Procedure
Recruitment took place in clinics at an academic medical center; the HSCT clinic, the Phase I Oncology Trials Clinic, and the gastrointestinal (GI), Lung, glioblastoma (GBM), and Genitourinary (GU) medical oncology clinics. Informed consent took place alongside a treatment visit or provider appointment. Potential participants were deemed eligible after if they endorsed a total score of 8 or above (moderate level of anxiety) on the HADS-A. Study staff reviewed study procedures, the consent form, and data collection procedures with eligible participants. After consent took place, the study staff administered baseline questionnaires. Randomization by permuted block design, set by the study statistician (SMG), was completed after baseline assessment. Participants were randomly assigned to receive either Pep-Pal in addition to TAU or assigned to TAU. Study staff provided access to Pep-Pal (passcode) through email. Caregivers were instructed to watch
Participants were informed that they could go back and watch sessions as many times as they like. Study participants filled out post-assessment questionnaires delivered via an automated RedCap email at twelve weeks post-enrollment. After post-assessment completion, study staff contacted a subgroup by purposeful selection of (n = 14) intervention completers to conduct a semi-structured qualitative interview. This study examined responses to semi-structured interviews conducted with 14 intervention completers. The trial was approved by the Colorado Multiple Institutional Review Board.

**Pep-Pal Intervention:**

Pep-Pal was delivered via a mobilized website that was conveniently accessible anytime via smartphone, computer, tablet, or laptop. Pep-Pal consisted of 9 full-length sessions that were each less than 20 minutes. The 9 sessions included 1) Introduction to Stress Management 2) Stress and the Mind-Body Connection 3) How our Thoughts Can Lead to Stress 4) Coping with stress 5) Strategies for Maintaining Energy and Stamina 6) Coping with Uncertainty 7) Managing Relationships 8) Getting the Support you Need and 9) Improving Intimacy. Additionally, “Mini-Peps” were included on the website. Mini-Peps were brief (less than 3 minutes each) video guided activities including relaxation exercise modules (e.g. body scan, deep breathing, and mindfulness meditation) and mood exercises (e.g., gratitude exercises) and relationship enhancement activities (e.g., communication exercises). See Multimedia Appendices 1 and 2.

**Measures**

**Demographic questionnaire.** Each participant completed a demographic questionnaire at baseline that included information on age, sex, race, ethnicity, marital status, religion, relation to patient, education level, living context (e.g., number of children in household and their ages), duration of caregiving specific to this illness, and patient’s diagnosis.

**Pep-Pal usability questionnaire.** Pep-Pal Usability questionnaire delivered at post-assessment included nine questions regarding the experience of using Pep-Pal on a 5-point Likert scale. Higher total scores indicated increased usability (Cronbach’s a=0.88).

**Helpfulness of intervention sessions questionnaire.** Helpfulness of Intervention Sessions questionnaire was delivered at post-assessment and included 10 questions regarding helpfulness of each intervention session on a 10-point Likert scale. Higher total scores indicate increased helpfulness (Cronbach’s a=0.96).

**Semi-structured interview.** A semi-structured interview guide was used by study staff to conduct qualitative interviews. Please see Multimedia Appendix 3 for semi-structured interview guide.

**Data analysis**

This mixed-methods substudy included analyses of both quantitative and qualitative data. Descriptive statistics were conducted on 14 intervention completers’ baseline demographic questionnaires using SPSS version 24 (IBM: Armonk, New York). The usability and acceptability of Pep-Pal was assessed using descriptive data that reported means and proportions. The qualitative data from interviews, which were audio-recorded and transcribed, were analyzed using an inductive approach to thematic analysis to draw out broad themes and subthemes within the data. Data analysis involved systematic organization of data through open coding in ATLAS.ti (V8.2.1)(ATLAS.ti Scientific Software Development GmbH: Berlin, Germany). Data analysis also involved repeated continuous comparisons across coded data to identify salient themes. A team approach was used to synthesize and contextualize the data. Team members (AC, NAP, and JJ) independently reviewed transcripts and met biweekly to discuss emerging themes, discrepancies, and alternative explanations. Ongoing modifications of conceptual framework of themes was a fundamental part of the analytic process. Informational saturation was reached when no new themes emerged regarding key outcomes.
Results
Fifty-six caregivers were enrolled and completed assessments. Fourteen caregivers participated in semi-structured interviews. All participants were recruited through medical clinics or referred by their medical team. The flow of participants through the study is shown in Figure 1.

Figure 1. Study Flow

Demographical characteristics are in Table 1. Caregivers that participated in semi-structured interviews were representative of characteristics in the larger trial and were not statistically significantly different than the remainder of participants in the trial regarding age, education, relationship status, and race/ethnicity. Participants were mostly female, at least college educated, married, employed full or part-time, and White.

Table 1.
Demographics and key characteristics at baseline by group

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Post-intervention Assessment Participants</th>
<th>Qualitative Interviewees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers’ characteristics, n</td>
<td>26 (52.5%)</td>
<td>14 (71.4%)</td>
</tr>
<tr>
<td>Caregiver age (years), mean (SD)</td>
<td>53.3 (17.7)</td>
<td>52.5 (17.9)</td>
</tr>
<tr>
<td>Patient disease category</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phase I</td>
<td>7 (26.9%)</td>
<td>5 (35.7%)</td>
</tr>
<tr>
<td>Lung</td>
<td>14 (53.8%)</td>
<td>5 (35.7%)</td>
</tr>
<tr>
<td>GU</td>
<td>1 (3.90%)</td>
<td>1 (7.14%)</td>
</tr>
<tr>
<td>GI</td>
<td>1 (3.90%)</td>
<td>1 (7.14%)</td>
</tr>
<tr>
<td>BMT</td>
<td>3 (11.5%)</td>
<td>2 (14.3%)</td>
</tr>
<tr>
<td>GBM</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Female caregiver, n (%)</td>
<td>19 (73.1%)</td>
<td>10 (71.4%)</td>
</tr>
<tr>
<td>Married/ Civil Union, n (%)</td>
<td>20 (76.9%)</td>
<td>9 (64.3%)</td>
</tr>
<tr>
<td>Relationship to the patient, n (%)</td>
<td>20 (76.9%)</td>
<td>10 (71.4%)</td>
</tr>
<tr>
<td>-------------------------------------------</td>
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</tr>
<tr>
<td>Spouse/ Civil partner</td>
<td>16 (61.5%)</td>
<td>10 (71.4%)</td>
</tr>
<tr>
<td>≥ College degree, n (%)</td>
<td>18 (69.2%)</td>
<td>8 (57.1%)</td>
</tr>
<tr>
<td>Total annual income ≥ $75,000, n (%)</td>
<td>18 (69.2%)</td>
<td>8 (57.1%)</td>
</tr>
<tr>
<td>Living with the patient, n (%)</td>
<td>22 (84.6%)</td>
<td>11 (78.6%)</td>
</tr>
<tr>
<td>Dependent children, n (%)</td>
<td>17 (30.4%)</td>
<td>6 (42.9%)</td>
</tr>
<tr>
<td>Current employment status as a caregiver, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>12 (46.2%)</td>
<td>7 (50.0%)</td>
</tr>
<tr>
<td>Part-time</td>
<td>6 (23.1%)</td>
<td>4 (28.6%)</td>
</tr>
<tr>
<td>On leave</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>2 (7.70%)</td>
<td>1 (7.10%)</td>
</tr>
<tr>
<td>Retired</td>
<td>6 (23.1%)</td>
<td>2 (14.3%)</td>
</tr>
<tr>
<td>Patient felt ill prior to diagnosis, n (%)</td>
<td>17 (65.4%)</td>
<td>9 (64.3%)</td>
</tr>
<tr>
<td>Chronic health issues prior to diagnosis, n (%)</td>
<td>7 (26.9%)</td>
<td>3 (21.4%)</td>
</tr>
<tr>
<td>Caregiving responsibilities began, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>At the time patient became ill</td>
<td>20 (35.7%)</td>
<td>5 (35.7%)</td>
</tr>
<tr>
<td>At the time patient was diagnosed</td>
<td>28 (50.0%)</td>
<td>7 (50.0%)</td>
</tr>
<tr>
<td>Prior to the time patient was diagnosed</td>
<td>3 (5.40%)</td>
<td>1 (7.10%)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (8.90%)</td>
<td>1 (7.10%)</td>
</tr>
</tbody>
</table>

Acceptability of Pep-Pal:
Acceptability of Pep-Pal was gathered via “Helpfulness of Intervention Sessions Questionnaire” and semi-structured exit-interviews with 14 completers. Participants rated intervention sessions as acceptable as measured by mean helpfulness scores at or above a rating of 5 out of 10 for all intervention sessions except for the “Improving Intimacy” session (M= 4.19, SD= 3.805; see Figure 2.). Qualitative analysis of interviews indicated acceptability of the “Improving Intimacy” session was less about the video content but more about the topic itself and other participants alluded to intimacy not being a priority when the partner is terminal.

When asked about an appropriate session length, 64.2% (9/14) of the qualitative participants indicated that they were satisfied with the current 10 to 20 minute session length while 28.5% (4/14) of qualitative participants indicated full sessions could be 10 minutes or less. Participants were satisfied with the delivery method of Pep-Pal. Despite support for the delivery method of the intervention, 21.4% (3/14) of caregivers indicated they would have preferred a more accessible mobile application instead of a web-based format. These caregivers reported preference for a mobile application format instead of a web-based format due to internet connectivity issues during their commute to work.
Usability of Pep-Pal:
Participants overall felt Pep-Pal was organized and easy to navigate (See Figure 3). In terms of modality used to access Pep-Pal, 64.2% (9/14) used computer or laptop, 42.8% (6/14) used iPad or tablet, and 21.4% (3/14) used their smartphone. Several participants reported that they used more than one modality to access Pep-Pal (e.g., computer, laptop, tablet, smartphone).
**Thematic Analyses Results**

Four major themes emerged in regard to usability: 1) Putting the caregiver first; 2) Guilt; 3) Isolation and Loneliness; and 4) Latent traumatizing effects. See Textbox 1 with narrative examples that highlight exit interviewee language, context, and interpretation of usability.

**Putting Caregiver First**

The overarching perspective described was that Pep-Pal was helpful in shifting caregiver focus towards “Putting the Caregiver first.” During the program, caregivers described how Pep-Pal helped shift focus and remind themselves to prioritize their own mental, physical, and emotional needs versus. One caregiver described this as, “I count as somebody that I need to take care of.” Additionally, caregivers described the program helped them to balance caregiving with their other daily roles (e.g. mother, spouse, friend). Some caregivers indicated that Pep-Pal was helpful in terms of prioritizing time for ‘spousal’ or ‘partner role’ in their relationship with the patient.

**Guilt**

The second theme that emerged was working caregivers felt guilty in falling short of their obligations (e.g., needing to take time off work). Caregivers described this sense of guilt when taking time off to care for their loved ones and/or needing to ask co-workers for help. Guilt was also evident when caregivers had to renegotiate caregiving time with family time. Much reported caregiver guilt was “self-induced” and was an internal perception of not living up to their own standards of how they should behave. One caregiver indicated Pep-Pal helped reframe this sense of guilt by identifying with the term caregiver as a way to validate the need to attend the patients’ hospital visits instead of going to work.

**Isolation and Loneliness**
The third theme emerging was a negative sense of “isolation and loneliness” from taking on the primary caregiver role. Most caregivers reported feelings of social isolation and feeling that “no one understands the emotional and physical demands in the process of being a caregiver.” One caregiver alluded to her “loneliness” as related to the changes in her relationship with her husband and how he could no longer fulfill a supportive role given his disease prognosis. Caregivers indicated that Pep-Pal was helpful in normalizing many isolating aspects of the caregiving experience such as the unpredictability of daily caregiving responsibilities. Caregivers also described Pep-Pal as being helpful in providing a sense of social cohesion with other caregivers’ experiences, notably without connecting them to other caregivers. Many caregivers expressed a desire for a chatroom feature within Pep-Pal as an additional means of social support.

**Latent traumatizing effects**

The fourth theme emerging from caregivers was a sense of latent “trauma or assault” with the patients’ terminal illness trajectory. Lay-terms “assault, trauma, and shock” were extracted from caregiver qualitative interviews by AC and JJ to contextualize the theme of latent traumatizing effects. Caregivers characterized their caring for a loved one with advanced cancer in terms of heightened arousal, negative affectivity and mood, and as a trauma itself. This was greater in caregivers’ descriptions of feelings of trauma upon initially hearing about their loved one’s terminal diagnosis. Anticipatory grief, defined as reduced levels of preparedness for their loved one’s imminent death, was reported in caring for a loved one with a terminal disease and adjusting to the new normal of their daily routines that involved frequent medical visits. Overall, a majority of caregivers described making sense of the latent traumatizing effects of caring for their loved one as the biggest mental, physical, and emotional challenge in caregiving.

**Textbox 1.**

**Summary of qualitative interview results on the usability of Pep-Pal**

<table>
<thead>
<tr>
<th>Usability:</th>
<th>ID/Type:</th>
<th>Quotation:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Putting the caregiver first</strong></td>
<td>1064; working caregiver,</td>
<td>She would say, “Stop and write down some things that you think you could do” … I didn’t have time to do that but I did like listening to them and having that time to reflect kind of on my own needs and … mental health.</td>
</tr>
<tr>
<td></td>
<td>caregiver with a family</td>
<td>Most working caregiver, caregiver with a family</td>
</tr>
<tr>
<td></td>
<td>1071: new caregiver</td>
<td>It’s talking about you need to get out and do things for yourself those things were great reminders.</td>
</tr>
<tr>
<td></td>
<td>1026; long term caregiver</td>
<td>It’s very, very difficult to figure out how to basically getting any of my needs met. … It’s really difficult because I feel like all of his energy is directed towards fighting his cancer.</td>
</tr>
<tr>
<td><strong>Guilt</strong></td>
<td>1060; working caregiver</td>
<td>… I feel guilty you know. And I think to myself, “Man, all of my paid time off has been sucked up from when my husband was in the hospital.”</td>
</tr>
<tr>
<td></td>
<td>and caregiver with a family</td>
<td>If I had to take work off, that’s …really difficult… I could say, “Well, I’m my brother’s primary caregiver so I need to do this” I could feel okay with that. It lessened the guilt.</td>
</tr>
<tr>
<td></td>
<td>1009; working caregiver</td>
<td>I am working full-time, so I guess so there is a little bit of guilt with that.</td>
</tr>
<tr>
<td><strong>Isolation and loneliness</strong></td>
<td>1075; working caregiver</td>
<td>During the beginning of my wife’s care it felt very lonely and very isolated and you feel like no one understands.</td>
</tr>
<tr>
<td></td>
<td>1021; long-term caregiver</td>
<td>The thing that probably most affected me, and still …is the isolation the disease causes.</td>
</tr>
</tbody>
</table>
That feeling that you’re not alone… that there are people who are dealing with similar things and then if somebody else is dealing…

It’s just not you… everyone is having some … situation going on and… you’re not alone.

I just felt really alone in that whole process.

I just feel sort of lonely in terms of him because he’s not there for me in a way he used to be.

When he first got diagnosed I thought my life was ending… There were emotions at the very beginning … very overwhelming and maybe if I had known about this then, it would have been more helpful for me then.

It [Pep-Pal] helped with feelings of a little bit of panic every time you get really bad news [laughter]. Like, “Uh-oh” but helped calm me down.

The illness in general … you get new information that might not be positive. And then trying to reframe it … “Okay, this is the new normal” and many times when something challenges the new normal … and you have to reset.

It’s not … easy… to deal with initially … You see people walking around traumatized… Initially, you think, oh, we’ll just do this… and then we’ll go back to our life… But going from shock to …start caregiving immediately.

Caregiver recommended future adaptations for Pep-Pal:

Three main suggestions emerged. The first suggestion resulted from a mixed-response towards the full-length Improve Intimacy session. Some interviewees (21.4%) indicated the intimacy session was not as helpful or relevant to their situation due to patient prognosis or identifying with a non-spousal role with their patient. Alternatively, several interviewees (28.6%) indicated the intimacy session provided a new perspective on redefining intimacy to include non-sexual activities to recapture meaning in their relationship.

The second suggestion to improve Pep-Pal was to include different actors to represent various caregiver demographics. One male caregiver recommended including different sex caregivers in Pep-Pal videos to better tailor the caregiver experiences. Despite the desire to have multiple caregivers featured in Pep-Pal videos, interviewees felt the ‘caregiver’ featured in the videos, normalized and validated isolating and lonely elements of the caregiving experience. For example, one caregiver expressed frustration around meal planning with her loved one, “It’s just these are common things that happen … I didn’t know that anybody else has had that very same thing where you’ll go here’s your dinner [laughter] or just a wide variety of things … You know you can’t take care of your own health needs sometimes because you can’t get out.”

The third suggestion to improve Pep-Pal was contingent on full-time employment of caregivers. Employed caregivers indicated they would have preferred a mobile application with audio features as an additional way to navigate through the videos on their commute to work. These interviewees were also the only exit interviewees to utilize their smartphone as their sole modality in viewing the program sessions. Caregivers’ recommendations to include an audio component is a means to further integrate the skills from Pep-Pal into their full schedules.
**Textbox 2. Summary of Caregiver recommended future implementation for Pep-Pal (Select Examples)**

<table>
<thead>
<tr>
<th>Exploratory Analyses:</th>
<th>ID/ Type:</th>
<th>Quotation:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intimacy Session</strong></td>
<td>1026; long-term caregiver</td>
<td>Improving intimacy was not as helpful ... sexuality isn’t an issue for us right now. He’s in a lot of pain. We have intimate times of holding hands, but I can’t put my arm around him.</td>
</tr>
<tr>
<td></td>
<td>Actual participant viewing:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Improve Intimacy (Full Session)</td>
<td>100%</td>
</tr>
<tr>
<td></td>
<td>1042; working caregiver and new caregiver</td>
<td>Our sexual relationship is not what it was... we are kind of recapturing it. Pep-Pal was right on, it’s not all about sex. It’s about intimacy. That was super good.</td>
</tr>
<tr>
<td></td>
<td>Actual participant viewing:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Improve Intimacy (Full Session)</td>
<td>100%</td>
</tr>
<tr>
<td></td>
<td>1064; working caregiver and caregiver with a family</td>
<td>I liked the intimacy video ... something I hadn’t seen addressed anywhere else...To be close and take time for ourselves ... not always have illness at the forefront</td>
</tr>
<tr>
<td></td>
<td>Actual participant viewing:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Improve Intimacy (Full Session)</td>
<td>93%</td>
</tr>
<tr>
<td></td>
<td>1022; long-term caregiver and working caregiver</td>
<td>I remember the sex one. I didn’t feel like that was very tied to, or relevant.</td>
</tr>
<tr>
<td></td>
<td>Actual participant viewing:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Improve Intimacy (Full Session)</td>
<td>26%</td>
</tr>
<tr>
<td></td>
<td>1071; new caregiver</td>
<td>The sexual one ... was kind of interesting. Not that I really hadn’t thought about it but right now [laughter] we don’t have sex... “Oh yeah, just hugging and touching even though we aren’t having sex. That’s fine.” That was very helpful.</td>
</tr>
<tr>
<td></td>
<td>Actual participant viewing:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Improve Intimacy (Full Session)</td>
<td>100%</td>
</tr>
</tbody>
</table>

**Actress in Sessions**

|       | 1022; long-term caregiver and working caregiver | Just the actress, Nancy, it was just like, oh yes, I’ve had that same problem at home... in real life, that’s not how it is. She makes it seem so simple. Like, I went out with my friends, we had a great time. I feel much better. That’s not how life is. |
I think her [Nancy’s] father in law had more acute symptoms from chemotherapy… problems for her [Nancy] wouldn’t have been the same problems I would have faced… tailoring it towards different… male versus female caregiver.

My favorite? I think definitely the first two or three …maybe because those had the caregiver and brought up situations I would ponder myself. Like, “Oh. Yeah. I didn’t think about that [laughter].”

The play acting of the caregiver expressing common concerns I thought was beneficial especially, to normalize …struggles that everyone as a caregiver goes through… You feel like no one else understands. Hearing the same concerns … was … beneficial.

I would have liked some sort of audio option because video requires you to be watching the screen… you could listen while falling asleep or something else …driving, would be very beneficial.

I wish there was an app or an easier way to access it and it was more user friendly when it comes to audio and video files. A lot of times I have to myself is when I am driving and can’t watch a video … if I could connect it to my radio and listen …that would be really helpful.

I’m not tech-savvy, so I’d go to my email to access the website and type in my password get in the car …but then it’d quit. I was like, “Oh man” it wasn’t user-friendly in the car. It could be an app that gets a better signal. That would have been helpful.

Discussion

Principal Results

Results from quantitative data and individual interviews supported the acceptability and usability of Pep-Pal. This caregiver feedback highlights the ease of use of the web-based platform modality and convenience that prior literature recommended for evidenced-based intervention platforms ⁵,²⁸,²⁹. Within the specific areas of improving stress management, improving relationships, and the use of the mini-peps, caregivers rated the usability of Pep-Pal as “neutral”. Despite neutral ratings, the majority of Pep-Pal participants watched sessions related to stress, getting support, and at least one mini-pee. User engagement in the various sessions as well as the helpfulness ratings emphasize how interviewees found Pep-Pal to be helpful in deeper ways. The themes of putting the caregiver first, guilt, isolation and loneliness, and latent traumatizing effects of caregiving indicate how Pep-Pal helped participants reconceptualize elements of self-care and acknowledge guilt as a stressor, which is overlooked in this population. The fourth major salient theme, latent traumatizing effects, is reflected in prior literature as knowledge of a loved one’s advanced cancer diagnosis and their prognosis is perceived as a traumatic event and can result in anticipatory grief ³⁰. These overarching themes further emphasize the multidimensional supportive needs of family caregivers and supports usability of Pep-Pal as helpful in addressing psychological, social, mental and emotional supportive needs for caregivers.

Feedback from individual interviews will be integrated into the final version of Pep-Pal to further enhance the helpfulness of the program for caregivers. Based on these interviews, it will be important to include session content or resources on grief to help caregivers process their loved one’s illness and prognosis. For working caregivers and caregivers with families, a full-length session on communication about their loved one’s illness to children and coworkers would be helpful in framing difficult discussions. Many caregivers reported feelings of isolation and loneliness in their caregiving role and felt Pep-Pal was useful in its helpfulness of normalizing these elements of the caregiver experience. An additional feature to the program such as online chatrooms for caregivers to seek social support from one another may help to further mitigate these feelings of loneliness.
Lastly, working caregivers expressed a desire for a mobile application of the program in addition to audio sessions, which would enhance the convenience of Pep-Pal. Variations in types of caregivers featured in session (e.g. male and female) would also further tailor Pep-Pal to fit individual user needs.

A mixed-methods approach was utilized to further assess intervention participants reasons for their below average ratings on the Improving Intimacy session. Feedback was less suggestive of improving the video content itself and more indicative about how variable the topic of intimacy is within the type of caregiver-patient relationships. Several interviewees indicated the intimacy session provided a new perspective on how intimacy can be redefined to include non-sexual activities to recapture meaning in their relationship, which was the main goal of the Improve Intimacy Session. The session was not exclusively tailored to the physical act of intimacy but broadly discussed having caregivers redefine intimacy (e.g. holding hands, cooking dinner together, or taking along walk) in their own relationship (regardless if the patient is their significant other – child-parent caregivers). As a result, the title of the session will be changed to “Improving Relationships” in the final version.

It is important to note despite positive perceptions of helpfulness in the program, this program is one of many forms of care and is not a “one-size-fits-all” model. Pep-Pal is geared towards caregivers who cannot physically attend in-person support or have limited time to get to the care they need. This program is one modality in addressing how evidenced based strategies can be disseminated in a convenient, cost-effective platform.

Limitations
Several study limitations were present. First, the majority of intervention caregivers were white, female, spousal caregivers which might limit generalizability. Second, this study involved a small qualitative sample of bone marrow transplant intervention caregivers, which might neglect to highlight the experiences of this type of advanced cancer caregiver in Pep-Pal. Third, technological interventions can yield their own disadvantages. For example, working caregivers described internet connectivity issues when using the web-based platform on their commute to work.

Future Directions
Suggestions for improvement based on the results of this study will be integrated into the final version of Pep-Pal. Specifically, a chatroom feature, audio sessions, content on grief, and communication strategies will be added. In addition, the title of the Improve Intimacy session will be changed to Improve Relationships. The next step is to demonstrate efficacy of a mobile application version of Pep-Pal in a fully powered randomized control trial with advanced cancer caregivers. Ultimately, the goal will be to conduct a larger, multi-site effectiveness-implementation study of Pep-Pal.

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Conflicts of Interest
None declared.

Abbreviations
- **Allo-HSCTs**: Allogenic hematopoietic stem cell transplants
- **Auto-HSCTs**: Autologous hematopoietic stem cell transplants
- **CBSM**: Cognitive-behavioral stress management
- **PEPRR**: PsychoEducation, Paced Respiration and Relaxation
- **Pep-Pal**: PsychoEducation and Skills-Based Mobilized Intervention
RCT: Randomized controlled trial
GI: Gastrointestinal
GU: Genitourinary
GBM: Glioblastoma
HADS-A: Hospital Anxiety and Depression Scale- Anxiety

Multimedia Appendix 1
Screen shot of the 9 full-length Pep-Pal sessions.

Multimedia Appendix 2
Screen shot of the mini-pep sessions.

Multimedia Appendix 3
Semi-structured interview guide.

References


