Welcome to your Caregiver Pep-Pal

A Qualitative Mobile Intervention Development Study for Improving Symptoms of Depression, Anxiety, and Intimacy in Caregivers of Patients Receiving Bone Marrow Transplants

By: Nicole Amoyal PhD
DISSERVICE TO OUR CAREGIVERS?

- Evidence-based treatment\(^1\)
  - Depression, Anxiety, Stress Management

- Integral in-person interventions; limited in scope and resources

- Technology allows for dissemination
"Do you want the pill, the suppository, the patch, or the app?"
CAREGIVERS ARE “SILENT PATIENTS”

- Bone Marrow Transplant (BMT) caregivers$^{1,2,3,4,5,6}$
  - Fatigue
  - Depression
  - Insomnia
  - Sexual Dysfunction
PSYCHOEDUCATION AND PACED RESPIRATION AND RELAXATION (PEPRR)

PEPRR: Laudenslager and Colleagues\textsuperscript{1}

- Cognitive Behavioral Stress Management (CBSM; Antoni)
- 8, semi-structured individual sessions
- 1 hour sessions
PEPRR

1. Introduction to Stress
2. Stress and Mind-Body
3. Thoughts and Stress
4. Coping with Stress
5. Energy and Stamina
6. Coping with Fears
7. Communicating Needs
8. Get Support
RCT of PEPRR for BMT caregivers indicated significant reductions in¹:

- **Perceived stress**
  - (PSS; ES = 0.39; p=0.039)

- **Anxiety**
  - (STAI; ES = 0.66; p= 0.0009)

- **Depression**
  - (CESD; ES = 0.46; p= 0.016)
SPECIFIC AIM

To adapt, enhance, refine, and expand the content of PEPRR into a mobilized stress management program (Pep-Pal) for caregivers

Criterion for Success: Pep-Pal will meet standards in 5 domains per expert review and qualitative feedback:

a. LOOK AND FEEL
b. CONTENT
c. ACCEPTABILITY
d. USABILITY
e. FEASIBILITY
1. Introduction to Pep-pal
2. Introduction to Stress
3. Stress and Mind-Body
4. Thoughts and Stress
5. Coping with Stress
6. Energy and Stamina
7. Coping with Fears
8. Communicating Needs
9. Get Support
10. Intimacy and Relationships*
Pep-Pal

- Mini-Pep Videos
  - Relaxation
  - Gratitude
  - Relationship Enhancement
STUDY FLOW: 3 STEPS

1 Stakeholder Groups
   - Mock up Pep-Pal Video

2 Focus Groups
   - Introduction Session
   - Session 1

3 Individual Interviews
   - Intro + Session 1
   - Sessions 2-9
STUDY FLOW: 3 STEPS

1. Stakeholder Groups
   - Mock up Pep-Pal Video

2. Focus Groups
   - Introduction Session
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3. Individual Interviews
   - Intro + Session 1
   - Sessions 2-9
STAKEHOLDER GROUPS

- Group 1
  - Professional Stakeholder Group (N = 20)
- Groups 2 and 3
  - Patient and Caregiver Stakeholder Groups (N = 9)
- Watched 1 session
- Provided open-ended feedback
RESULTS: STAKEHOLDER GROUPS

**Before**

**Session 1:** Introduction to Stress

**After**

**Session 1:** Introduction to Stress Management

**Additional Features of Pep-Pal**

- Change Main Character
- Separate Intro and Session 1
- Introduce Team
- Add Human Content to Session One
- Encourage Caregiver to Ask for Support from Providers
- Ask for more support from your health care provider
METHODS

STEPS 2 AND 3

1 Stakeholder Groups
   • Video: Mock up Pep-Pal

2 Focus Groups
   • Video: Introduction to Pep-Pal
   • Video: Session 1

3 Individual Interviews
   • Video: Intro, Session 1
   • Video: Sessions 2-9
RECRUITMENT AND ELIGIBILITY

- Convenience sampling
- Referred by BMT clinic
- Approached over phone

Inclusion
- Caregivers of patients receiving BMT
- Ability to speak/ read in English
- At least 18 years of age

Exclusion
- Hx of psychiatric or medical condition preventing participation
STEPS 2 AND 3

1 Stakeholder Groups
- Video: Mock up Pep-Pal Video

2 Focus Groups
- Video: Introduction to Pep-Pal
- Video: Session 1

3 Individual Interviews
- Video: Intro, Session 1
- Video: Sessions 2-9
Two Focus Groups

- Semi-structured
- 60 minutes each
- Audio-recorded
- Watch Introduction + Session 1
## RESULTS: FOCUS GROUPS FEEDBACK

<table>
<thead>
<tr>
<th>Category</th>
<th>Feedback</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregivers (N=6)</strong></td>
<td></td>
</tr>
<tr>
<td>Look and Feel</td>
<td>Majority prefer mix characters</td>
</tr>
<tr>
<td></td>
<td>• animation (&quot;<em>keeps it light</em>&quot;) human (&quot;<em>provides credibility</em>&quot;)</td>
</tr>
<tr>
<td>Content</td>
<td>“HELPS YOU BECOME AWARE OF WHAT’S GOING ON WITH YOUR BODY.”</td>
</tr>
<tr>
<td>Acceptability</td>
<td>“I WISH IT WAS AVAILABLE NOW.”</td>
</tr>
<tr>
<td>Usability</td>
<td>“INCLUDE MORE STEP-BY-STEP INSTRUCTION IN THE BODY SCAN VIDEO.”</td>
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<tr>
<td>Feasibility</td>
<td>Would like reminders to complete the sessions throughout week</td>
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### Participants

- **100% Women, White, Spousal**
- **Ages 46-66**
- **Attrition**
  - FG 1:2/4
  - FG 2: 4/4: “Is there something I can do online?”
FINALIZE VIDEO DEVELOPMENT

My Pep-Pal

Session 1: Introduction to Stress
Session 2: Mindfulness + Gratitude
Session 3: Thoughts + Stress
Session 4: Coping with Stress
Session 5: Energy + Stamina
Session 6: Coping with Fears
Session 7: Communicating Your Needs
Session 8: Get Support
Session 9: Intimacy + Relationships
RELIABILITY

- 2 PEPRR Interventionists reviewed Pep-Pal videos
- Independently rated Pep-Pal videos as covering all topics from PEPRR
STUDY FLOW: 3 STEPS

1 Stakeholder Groups
   • Video: Mock up Pep-Pal Video

2 Focus Groups
   • Video: Introduction to Pep-Pal
   • Video: Session 1

3 Individual Interviews
   • Video: Intro, Session 1
   • Video: Sessions 2-9
SAMPLE

- 9 Spousal Caregivers
- 7 Women, 2 Men
- 100% White
- Age Range 34-69; M= 59.3
- Semi-structured interview
- 90 minutes each
- Audio recorded, transcribed, coded
QUALITATIVE INTERVIEWS RESULTS

Preferred Mode of Viewing:

<table>
<thead>
<tr>
<th></th>
<th>Laptop</th>
<th>iPad</th>
<th>iPhone</th>
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<tbody>
<tr>
<td>Sessions: 1,2,3</td>
<td>8</td>
<td>1</td>
<td>0</td>
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</table>

Videos Watched Introduction + Session 1

<table>
<thead>
<tr>
<th>Participants 1,2,3</th>
<th>Participants 4,5,6</th>
<th>Participants 7,8,9</th>
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<td>Sessions: 1,2,3</td>
<td>Sessions: 4,5,6</td>
<td>Sessions: 7,8,9</td>
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QUALITATIVE ANALYSES

- Currently in coding stages
- Conventional content analysis
- 2 independent coders
- Preliminary themes
### RESULTS: INDIVIDUAL INTERVIEWS

<table>
<thead>
<tr>
<th>Preliminary Themes (N=9)</th>
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<tbody>
<tr>
<td><strong>Look and Feel</strong>*</td>
<td>➢ Prefer Mix of Animation and <em>Human</em> Character</td>
</tr>
</tbody>
</table>
| **Content**              | ➢ Want more specific caregiver examples  
                ➢ **INTIMACY:** *“That was brave information and I am really impressed. I really liked that. That would have been helpful so thank you.”* |
| **Acceptability***       | ➢ *“You know you spend a lot of time in hospitals and waiting rooms and doctor’s offices and I think to have something like that to just review would be great.”* |
| **Usability***           | ➢ Liked that program was not linear, most meaningful sessions |
| **Feasibility***         | ➢ Make videos downloadable, do not rely on internet |

*Saturation*
LIMITATIONS

- All spousal, White caregivers
- Sampling Bias
- Sample Size
- Interviewer Bias
FUTURE DIRECTIONS

- Finalize Mobilized Website and Videos
- Career Development Award Application for Pilot RCT
- Mixed Methods
- Test with other caregiver populations
  - Phase I Clinical Trials
  - Dementia
- Comparative Effectiveness Trials
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REFERENCES


QUESTIONS