Lessons learned: Results from two randomized pilots of Internet-based intervention for cancer-related distress

Jason E. Owen, PhD
Erin O. Bantum, PhD
Annette L. Stanton, PhD

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UNIVERSITY OF HAWAI'I CANCER CENTER

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Translation of Evidence-Based Interventions for Cancer-Related Distress

- F2F interventions for survivors:
  - Supportive-expressive group therapy has strong empirical support, replicated across trials
  - Cognitive-behavioral elements associated with benefit
  - As a result coping-skills training, SEGT were prime targets for translation to internet
- development of Internet interventions parallels progress of face-to-face interventions
- Complicated by multitude of methods, very few replications, generally small n & unknown potential for dissemination

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Overview

- Goal is to describe 4 key lessons learned from 2 previous trials
  1. Population-level view necessary for dissemination
  2. Treatment elements drive engagement
  3. Patterns of engagement likely linked with outcomes
  4. Tremendous potential to elucidate mechanisms
- Data sources:
  - Survive intervention, $n = 60$ (Owen et al., 2005)
  - Health-space.net, $n = 296$ (Owen et al., *in press*)
  - Retrospective qualitative analysis of:
    - Participants' personal goals, at baseline, for using the intervention ($n = 296$)
    - Barriers to engagement among minimally-engaged users ($n = 25$)

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Dissemination Potential: Sampling Matters

- Recruitment fractions: 24% in registry vs 32% in Internet sampling; follow-through twice as high in Internet sample
- Survivors recruited via population registry compared to Internet sample were less highly educated, closer to time of diagnosis, and less likely to have advanced disease

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Dissemination Potential: Sampling Matters

Owen et al. (in press) *J Behav Med*

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Treatment Elements Drive Engagement

- Key assumption is that engagement is important to outcomes; most internet txs don't come close to matching times spent engaged in f2f trials
- Discussion board, even if professionally-facilitated, is associated with very weak engagement
- Weekly, facilitated chat associated with much higher engagement
- Professional facilitation is critical, and the better we got, the more engaged participants got (e.g., alumni group)
- Patients are not however, after facilitation- their goals are primarily around personal connection with other survivors
- Social-networking results in high engagement and is closely linked with engagement with psychoeducational modules, but time spent using social-networking far outweighs time spent engaged with tx modules

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Treatment Elements Drive Engagement

	Non-Engaged Users (n = 59)	Low-Engaged Users (n = 113)	Moderate – Highly Engaged Users (n = 124)	All Users Combined (n = 296)	Between-Group Differences
Social-Networking Components					
Discussion Board	2.2 (2)	29.8 (28)	312.9 (300)	142.9 (243)	***
Personal Pages	0.5 (1)	17.6 (20)	300.0 (303)	132. 4(243)	***
Webmail	0 (0)	0.1 (0.6)	4.1 (9.1)	1.8 (6.2)	***
Structured Intervention Components					
Guidance Modules	0.3 (1)	8.3 (14)	96.0 (82)	43.4 (70)	***
Facilitated Chat	0.1 (0.4)	2.9 (12)	278 (305)	117.7 (240)	***
Total Time Using Intervention	3.1 (3)	58.8 (45)	991.0 (808)	438.2 (703)	***

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Treatment Elements Drive Engagement
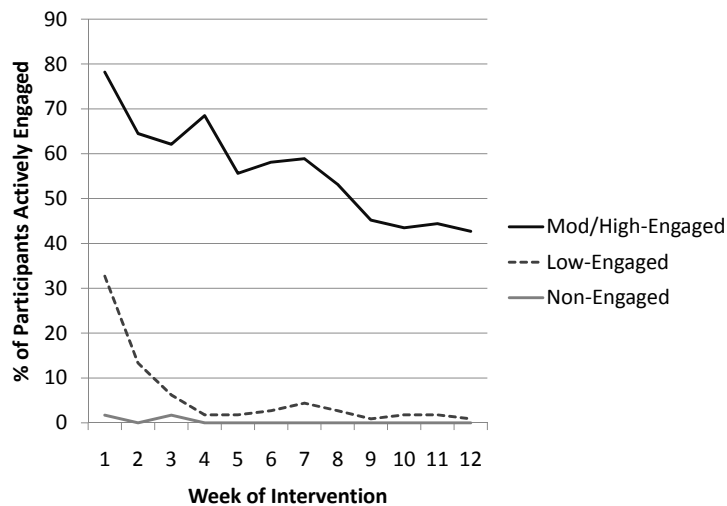
Understanding & Improving Engagement

- Intervention only effectively reaches 42% of survivors
- On average, however, engagement was higher than most common social-networking sites, with the exception of Facebook
- Qualitative analysis tells us quite a bit about what the other 58% might need from I-I:
  - "People like me"
  - More intense assistance in using the site
  - Personal attitudes about internet intervention

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Elucidating Mechanisms of Action

- Survive linguistics data
- Linguistic predictors of responsiveness from other group members in health-space

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Summary

1. How can we better understand how to mix & match treatment elements? *Open sourcing & sharing of evidence-based methodologies in the service of maximizing effect sizes*
2. How can we improve engagement? *Finding a better match between intervention & participant goals, understanding survivors' needs, through participatory research.*
3. How to improve tx effects? *Tremendous, currently unleashed potential for identifying mechanisms of action using linguistic, social-networking, and other behavioral data*

health-space.net

Acknowledgments