

A Web-based tool to help Family Caregivers Address Behavioral and Psychological Symptoms of Dementia (BPSD)

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Tool Development – Iterative Design Process



- Data gathering (N>102)
- Focus groups (families, Providers)
- Facebook survey
- Semi-structured interviews

Phase II

- Tool Development (content and look and feel)
- · Feedback from end-users

Phase III

- Pilot 2 group randomized trial
- 2 sites (Hopkins/Michigan)
- N=57

Family caregiver focus groups: 3 Key Themes

1. Minimize difficulty and training needed

- "If it needs training, it's too complicated."
- "Make it intuitive or you will scare people away. We are stressed already."

2. One-stop shopping

- "Information is all piecemeal, nothing is brought together."
- "I had a specific question and there was no systematic way to find an answer. I had to look through topic threads and hope someone responded."

3. Tailored output

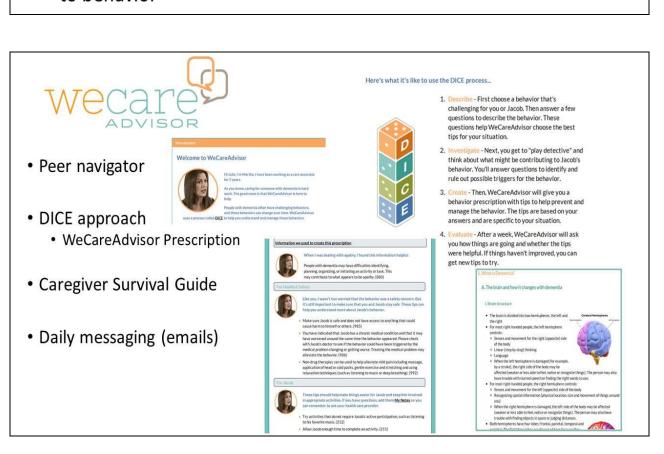
- "I'm going to strangle somebody if I see a frequently asked questions. I can't be put into one category."
- "One of my frustrations about support groups is the disparity in the kind of issues people are dealing with."

Majority (>88%) willing to use a web-based program for BPSD

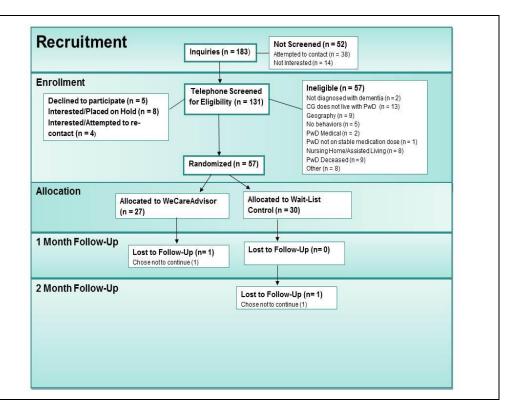
Kales et al Alzheimer Dis Assoc Disord 2016 Werner et al Applied Clinical Informatics 2017

Principles Underlying Tool Development

- Easy to use
- On demand
- Opportunity for repeated use
- Attention to health literacy (8th grade level)
- Consideration of race/cultural diversity
- Peer navigator
- Addresses full range of behaviors
- Strategies customized to a specific symptom and context
- Generation of a treatment plan reflecting the varied contributors to behavior



Study Flow Chart

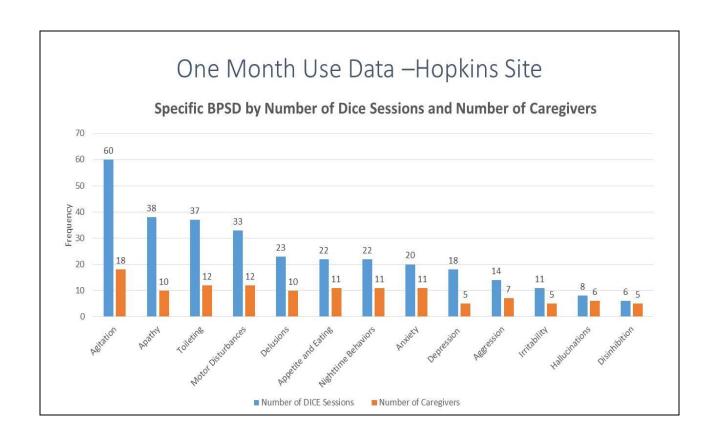


Caregiver Demographics (n=57)

- No significant differences between WeCareAdvisor and Waitlist groups
- 65 years old
- Mostly women (>70%)
- Most had high school education
- Most spouses
- 63% White
- 33% African American

One Month Use Data (N=33)

- Total Logins = 608
 - Avg. 18.4 logins (SD=18.5, range 1 − 108)
- Total DICE Sessions = 312
 - Avg. 9.5 sessions (SD=7.0, range 1 − 29)
- Number of Logins significantly associated with
 - Number of DICE Sessions (r = .483, p = .004)
 - Gender (Male) (r = .433, p = .012)



Reduced Caregiver Distress with BPSD (N=57)

Effect	Estimate	Standard Error	t-value	Pr>t
WeCareAdvisor (1 month – Baseline)	-6.25	1.39	-4.51	<0.0001
WeCareAdvisor vs. Waitlist	-4.45	1.88	-2.37	0.02
Waitlist (2-month-1 month)	-3.83	1.29	-2.97	0.004

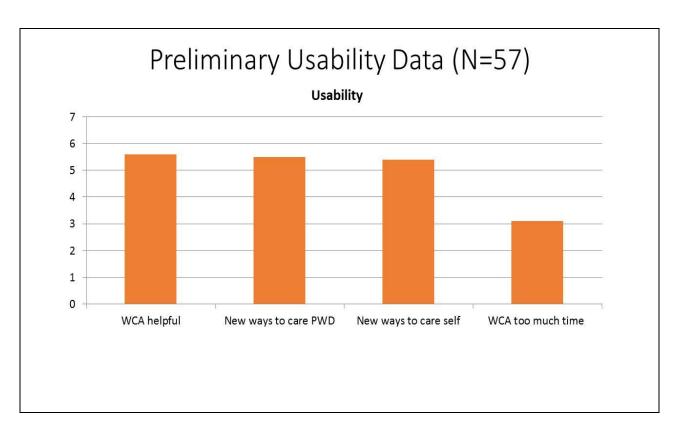
WeCare had significant improvement from Baseline to 1 month, **significantly greater improvement than Waitlist. After** receiving tool, Waitlist also had a significant decline in distress

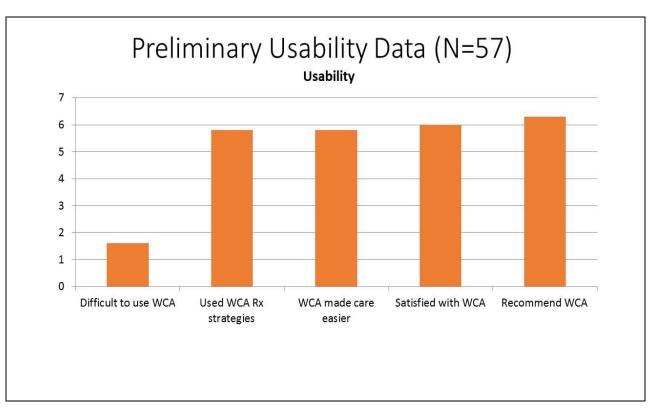
• Mixed model results adjusted for site:

Improved Caregiver Confidence (N=57)

Effect	Estimate	Standard Error	t-value	Pr>t
WeCare (1 month- baseline)	1.12	1.84	0.61	0.54
WeCare vs. Waitlist	7.52	2.52	2.99	0.004
Waitlist (2 month-1 month)	4.67	1.74	2.68	0.009

- · WeCare had significantly higher change in confidence as compared to Waitlist
- Waitlist had a significant improvement in confidence after 1 month of tool use (t=4.56, p<0.0001)
- · Mixed model results adjusted for site:





Caregiver Feedback-Positives

- "Wonderful new tool in my caregiving arsenal"
- · "DICE structures my thinking"
- "Survival guide is comprehensive"
- "I shared the tool with my support group and everyone was impressed by the content and ease of use"
- · "Love the feeling of support"
- · "Ease of use very nice"
- · "Daily tips are awesome"
- "I wish I would have had this a long time ago"
- "I learned a great deal more about dementia and the skills to use in dealing with related behaviors"
- "This week PWD had a UTI and the WeCareAdvisor helped to trigger in my mind that something was wrong and he should see the doctor
- "We can go to the doctor, go to support groups, but I see the value of having this daily. This is advice every day.

Caregiver Feedback-Suggestions

- Videos to demonstrate strategies
- Too much text, more graphics
- For some, would have been more helpful to have earlier in the disease process
- Some highly specific symptoms not addressed by tool





Summary

- Significant decrease in caregiver distress
- Significant change in caregiver confidence
- Waitlist showed similar benefits
- No significant impact for BPSD
- Preliminary usability data very positive.

