

University of Wisconsin's CECCR



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Feel out of control
What do I say
How do I help?

pick a doctor; How?
Conflicting advice
We must decide -

Alone
Their own lives
Someone like me

The foundation of our work

TECC

Competence

- Information
- Skills

Relatedness

- Loneliness
- Social support
- Being new person

Autonomy

- Self efficacy
- Control over lives

**Quality
of Life**

Quality of life matters



- **Cancer Patients and families suffer physically and emotionally!**
 - **Patients**
 - Clinical depression 350% more likely w Ca.
 - Tell M.D. only 54% of their symptoms.
 - **Caregivers**
 - Clinical depression - up to 50%
 - If depressed, 63% higher mortality risk
 - Divorce rate 70% after BMT

French D (1988) "Predictors & consequences of symptom reporting behaviors." Med Care; 26: 1000-1008.

Schulz R and Beach S (1999) "Caregiving as a risk factor for mortality." JAMA; 282(23): 2215-2219.

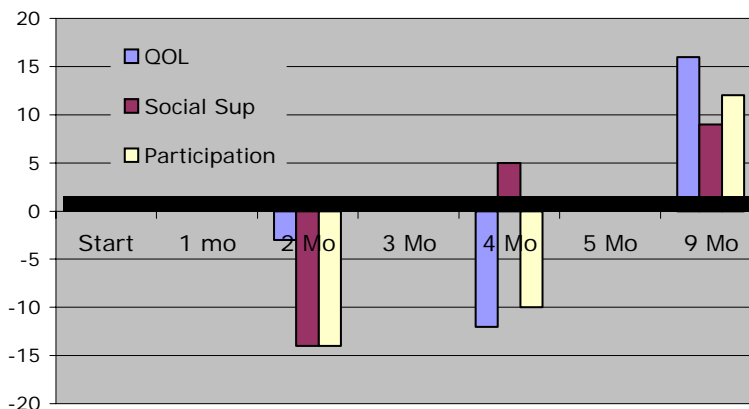
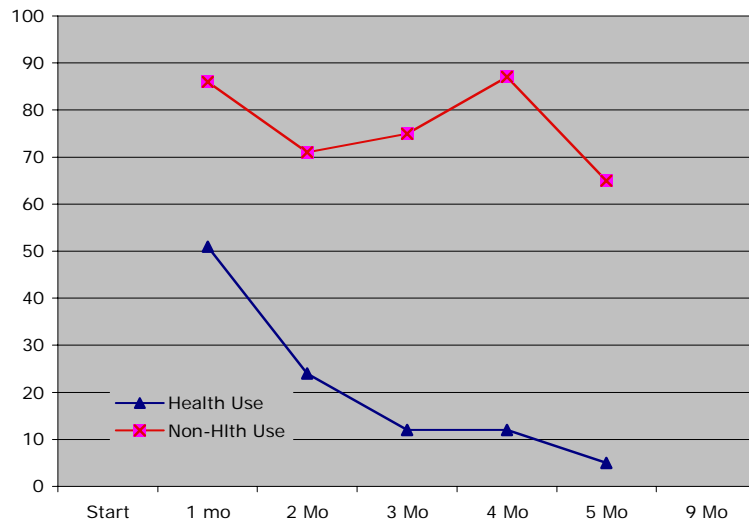
Then came the Internet



TECC

- Promise
 - Lots of health information
 - Anonymity
 - Tailoring
 - Social support
 - Widespread access
 - Immediate updating
- Response
 - Enormous use (34% BCa pts)
 - 2nd choice after MDs
 - Physicians give list of sites
 - Also source of concern
- Research?
 - Number of hits
 - Testimonials
- But:
 - **Little use research beyond hits.**
 - **Very little outcomes research in cancer.**
 - **Virtually no RCTs.**

RCT - Internet vs. Standard Care



- 85 subjects per arm
- Internet arm
 - Computers/Internet 5 months
 - Post test 2, 4, 9 months
 - 50 minutes training
 - Six high quality internet sites
- Results
 - Use
 - Quickly leave health sites
 - Non-health communication
 - Outcomes
 - **No significant differences**
 - Trends favor control group
 - Until 4 months after computer

Why was Internet not better?



- Single transaction
- Contradictory info
- Hard to navigate across multiple sites
- Something to sell
- Information is hard to find

Need research on internet effects

A trans-disciplinary team with CHESS as its research base



TECC

- **Oncology**
 - James Cleary (Palliative care)
 - Beth Burnside (Radiation)
 - James Stewart (Breast)
 - Joan Schiller (Lung)
 - George Wilding (Prostate)
- **Communications**
 - Robert Hawkins
 - Suzanne Pingree
 - Bret Shaw
 - Fiona McTavish (Media)
- **Systems Engineering**
 - David Gustafson
 - Patti Brennan (also nursing)
- **Nursing**
 - Barbara Bowers (qualitative)
 - Karin Kirchhoff (end of life)
- **Statistics**
 - Roger Brown (nursing)
 - Ronald Serlin (educ psych)
- **Psychology**
 - Timothy Baker (TTURC)
 - Linda Roberts (Family studies)
 - Lori DuBenske (Bereavement)
- **Computer Science**
 - Haile Berhe
- **Education**
 - Meg Wise
- **Public Health**
 - Helene McDowell

CHES Cancer Modules

- Breast cancer**
- Spanish breast cancer**
- Prostate cancer**
- Lung cancer**
- BMT (anticipated)**
- Teen smoking**
- Adult smoking**
- End of life/Bereavement**

CHES: Deep Support



- **Competence**

- Questions and Answers
- Library
- Resources
- Web Links

- **Relatedness (peer & expert)**

- Ask an Expert
- Discussion Group
- Instant Messaging
- Personal Stories

- **Autonomy tools**

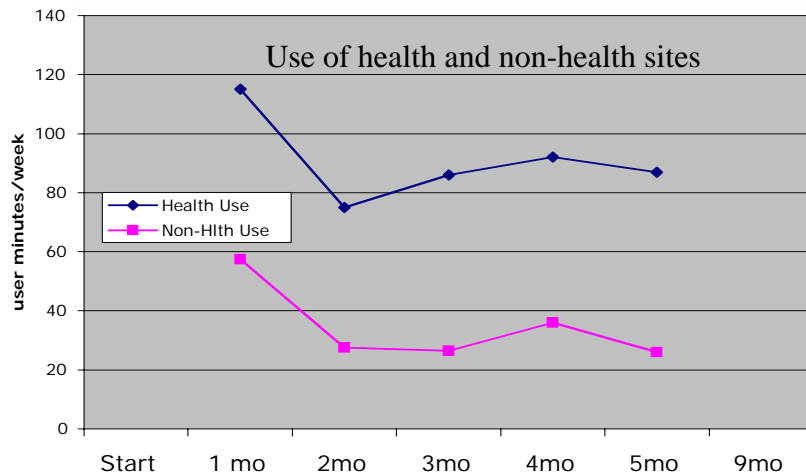
- Decision Making
- Action Planning
- CBT (Healthy Relating)
- Adherence Coach
- Calendar/Reminder
- Family Informant

- **Content Management**

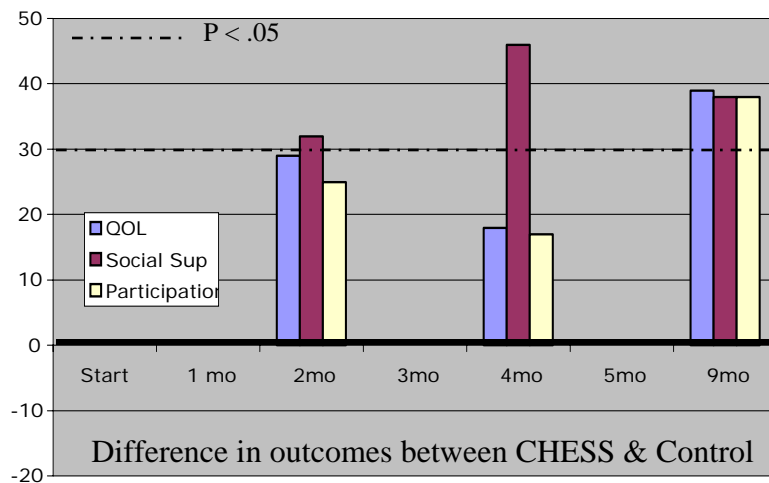
- Case Management

An Integrated System!

With “deep support”, eHealth can work



- Same RCT
- Results compare CHES vs. Control
- Note benefits sustain four months after CHES is removed



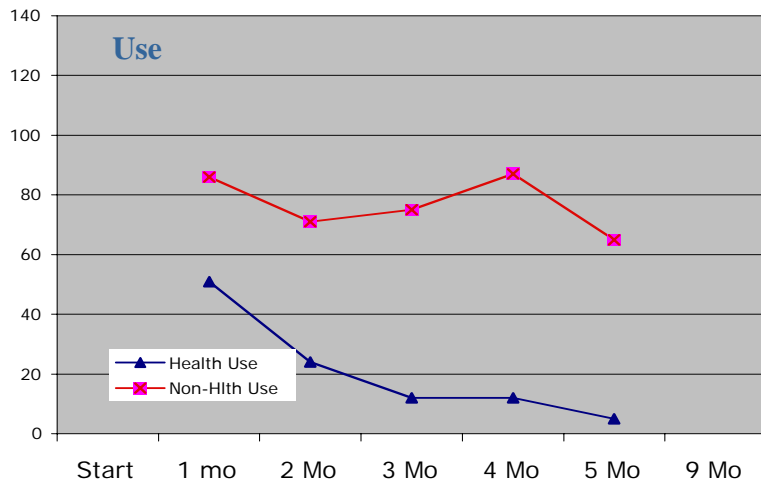
Why?

- Discussion group
- Convenience
- Multiple sources of info

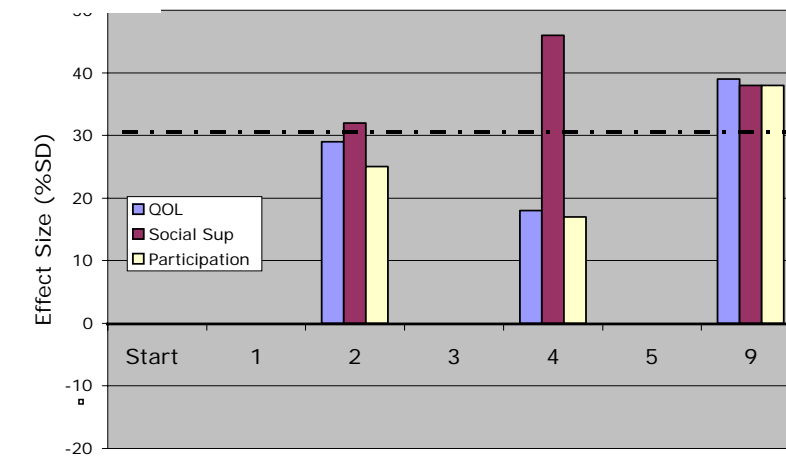
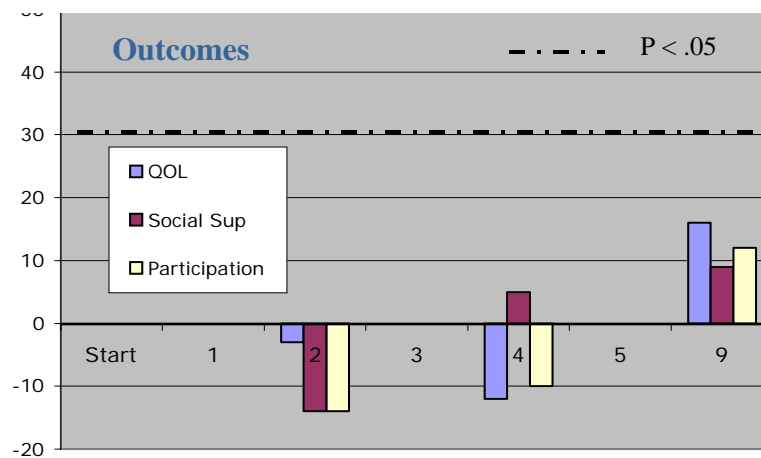
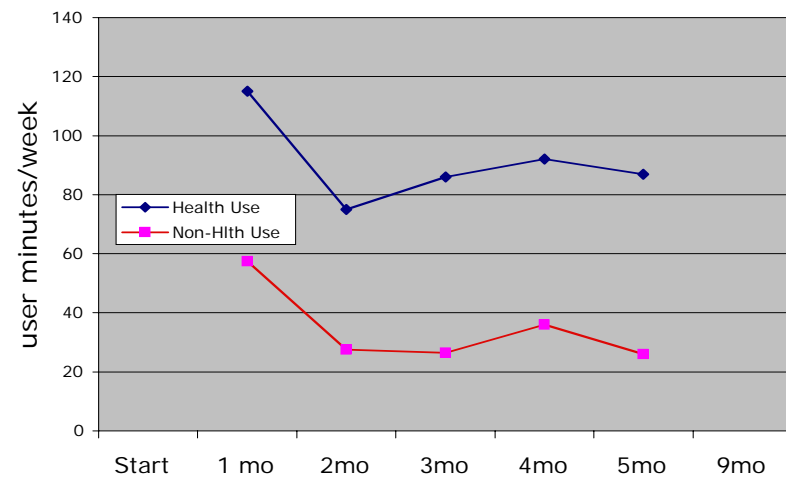
Control vs Internet and CHESS



Internet vs. Control



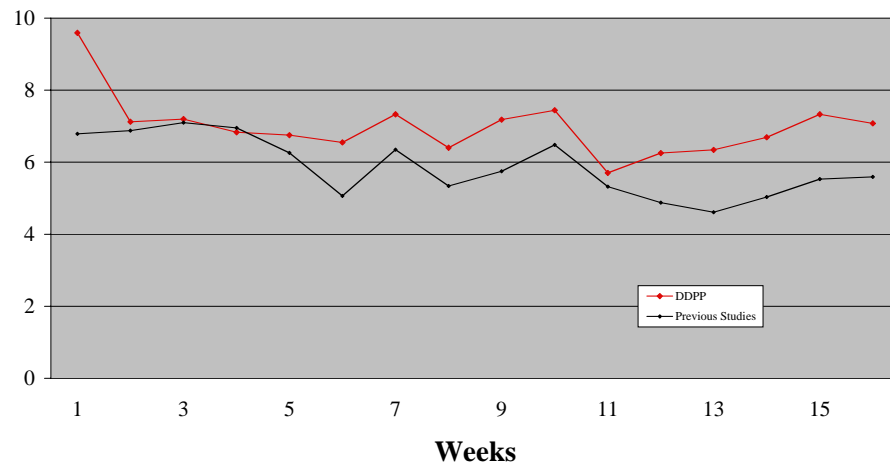
CHESS vs. Control



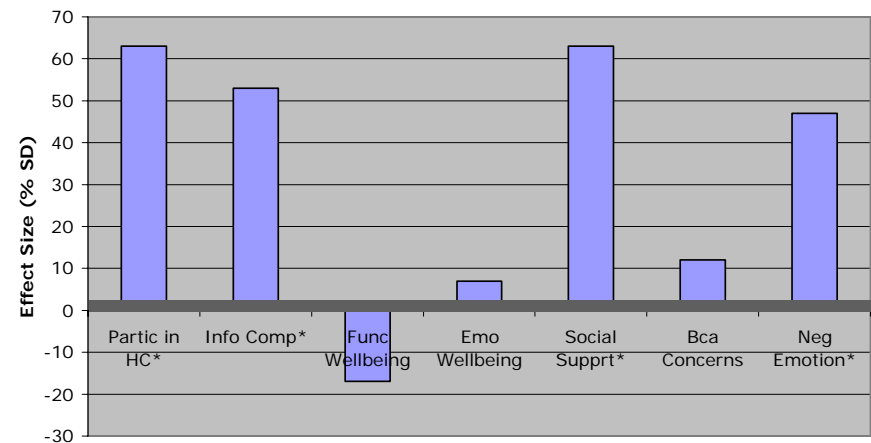
Typically information helps “Haves” more than “Have-nots”. Not so with CHESS.



Average Number of Logins



Outcomes: CHESS - Comparison Group



And low SES populations seem to use it right.

- Pingree S, Hawkins R, Gustafson D, et al (1996). Can the disadvantaged ride the information highway? *J Broadcasting & Electronic Media*, 40, 331-353.
- Gustafson D, Hawkins R, Pingree S, et al. (2001). Effect of computer support on younger women with breast cancer. *J Gen Int Med*, 16, 435-445.
- Gustafson D, McTavish F, Stengle W, et al (2005) Use & impact of eHealth System by low-income women with breast cancer. *J Hlth Com*; 10 (S 1), 157-172.
- Gustafson D, McTavish F, Stengle W, et al (2005). Reducing the Digital Divide for Low-Income Women with breast Cancer. *J Hlth Com* 10 (S 1): 197-194.

CHES works but



- How does it work?
- What could make it better?
 - **Other cancers?**
 - **Case manager?**
 - **Links to physicians?**
 - **Caregivers?**
 - **Tailoring?**
 - **Relationships?**
 - **End of life and bereavement?**
 - **Functionally illiterate?**
- How disseminate?

Study 1 - How does CHES work?



TECC

- **Breast cancer**
- **Examine**
 - **Quality of life**
 - **Efficiency**

Internet

Info (Book)

+ Support (Telephone)

+ Computer/user interaction (Coach)

**Baker, Roberts (PIs)
McDowell (Proj Mgr)
Hartford, MD Anderson, UWCCC.**

Study 2: Mentor/CHES case manager



- **Breast cancer**
- **Examine**
 - Quality of life
 - Efficiency
 - Mechanism of effect

Internet

Book, Phone & Coach (ICCS)

Mentor

ICCS + Mentor

**Hawkins & Pingree; Pls
Shaw: Project Manager
Hartford, MD Anderson, UWCCC**

Study 3. Clinician



- Lung Cancer family Caregivers
- Patient/Partner info to clinician
- Examine
 - Partner QoL
 - Bereavement
 - Patient symptom distress
 - Mechanisms of effect

Internet

ICCS w clinician report

**Gustafson & Cleary: PIs
Lori Bernard (Proj. Mgr.)
Dana Farber, MD Anderson, UWCCC**

New Studies Spawned by CECCR



CECCR

