"No one should suffer twice!"

The Wisconsin CECCR

Our Partnerships

Organizations

- U of Wisconsin
- MD Anderson
- Dana Farber
- Hartford Hospital
- U of Wash. St. Louis

- U of North Carolina
- Kaiser Portland
- Tufts University

Disciplines

- Communication science
- Computer science
- Educational psychology
- Nutritional science
- Nursing
- Oncology
- Psychology
- Radiology
- Statistics
- Systems Engineering

QuickTime™ and a
decompressor
are needed to see this picture.

Coping with Lung Cancer
a Network of Support

CHESSMarks   Dictionary   Search: [_____] GO   Exit

information

Cancer & Caregiving Topics
Ask an Expert
Resources
Caregiver Tips

support

Discussion Group
Personal Stories

Click Here
for the latest
Cancer News
▶

tools

Easing Distress
Healthy Relating
Calendar
Contact List
Respite Planning
Action Plan
My Journal

Health Status

Update Health Status
View Health Changes

Information You Wanted:
Sadness/Depression

Your Messages

Discussion Messages
Ask an Expert Messages

Appointments:

Make an Appointment

Your Website

View your help calendar.

Latest message: 12/05 09:13 AM

Internet

Start | Inbox - Microsoft Outlook | Microsoft PowerPoint - [...] | CHESS Administrative To... | Coping With Cancer - ... | 10:22
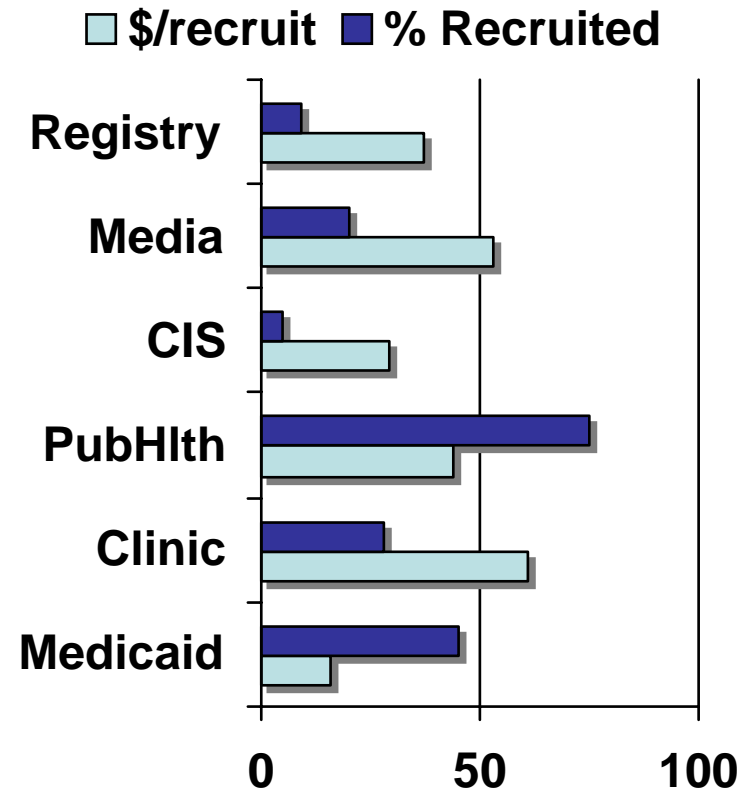
1) With "deep support", eHealth can work

- RCT of 300 breast cancer pts

- Internet access v. CHESS

- Results compare CHESS vs. Control

- Note benefits sustain four months after CHESS is removed

- Why?
  - Discussion group
  - Consistent source of info
  - Service integration
  - Training

Gustafson, D., Hawkins, R., Pingree, S., McTavish F. et al.   (2008).   Internet-based interactive support for cancer patients: Are integrated systems better? *J of Communication*. 58(2) in press.

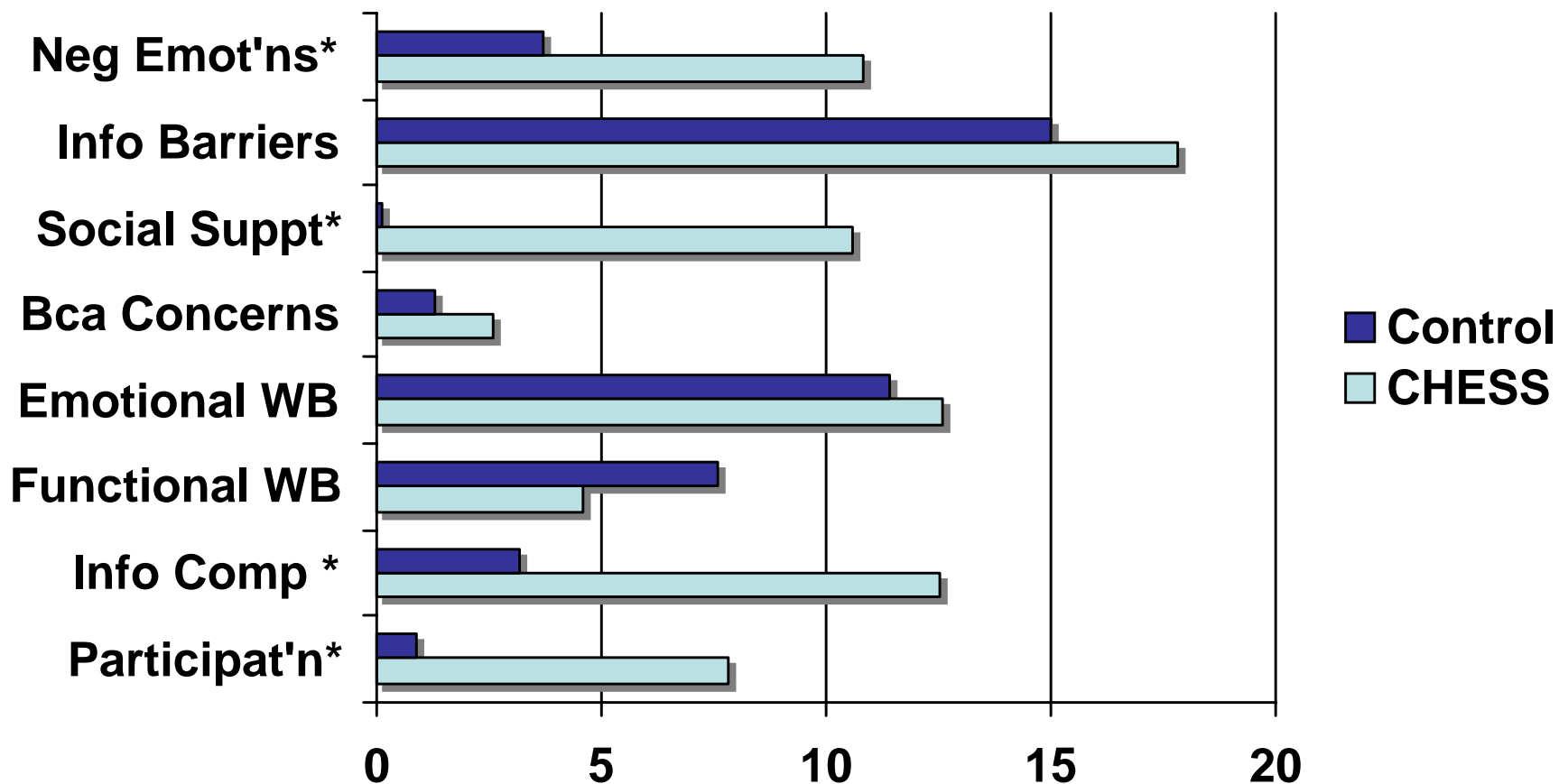# 2) Population-based Intervention

- Low income Bca Pts
- Rural Wisconsin
- Detroit
- Multi-method recruit
- Cheapest/recruit
  - Medicaid ($16)
  - CIS ($29)
- Best recruit rate
  - Public Health (75%)
  - Medicaid letters (45%)
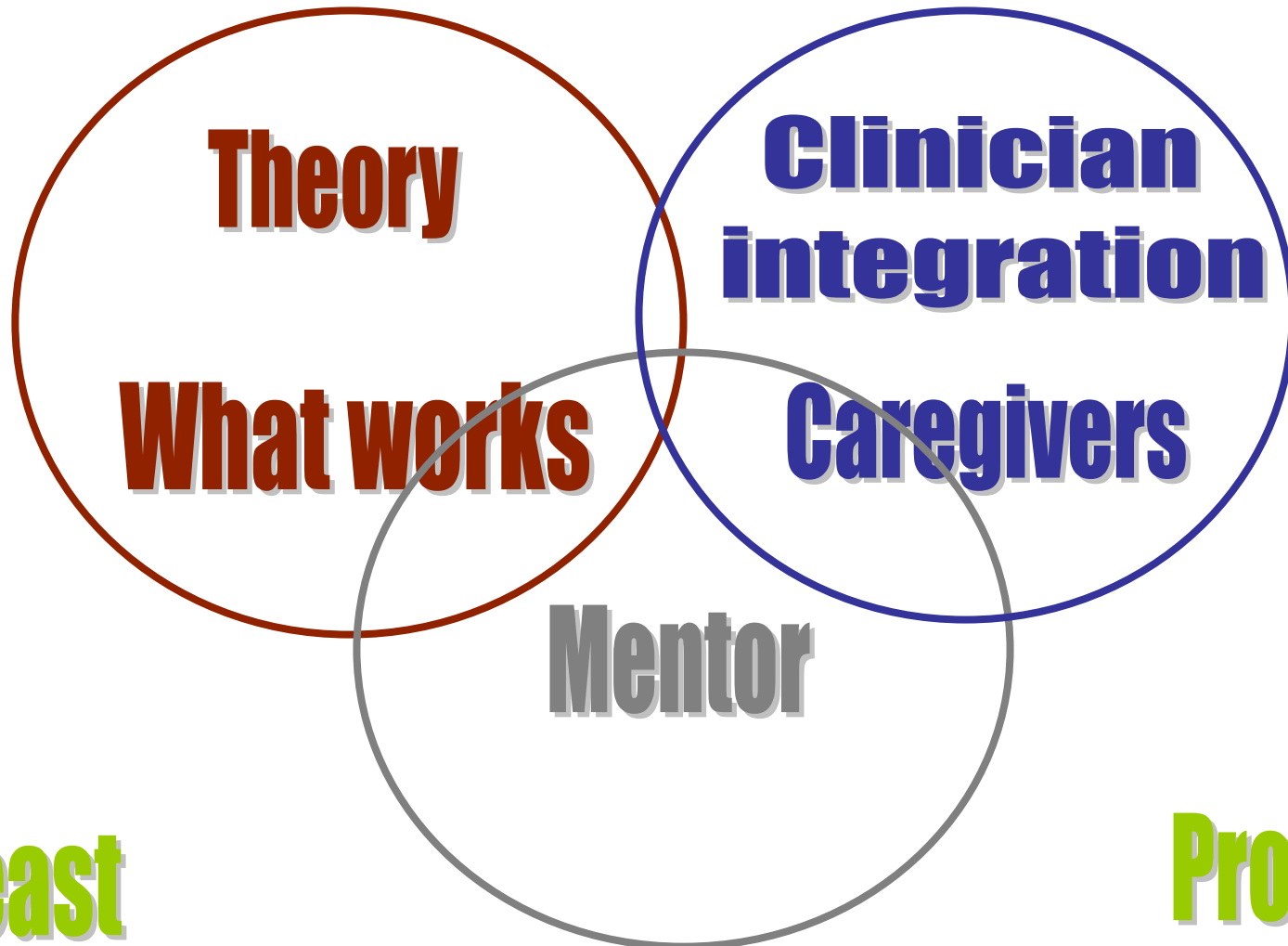- **Cost per installation**
  - **$180: 4 month access**

□ **$/recruit** ■ **% Recruited**

Registry

Media

CIS

PubHlth

Clinic

Medicaid

0   50   100

Gustafson, McTavish, Stengle, et al (2005) Use & impact of eHealth System by low-income women with breast cancer. *J Health Com* 10 (1S).
Gustafson, McTavish, Stengle, et al (2005). Reducing Digital Divide for Low-Income Women w breast Cancer: *J Health Communications* 10 (1S).

CHESS Helps Underserved
(Higher Score is Better)

Low income women w Breast Cancer in rural Wisconsin & Detroit (n=228).
Vs. Comparison Group (n=52)

Theory Mentor

Communication and Self Determination Theory

CHESS

Active Processing

Competence
- Information
- Skills

Relatedness
- Loneliness
- Social support
- Being new person

Autonomy
- Self efficacy
- Control over lives

Health behavior

Quality of Life

?

What works

Info vs. Info + Support vs.
Info + Support + Skills
(Sample result)

QuickTime™ and a
decompressor
are needed to see this picture.

Clinician integration

Caregivers

What are informal caregivers facing?

- Medical care and monitoring
- Be assertive w medical system
- Treatment decisions
- Instrumental support
- Emotional support for patient
- Communication with family

It is a family disease.

Coping with Lung Cancer
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Health Status	Your Messages	Your Website
Update Health Status **View Health Changes** **Information You Wanted:** Sadness/Depression	**Discussion Messages** **Ask an Expert Messages** **Appointments:** **Make an Appointment**	View your help calendar. Latest message: 12/05 09:13 AM

Address https://chess.chsra.wisc.edu/pc/CheckIN/ClinicReport.aspx?UID=1950

Coping with Prostate Cancer
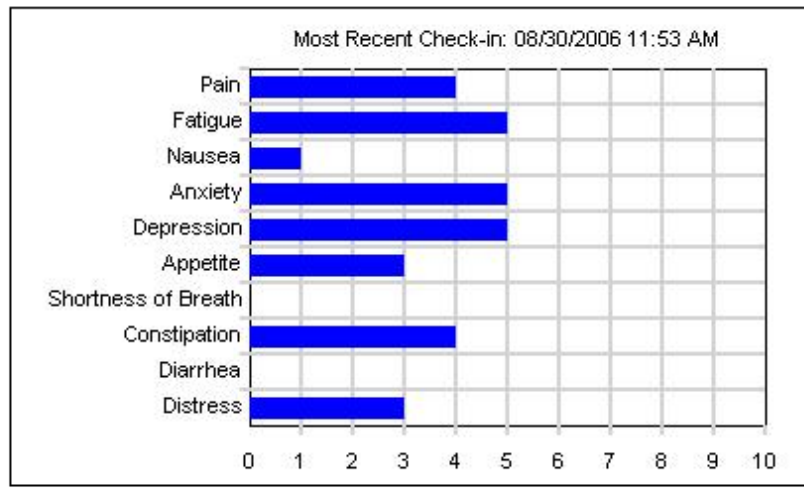**A Network of Support**

Exit

Health Status   Need Help

Health Status Summary Page

This CHESS Clinician Report is based on information provided by the patient (**Frank Adams**) and the caregiver (**Jane Adams**).
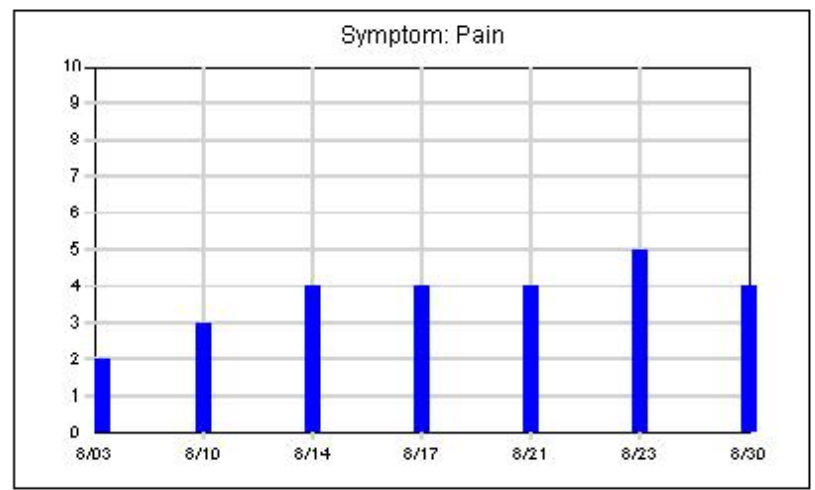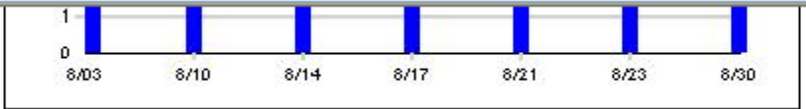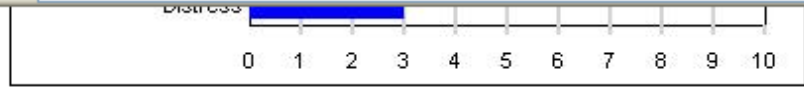
Frank's Clinic Report. (Show Caregiver Jane's Report)

Compare Frank's and Jane's Data

Latest ECOG/Activity Level: 1-Normal activities with some effort

See graph for: Pain

Most Recent Check-in: 08/30/2006 11:53 AM

Symptom: Pain

Patient Needs:

- Changes in Household Roles
- Communication: Spouse/Partner
- Estate Planning
- Pain
- Sadness/Depression

Caregiver Needs:

- Fatigue
- Pain
- Sadness/Depression
- Sleep Problems
- Work

Clinic Visit Questions:

Note that the patient and the caregiver sent these questions separately and may not be aware of each other's concerns.

Patient Questions:

I am feeling troubled about the future, but don't want to worry my wife. It's hard to talk about these issues.

Caregiver Questions:

What are the options if the current treatment doesn't work?
Is there anyone on staff who can help me figure out the family leave options that are supposed to be available from an employer?

Caregiver Status: Physically, Jane reported coping poorly at the last check-in. At the last check in, Jane reported some lack of confidence in caring for Frank's needs.

(Print Report) (Home)

About CHESS   Contact Us

Lung cancer: CHESS w clinician report

CHESS w
Clinician report
v. Control

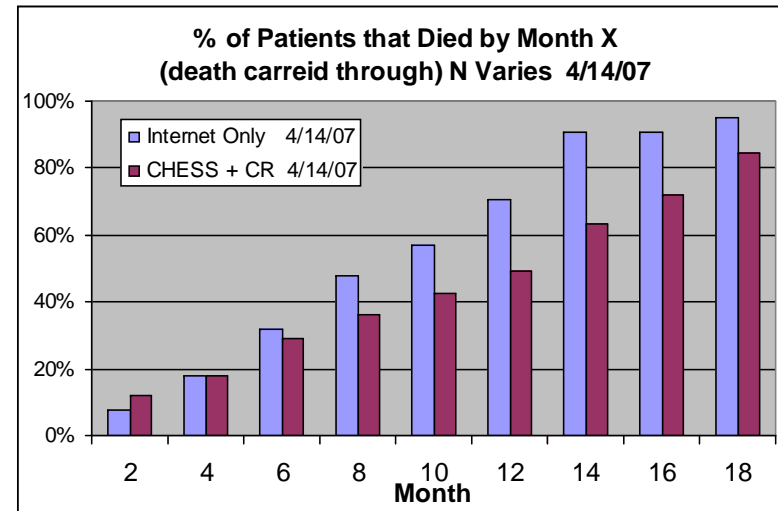Positive effect on
Physical health (p<.05)
(Patient report)
• Pain
• Fatigue
• Physical Qual of Life

**Improved
Life Expectancy
P<.025**

No effect on
Mental health
• Anxiety
• Depression
• Distress

No effect on caregiver

**% of Patients that Died by Month X
(death carreid through) N Varies 4/14/07**

- Internet Only   4/14/07
- CHESS + CR 4/14/07

Month

Future

Pre-diagnosis
Developed very accurate mammogram analysis

QuickTime™ and a
decompressor
are needed to see this picture.

Should CHESS be provided pre-diagnosis?

QuickTime™ and a
decompressor
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Family Support Systems
Collaboration w Tufts University
Susan Parsons MD

QuickTime™ and a
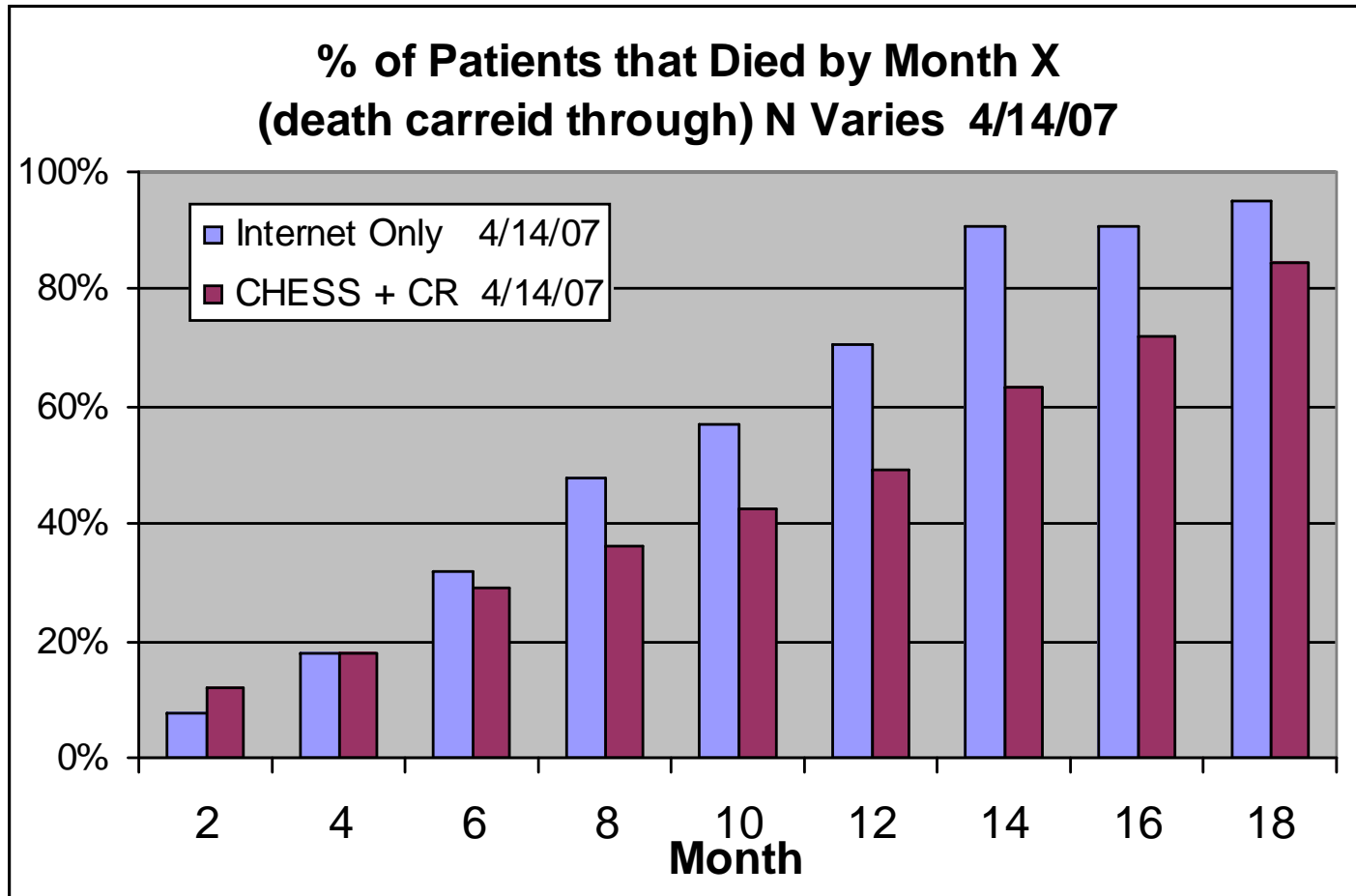decompressor
are needed to see this picture.

Diffusion/Dissemination/Spread

- **Integrate CHESS Bca into large managed care provider network**

- **Examine outcomes**
  - **Patient (affect and quality of life)**
  - **Clinician (visit satisfaction & job satisfaction)**
  - **Cost to provider of implementation and operation (business case)**

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47% Functionally illiterate!

See you in the Poseidon Room!