Nursense, innovation, and you: Engaging geriatric patients and caregivers with technology

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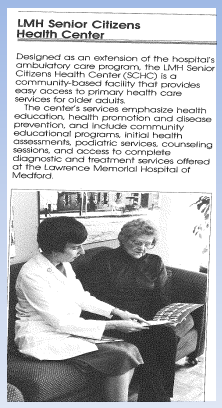
Share my story

- Advocating for client /patient service improvements
- Advancing nursing role as a technology innovator
- Providing a legal nursing basis for developing activity sensing technologies
- Disseminating lessons learned to promote user adoption, engagement, and positive outcomes

Advocacy

1980 - Massachusetts first health center developed and licensed under the directorship of a Gerontological Nurse Practitioner, not an MD


LMH Senior Citizens Health Center

Designed as an extension of the hospital's ambulatory care program, the LMH Senior Citizens Health Center (SCHC) is a community-based facility that provides easy access to primary health care services for older adults.

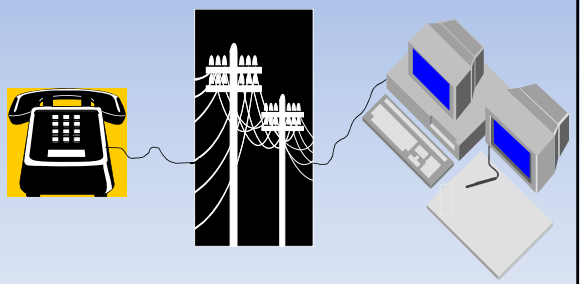
The center's services emphasize health education, health promotion and disease prevention, and include community educational programs, initial health assessments, podiatric services, counseling sessions, and access to complete diagnostic and treatment services offered at the Lawrence Memorial Hospital of Medford.

Mahoney, D. The Role of the GNP in Establishing a Senior Health Center **The Mass Nurse**, 1983;52(11):8,20. PMID 6558387

Mahoney, D. "An Innovative Design: A Hospital Sponsored Nurse Managed Center" in **Nurse Managed Centers: Impact on Health Care Delivery**, U of Wisconsin, 1984, p19

Mahoney, D. Marketing Health Care Programs to older adults: Strategies for Success. 1994. **Geriatric Nursing.** Jan/Feb, 15,10-15; PMID 8314122

Telephone Linked Computer Interactive Voice Response



Friedman, R. Stollerman, J., Mahoney, D. & Rozenblyum, L. (1997). Virtual Visit: Using Telecommunications Technology to take care of patients. **Journal of the American Medical Informatics Association**. 4:413-425

Reach

Resources For Enhancing Alzheimer's Caregiver Health

Diane Feeney Mahoney PhD GNP
Principal Investigator, Boston Site

1995-2002 NIH My Funding: NIA U01-AG13255

Resources Enhancing Alzheimer's Caregiver Health (REACH) Leadership Team:

Rich Schulz / Steven Belle	**University of Pittsburgh Pittsburgh, PA**
Lou Burgio	**University of Alabama, Tuscaloosa, AL**
Robert Burns	**VA Medical Center Memphis, TN**
Carl Eisdorfer	**University of Miami Miami, FL**
Dolores Gallagher- Thompson	**VA, Palo Alto Stanford University**
Laura Gitlin	**Thomas Jefferson University Philadelphia, PA**
Diane Feeney Mahoney	**Medical Informatics Unit, Boston Medical Center, Boston MA**
Marcia Ory	**NIA**
Mary Leveck	**NINR**

Reach goal

To evaluate the effect of the ***Reach for TLC*** system on:

reducing caregiver stress related to the bothersome nature of managing the care recipients' disruptive behaviors

The 2am telephone message

Personalized by

- Tailored information
- Offering choices
- Response to personal goals
- Giving feedback

Reach for TLC Telephone System

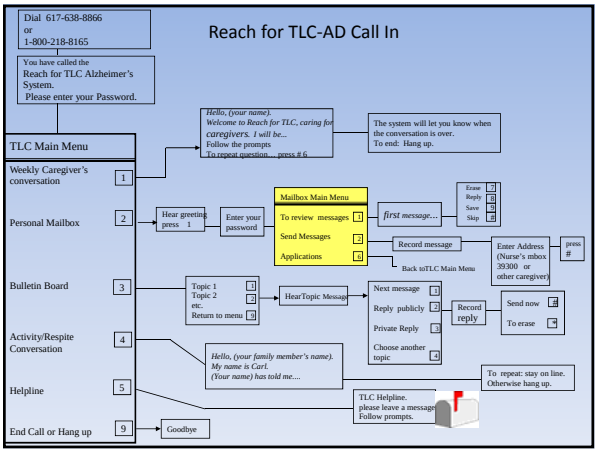
- Weekly caregiver IVR conversation (1-10 min)
- Personal Mailbox*
- Bulletin Board*
- CG Respite/ CR Distraction Activity conversation (18-40 min) *

***Available 24 hours a day**

Mahoney, Tarlow, & Sandaire (1998) A Computer-Mediated Intervention for Alzheimer's Caregivers. Computers in Nursing, 16(4),208-216.

Mahoney, D. (1998). A content analysis of an Alzheimer family caregivers virtual focus group. **American Journal of Alzheimer's Disease,** Nov/Dec, 13(6),309-316. doi: 10.1177/153331759801300606

Mahoney, D. (1999) Using a Website for Qualitative Research: Feasible or Foolish? Proc 1999 **American Medical Informatics Association** AMIA symposium published proceedings iiii PMCID:PMC2232511



Study Sample

- 100 randomized caregiving dyads (n=200)
- 100 persons with an AD presumptive diagnosis
- 100 Primary AD family caregivers
- 80% female, 30% minority rate
- Intent-to treat analysis

Tarlow, B. & Mahoney,D. (2000) The cost of recruiting AD caregivers for research. J of Aging & Health 11(4),519-539.

Nichols, L., Martindale-Adams, J., Burns, R., Coon, D., Ory, M., Mahoney, D., Tarlow, B. Burgio,B. Gallagher-Thompson, D., Guy, D., Arguelles, T. * Winter, L. (2004) Social marketing as a framework for recruitment: Illustrations from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study. **Journal of Aging and Health** 16(5):157S-176S. PMID 15448292

In Sum

- It worked!!

Effects of an automated support system on caregiver burden and anxiety: Findings from the REACH for TLC intervention study, D. Mahoney, B.Tarlow, & R Jones (2003) Gerontologist 43(4)556-567.

Gitlin, L. N., Belle, S. H., Burgio, L.,D., Czaja, S., J., Mahoney, D., et al. (2003). "Effect of multicomponent interventions on caregiver burden and depression: The REACH multisite initiative at six month follow-up. *Psychology and Aging*, 18, (3), 361-374. PMID 14518800

Uniquely Reach for TLC

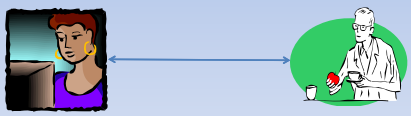
- Available anywhere there is a telephone
  - at home or while traveling / visiting
  - regular or cell phone
- 24 hours a day, 7 days a week
- Tailors to cgs needs + preferences
- Multiple intervention options
- Completely Automated Intervention
- Capacity for large scale use over long periods of time

Providers' Beliefs…&…Realities

- Technology is a-humanistic
- Human support is always preferred
- The more intensity of human support, 1 : 1 time, the better the outcomes (dose response)
- Aka: No referrals
- Many people dislike in-person groups or 1:1s
- Low intensity, 24/7 multi-component technology that tailored support produced = effects with < dropouts

Linking Home Care and the Workplace Through Innovative Wireless Sensor Technology

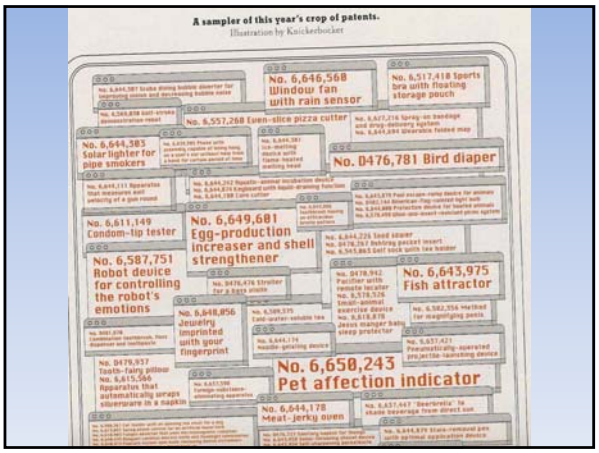
The Worker Interactive Networking (WIN) project.



Funded by the Technology Opportunities Program, (TOP), NTIA, U.S. Dept of Commerce ('2001-04) D Mahoney, Principal Investigator

Main Research Question:

Could wireless sensor based technology be used in elders' homes and linked to the workplace to offer working caregivers a means to allay their concerns?



Process – *Nursense©*

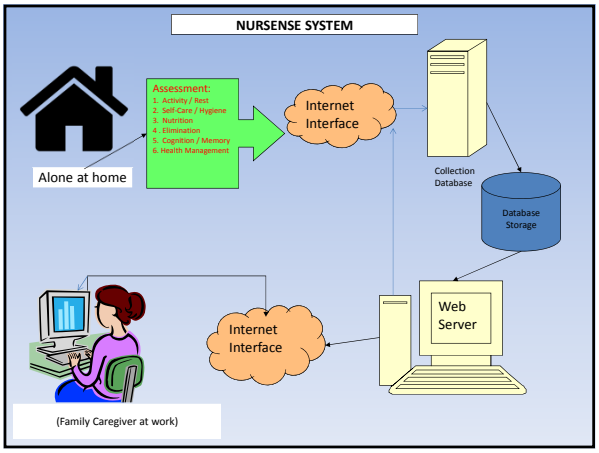
- Nursing assessment
- Carers and Care Recipient's input

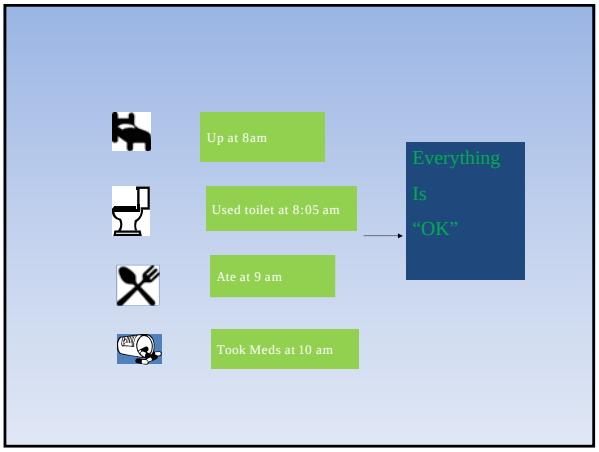
- Customizes Installation
- Tailors to specific concerns
- *Consumers' choice drives the technology not vice a versa*

Mahoney, D. (2004) Linking Home Care and the Workplace Through Innovative Wireless Technology: The Worker Interactive Networking (WIN) project. *Home Health Care Management and Practice* 16(5),417-428.

Nursense©

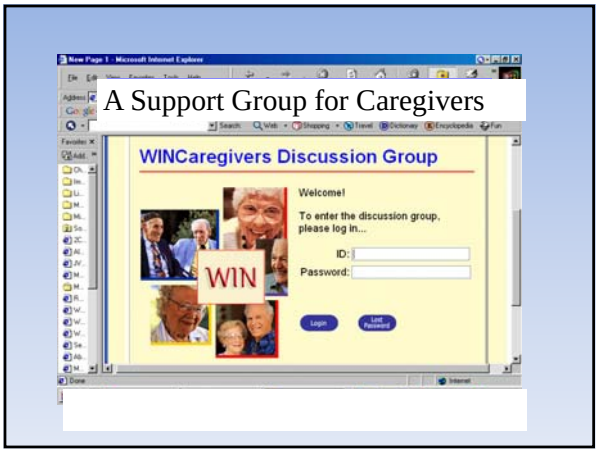
- My definition: A systematic appraisal using the nursing process to tailor technology based applications to endusers' needs and wants
- A nursing action that engages endusers* to personalize and develop the optimal balance between in- person and automated sensing support
  - Endusers*: Older adults; clients; patients; residents and/or formal/informal family caregivers, carers

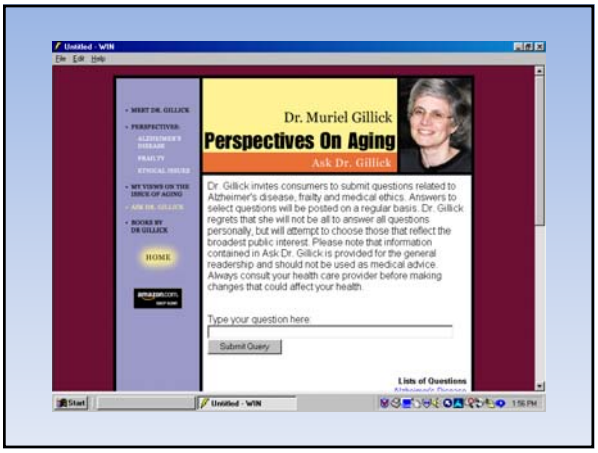




Caregivers' Report

- Concern present; Attention
- Nearing level of concern, on Watch
- No concern, OK

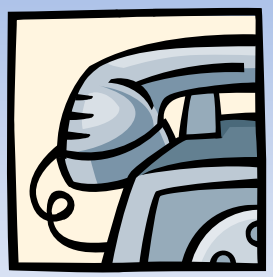




Critics ---- Truth or Myths?

- Worker productivity will be reduced
- Personal contacts by family members will decline
- Tech will increase elders' social isolation
- It crosses the line for being intrusive
  - Who would want this technology in their home?
  - Big brother is watching in one's private space

No increased social isolation



- "What I do is call her several times a day. If she didn't answer, I would then check home monitoring. It didn't replace my calls…it was more of a backup"

No Loss of Privacy

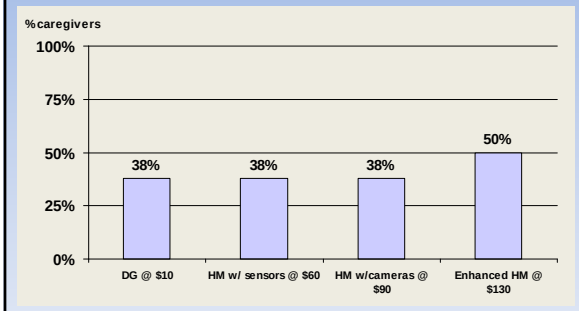
- All Elders Strongly disagreed that they felt
  - Their personal space was violated
  - "Big Brother" was watching
  - Embarrassed by the presence of equipment in home

No Intrusiveness

- All users strongly disagreed that:
  - Installation was a hassle
  - Installation caused damage to the house
  - Equipment got in the way at home
  - Equipment caused a change in daily routine
  - System maintenance visits were a nuisance

Willingness to self pay for service per month

(N=16)



"Peace of Mind"

I enjoyed it and it helps me at work. Even if someone used it occasionally, it is good to have it.

There is nothing to lose. The information makes you feel more ***at-ease.***

it was wonderful to make sure my mother hadn't fallen down or had an accident. It keeps worry down, to track her movements from room to room, knowing she was getting around.

It is very easy to use. It is easy to install and you get help with that. It was worth the effort – you get more out of it than you need to put in.

It is a unique way to check in without altering their [family member's] trust. It give you **peace-of-mind**, definitely. It becomes like part of the furniture and is not a problem.

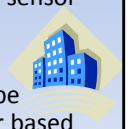
Great for ***peace of mind*** *because it helps keep you informed of what is going on behind closed doors.*

gives peace of mind. I don't think you need to monitor every move, but it is nice to have as a checking system if something seems wrong.

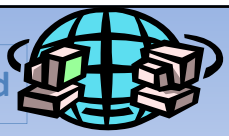
It provides ***peace of mind*** *as to your family member's condition and gives a hint of dangerous situations that may occur.*

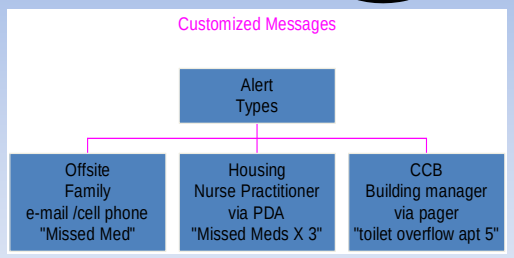
"At EASE" Purpose

- 1) to gain an understanding of the concerns in ILRs from the perspectives of the elders, families, building staff, and consulting NPs
- 2) to assess the feasibility of using X10 sensor technology in ILR
- 3) to determine if the concerns could be addressed through our wireless sensor based remote 24/7 monitoring system



Information Triaged





Methods & Samples

Qualitative
Phase 1
- Focus groups: 8, n=26
  - 5 Resident / family
  - 2 Building Staff
  - 1 NPs
- Content Analysis
  - Themes of concern
  - Across and within groups

Quantitative
Phase 2. Technical X10 feasibility & reliability beta study n=2 units
Phase 3.
ZigBee system 4 mo intervention study
n= 10 "sets" of endusers
pre/post pilot outcomes

Phase 3 – Intervention Results

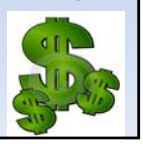
Pre-Post comparisons:

- Endusers reported increased:
  - "Peace of Mind" Security
  - Safety Satisfaction
- Elders reported no sense of intrusiveness or loss of privacy from this technology
- Emergency Alerts occurred for 6 cases over 12mo period.
  - No false positives

Theoretical Challenge

Research critics call for studies to **advance theoretical development** and **understanding about the multiple influences on older adults' technology adoption**

– The high development cost of new technology interventions leads to predominantly small sample sizes that limit outcome analyses



Purpose

To develop an

Adoption of Gerontechnology Monitoring Model

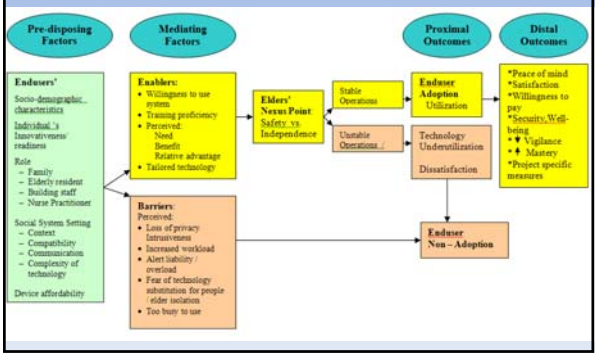
to guide future implementation and outcome studies

Publication: *D.F. Mahoney (2011)* An Evidence-based Adoption of Technology Model for Remote Monitoring of Elders' Daily Activities. *Ageing International 36(1)66-81*

Method

- Data were re-analyzed guided by constructs from Roger's Diffusion of Innovation Model and prior TAMs
  - Factors affecting the endusers' acceptance and use of the monitoring technologies were the focus
- Model **components** arose as **major factors** in **two or more** of the contributing studies

Mahoney's Adoption of Gerontechnology Model



Acknowledgments & Citation

Original research studies were supported by grants from :

- NIH/ National Institute on Aging
- Dept of Commerce, TOP Program
- NIH/ National Institute of Nursing Research
- The Boston Foundation
- Alzheimer's Association

Colleagues : Medical Informatics Unit Boston Medical Center, Hebrew Senior Life Aging Research Institute, WebZest,LLC Quiescence,LLC, MIT Media lab, New England Research Institute, BU School of Public Health, MGH -IHP

Publication: ***D.F. Mahoney (2011)*** **An Evidence-based Adoption of Technology Model for Remote Monitoring of Elders' Daily Activities.** ***Ageing International 36(1)66-81***

Development of a Responsive Emotive Sensing System (DRESS)

alz.org | alzheimer's association

ETAC grant 11-200316
2011-2013

Prototyping a Context Aware Affective Emotive Sensing Intervention for Persons with Dementia and their Caregivers

NIH National Institute of Nursing Research
Building the Scientific Foundation for Clinical Practice

R21NR013471
2014-2017

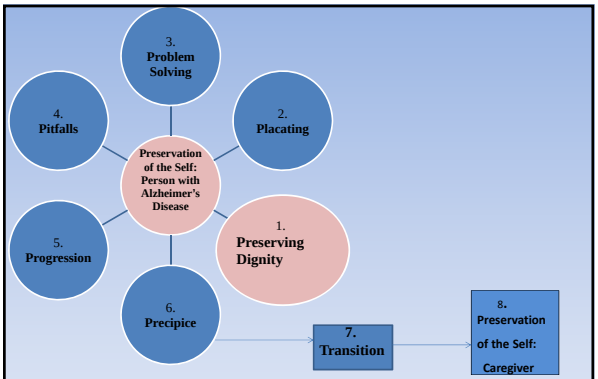
MGH Institute – D Mahoney PhD, RN, PI 2011-2017
S LaRose RN MS 2011, J McReynolds RN MS, (NP students) 2012
E Mahoney MS 2011-2012

Arizona State University - W Burleson PhD 2011- 2014
College of Nursing and Innovation – D Coon PhD 2014-2015
College of Computer Science – C Lozano PhD post-doc, Vjay PhD, doctoral student 2011 -2014

New York University – W Burleson PhD, J Rowe EdD, E Mahoney MS 2014-16

Significance

- Family caregivers are the critical service provider for older adults with AD
- 85% of family caregivers help with ADL's
- Dressing is the most common (61%) ADL
  - Most pressing daily concern in early to mid-stage AD
    - > for adult children aiding parents
    - > for those of opposite gender
  - Yet relatively ignored by researchers



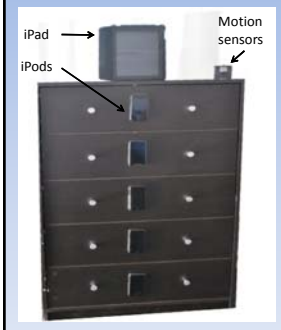
Mahoney, D., La Rose, S., & E. Mahoney(2015) Family caregivers' perspectives on dementia related dressing difficulties at home: The Preservation of Self Model. Dementia 14(4)494-512; doi:10.1177/1471301213501821

Mahoney, DF, Coon, DW, & Lozano, C. Latino/Hispanic Alzheimer's Caregivers' Experiencing Dementia Related Dressing Issues at Home: Corroboration of the Preservation of Self Model and Reactions to Using a "Smart Dresser" Computer-based Dressing Aid. **Digital Health** 2016,

Caregiver Focus Group Findings

- Verified DRESS applicable late early to early mid-stage AD
- technology design not seen as "intrusive", but promoted dignity and independence
- 90% of DRESS prototype features were affirmed
- **CG Recommendations**:
  - *Change to dresser top "TV screen" aka* IPad
  - *Send alert if wandering out of the room occurs*
  - *Include option to use the CG's voice for system prompts*
  - *Add chair and mirror to dress routine*
  - *Make interoperable with other monitoring devices*

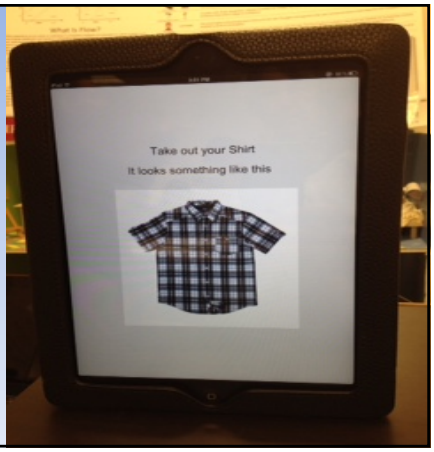
Interactive Dressing Coaching System



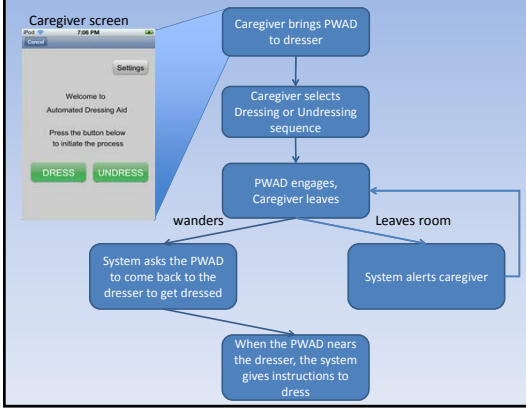
I Pad

audio prompting

visual cueing



Dress Wander Sequence



Prototype Validity and Reliability Testing

- 6 AD"actors"
- simulated 9 dressing scenarios encompassing a variety of
  - Common dressing problems
  - Correct dressing responses
- Randomly ordered
- Outcome: Detection accuracy rate

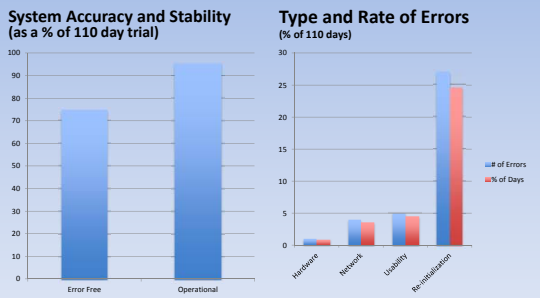
1. DRESS overall correctly identified 78% of actions
   - Shirt related dressing +/- actions were consistent at 100%
   - Pants / inside out actions were most problematic
2. Adjustment of Kinect thresholds improved overall rate to 100% with 4 new testers

www.ncbi.nlm.nih.gov/pubmed/26321895

Stability over time and Accuracy Testing

- Technical operations testing over a 110 day period
- The same 69 yr old male tested the system weekdays am and/or pm in a studio unit where the system's hub was plugged in and DRESS operated 24/7 using the local Wi-Fi network. He alternated the role of the helper, using the caregivers' device, or the PWD by putting on fiducial imbedded clothing, getting "stuck," distracted, perseverating, and completing the task. He recorded usability issues in a diary
- In-person and remote system diagnostic checks were conducted to identify issues, validate the reliability of operations, confirm and annotate the system generated error log reports
- A content analysis was conducted on the event diary recordings and the annotated log reports. Quantitative analyses employed descriptive statistics to report the % of days with errors & types

Results



In Sum: Advancing nursing innovation

- Risk taking can be energizing
- Rogue can be rewarding
- Apply your Nurse Sense
- Qualitatively know your clients' needs and wants
- Integrate evidence based design principles / models
- Plan to engage & sustain usage