



NIA Roybal Centers for Dementia Care Provider Support

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Edward R. Roybal

- Edward Ross Roybal
 - One of 10 children born in Albuquerque, New Mexico
- Served in the House of Representatives, representing Los Angeles (1960s-1980s)
- Advocate for senior health and Alzheimer's research
- Cofounder of the Congressional Hispanic Caucus; deemed one of the country's most influential Hispanic politicians
- Thirteen Roybal Centers translate basic behavioral and social research findings into programs and practices addressing aging.



Roybal Centers for Translational Research on Dementia Care Provider Support

- Oregon Health & Science University (Kaye)
- University of Rochester (Heffner & Van Orden)
- Emory University (Hepburn & Perkins)
 - Whitney Wharton
- University of Pennsylvania (Halpern)
 - This is a partnership with Genesis HealthCare, the largest owner of nursing homes in the U.S., with most pilot studies funded by the Center being conducted among Genesis facilities as our “learning lab”
 - The Center will primarily focus on using insights and methods from the fields of behavioral economics and data science to improve residential palliative care for persons with dementia and their caregivers
 - Scott Halpern: shalpern@upenn.edu
 - Honora.Kelly@Pennmedicine.upenn.edu>

NIH Stage Model

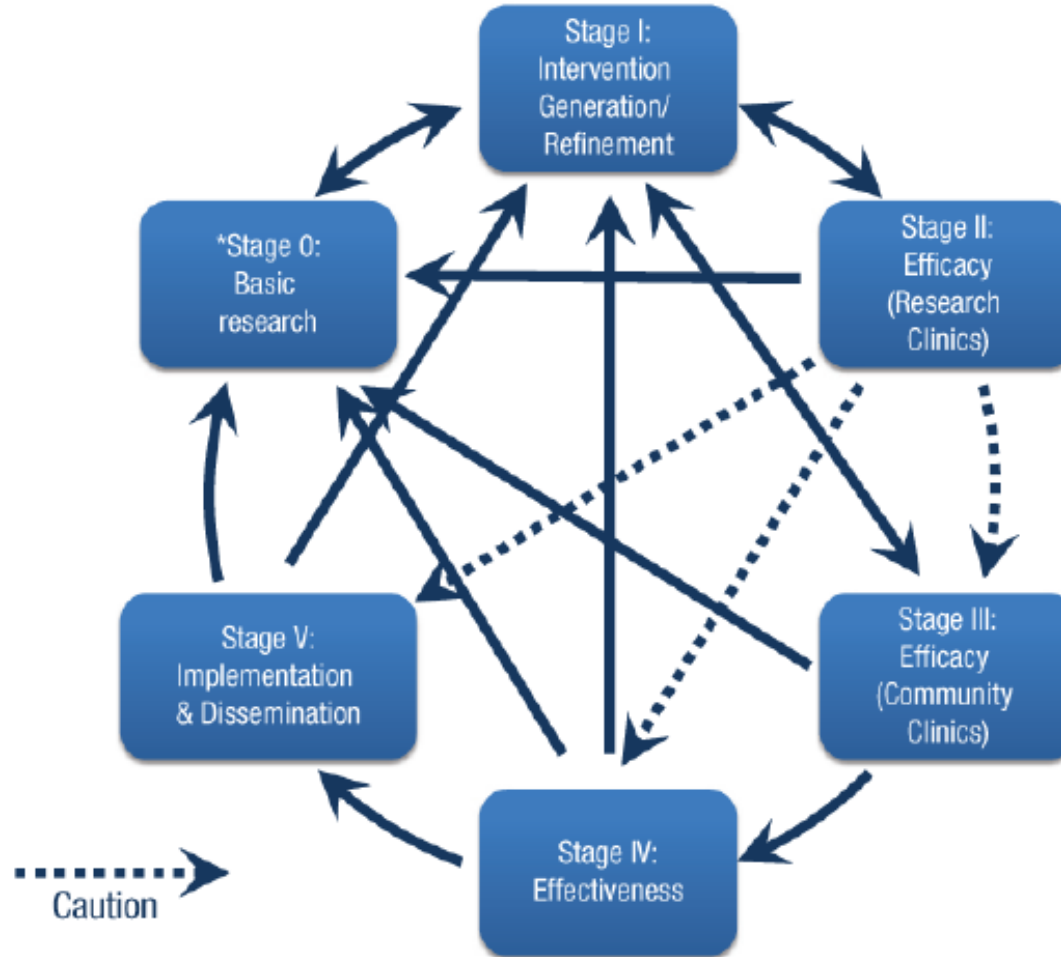


Fig. 1.

NIH stage model: common and cautionary pathways.

Note: Dotted arrow indicates the importance of using caution when considering this pathway.

A vertical photograph on the left side of the slide. It shows a cable car (gondola) suspended from cables, moving upwards. In the background, there is a modern building with a glass facade and a brick building. The foreground shows a concrete retaining wall with a metal railing.

ORCASTRAIT

- Oregon Roybal Center for CAre Support
Translational Research Advantaged by
Integrating Technology
- Supported and informed by findings from
the Oregon Roybal Center for Aging and
Technology (ORCATECH)

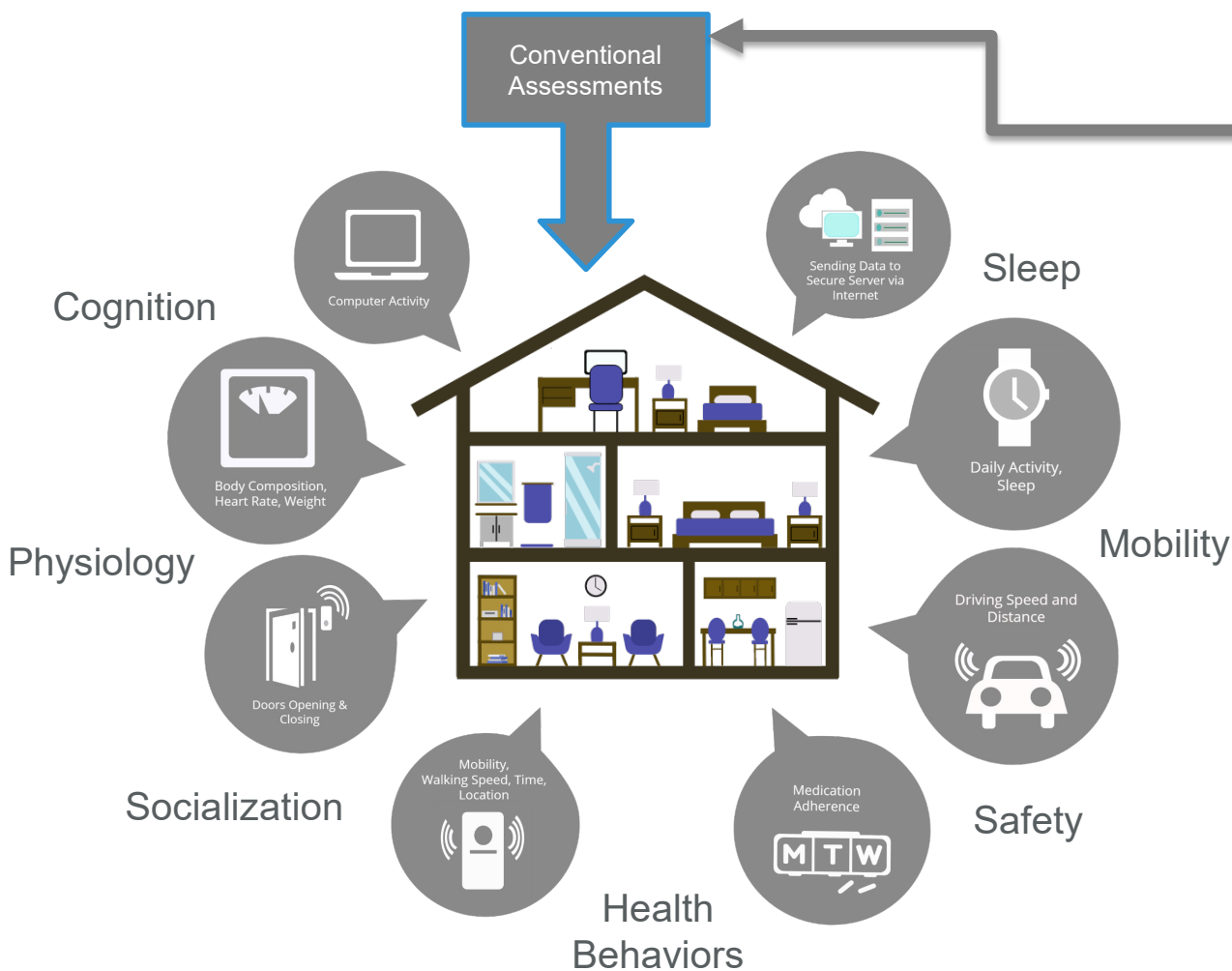
ORCASTRAIT Aims and Components

- Support a unique *organizational infrastructure* that accelerates the process of developing, translating and disseminating innovative care provider interventions facilitated by technology
- Advance real-world development of care support intervention research using:
 - *ORCASTRAIT Life Laboratory* network of ADRD volunteers and care providers whose residences in the community are enabled with pervasive computing capabilities
 - Participatory research community informing user activities, attitudes and beliefs: *Response via Internet Technology and Experience (RITE)*
 - Shared data resources
- Pilot Core
 - Sponsor two early-stage scientists
- Structured, but flexible educational opportunities to advance the workforce:
 - Technologies for Intervention Practicum and Study (TIPS) program
 - Technology Research and Care Support (TRACS) online study modules

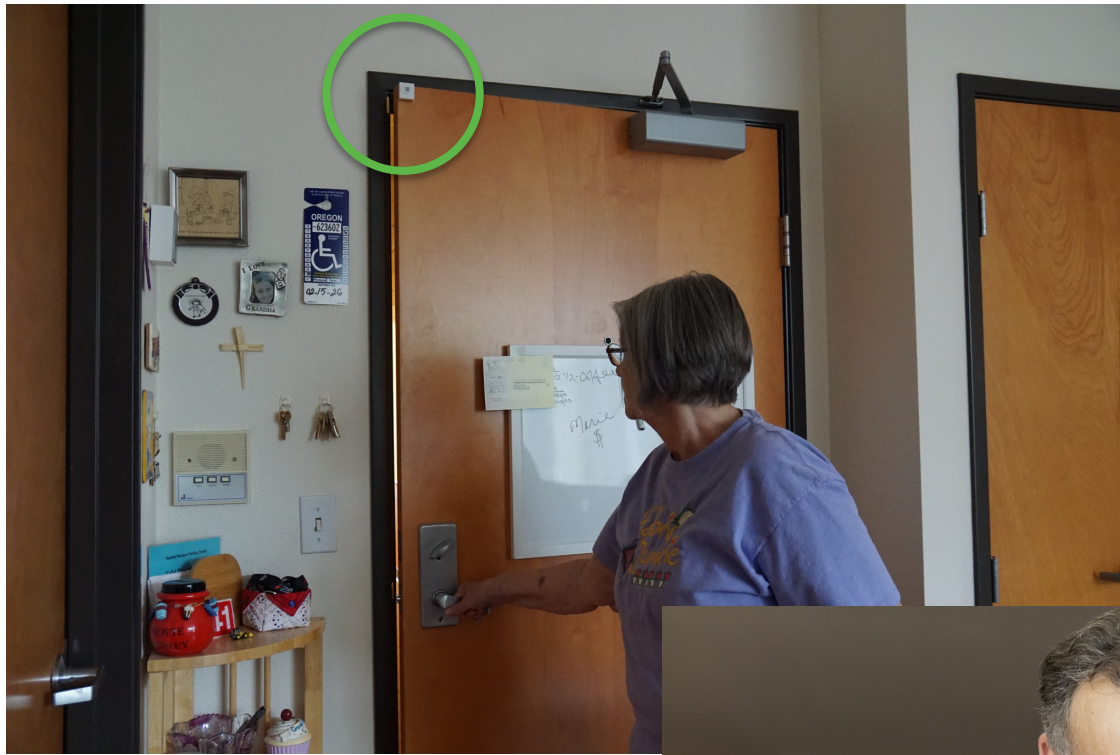
Pilot Core

- Support innovative pilot studies necessary to build and deliver evidence-based, standardized interventions grounded in sound principles of technology research.
- Provide infrastructure for technology-based research with persons with dementia and their care providers (Developed and tested with ORCATECH).
- Up to \$100,000 annual funding for pilots
- Provide instruction and guidance to early-career scientists

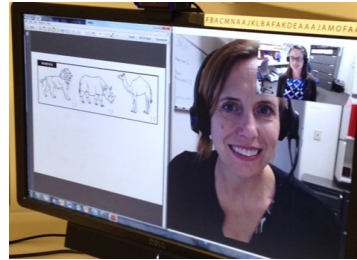
ORCASTRAIT Home-based Life Laboratory



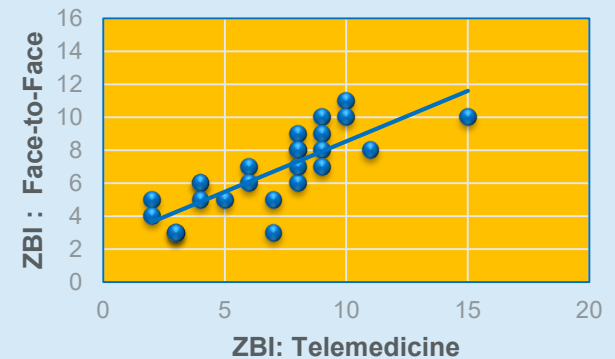
Data Collection Instrument	Screening	Baseline Visit
Demographics	<input type="radio"/>	<input type="radio"/>
Phone Script	<input type="radio"/>	<input type="radio"/>
NACC Ivp A1 Subject Demographics	<input type="radio"/>	<input type="radio"/>
CART SES & Employment	<input type="radio"/>	<input type="radio"/>
CART Cognitive Status	<input type="radio"/>	<input type="radio"/>
CART Mobility	<input type="radio"/>	<input type="radio"/>
NACC Ivp C2 Neuropsych Battery	<input type="radio"/>	<input type="radio"/>
NACC Ivp B1 Physical	<input type="radio"/>	<input type="radio"/>
NACC Ivp A5 Health History	<input type="radio"/>	<input type="radio"/>
NACC Ivp D2 Clinician Assessed Medical Conditions	<input type="radio"/>	<input type="radio"/>
RAND Health Survey SF-36	<input type="radio"/>	<input type="radio"/>
OARS ADL/IADL	<input type="radio"/>	<input type="radio"/>
CART Habits	<input type="radio"/>	<input type="radio"/>
PASE	<input type="radio"/>	<input type="radio"/>
Modified Sleep	<input type="radio"/>	<input type="radio"/>
UCLA Loneliness	<input type="radio"/>	<input type="radio"/>
Lubben Social Network Scale	<input type="radio"/>	<input type="radio"/>
Zarit Burden	<input type="radio"/>	<input type="radio"/>
NACC Ivp B6 GDS	<input type="radio"/>	<input type="radio"/>
GAD-7	<input type="radio"/>	<input type="radio"/>
ADCO MCIRS	<input type="radio"/>	<input type="radio"/>
NACC Ivp B4 Global Staging CDR	<input type="radio"/>	<input type="radio"/>
NACC Ivp B8 Neurological Examination Findings	<input type="radio"/>	<input type="radio"/>
NACC Ivp B9 Clinician Judgement of Symptoms	<input type="radio"/>	<input type="radio"/>
NACC Ivp D1 Clinician Diagnosis	<input type="radio"/>	<input type="radio"/>
Study Staff Reportable Event	<input type="radio"/>	<input type="radio"/>
Scanned Data Collection Forms	<input type="radio"/>	<input type="radio"/>



Teledementia Care: *Direct to Home Assessment & Care*

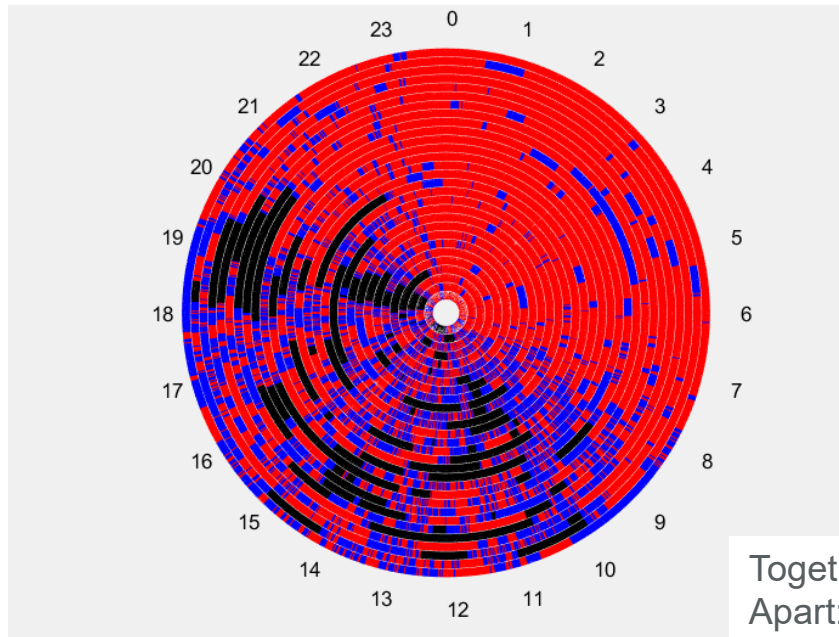


ZBI score: Face-to-Face vs. Telemedicine

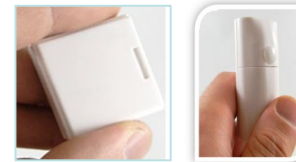


Lindauer et al. Gerontologist, 2017.

Couples & Caregiving Analysis: *Time spent together*



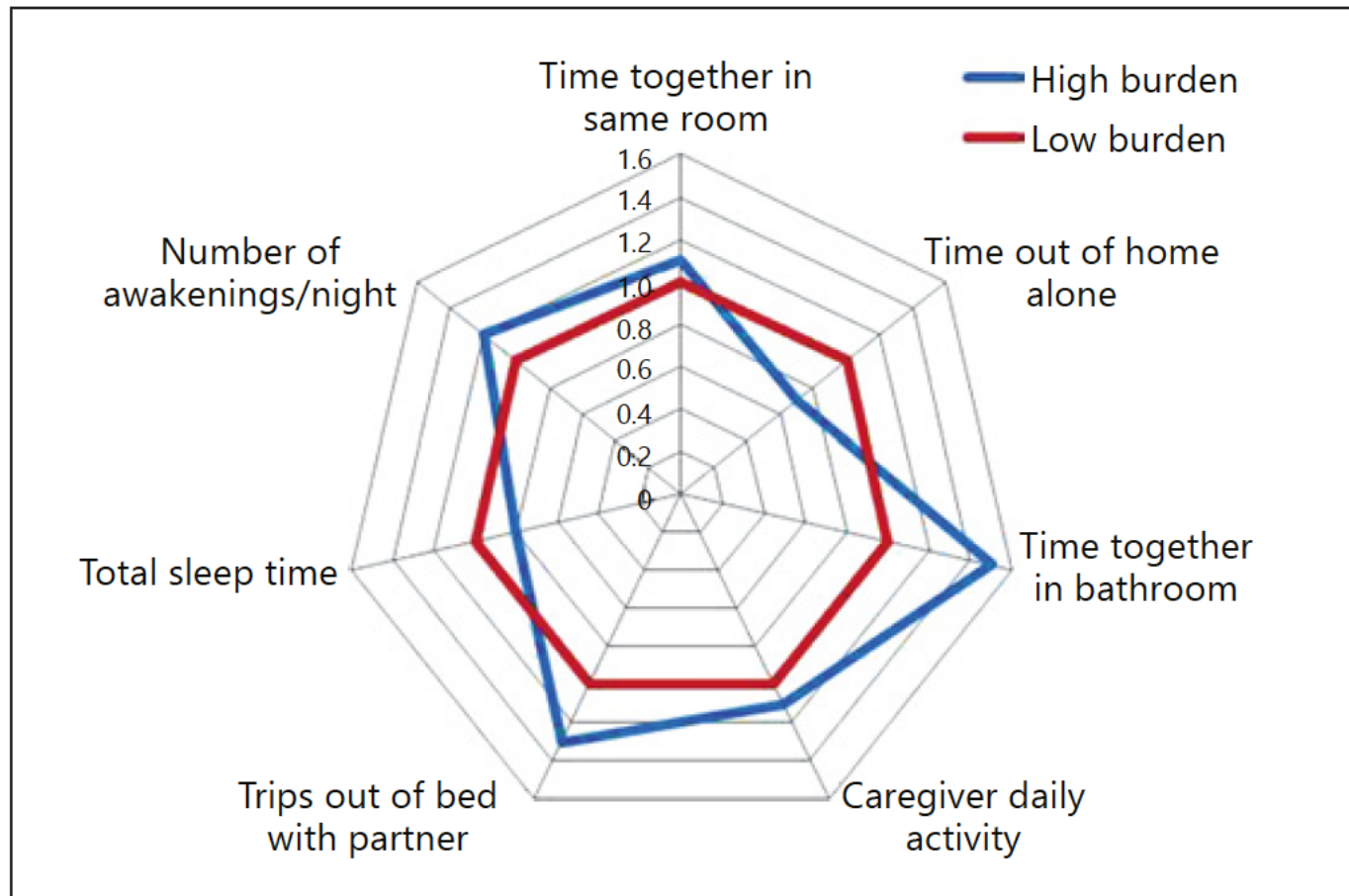
- Together
- Separate
- Out of Home



Together: 1285 minutes (21.4 hrs/day)
Apart: 155 minutes (2.6 hrs/day)

Novel Assessment of Caregiver Burden

Fig. 4. Composite model of digital biomarkers showing potential domains associated with the degree of caregiver burden. Values in the figure represent odds ratios, with low burden values normalized to 1.0.



Thomas et al. Dementia & Cognitive Geriatric Disorders, 2019

2019 Pilots

Lyndsey Miller, PhD, RN

- SHARE-Sense (Support, Health, Activities, Resources, and Education—integrating objective sensing), an intervention with counseling-based techniques and technology (IRB #: 20397)
- SHARE-Sense will integrate unobtrusive in-home monitoring to help assess evolving care needs and inform a family care planning program for early stage dementia

Allison Lindauer, PhD, NP

- STELLA (Support via Technology: Living and Learning with ADRD) pilot study provides education and skills training to help family care partners reduce upsetting behavioral symptoms of dementia (IRB # 19306).
- STELLA will use objective data from the home-based platform to assess the efficacy of the intervention on reducing Care Partner burden and depression

2020 Pilots

- Seeking scientists for 2020 pilots:
 - Innovative interventions that would be advantaged or enhanced by technology
 - Advances care provider science
 - Plan for advancement along the NIH Stage Model
 - Encourage collaboration across ADRCs
- Contact us for information: Tracy Zitzelberger (zitzelbe@ohsu.edu)

Thank you!

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