Abstract Book and Program

Monday, October 21, 2013

Presented by
Buehler Center on Aging Health & Society
Northwestern University Feinberg School of Medicine
The Buehler Center is committed to improving the quality of life and quality of care for older people. It seeks to achieve this mission by:

• conducting clinical, applied, and policy research
• disseminating education programs
• supporting community outreach

The Buehler Center on Aging, Health & Society was established in 1982 in response to an increasing need for expertise on aging. It was renamed in honor of the Buehler family in 1990. Although there are approximately 100 centers on aging in the United States, the Buehler Center is one of only a few that are affiliated with a medical school.

As part of a not-for-profit organization, the Buehler Center’s continued success is largely supported by the generosity of our dedicated philanthropic base.
Schedule of Events

The 18th Annual James E. & Bonnie L. Eckenhoff Lecture
and John & Gwen Smart Symposium

Welcome & Opening Remarks 1:00pm
Dr. Linda Emanuel
Buehler Center on Aging, Health & Society

Introduction 1:10pm
Joyce Gallagher
Executive Director, Chicago Department of Family and Support Services

Eckenhoff Lecture 1:20pm
Martin J. Hatlie, Esq.
President of Partnership for Patient Safety & CEO of Project Patient Care

Smart Symposium 2:00pm
Poster Exhibition & Reception

Age Friendly Chicago Roundtable 3:00pm
Joyce Gallagher, Moderator

Adjourn 4:00pm
Eckenhoff Lecture

James E. & Bonnie L. Eckenhoff

While working in a small Lexington, Kentucky hospital, James E. Eckenhoff developed his devotion to medicine and met a young nurse named Bonnie Lee Youngerman, who would shortly become his wife. Having much impressed the medical leadership at this hospital, James was encouraged to attend medical school and was admitted to the University of Pennsylvania School of Medicine in 1937. He went on to build a career in academic anesthesiology, first at the University of Pennsylvania and then at Northwestern University, where in 1966 he became the first chair of a newly independent department of anesthesiology. James rose quickly to hold the position of dean of the School of Medicine at Northwestern for thirteen years and was appointed president of the McGaw Medical Center.

Both James and Bonnie had a devotion to the elderly and their unique needs. Bonnie returned to nursing in an institution on the North Shore that cared for Alzheimer patients, and James helped establish this Center for Aging at Northwestern. Interestingly, both died of the neurodegenerative disorders that each had cared for in some way during their careers. James of multi-infarct dementia in 1996 and Bonnie in 2008 of Alzheimer’s disease. This lecture is intended to recognize their unique contributions to elderly care. Bonnie for her front-line care focused on the individual, and James for his broad perspective for all the elderly.
Eckenhoff Speaker

“In Action to Transform:
The Journeys of Patient Safety Advocates in the 21st Century”

Presented by
Martin J. Hatlie, Esq.

Martin J. Hatlie, Esq., a long-time patient safety advocate, shares the remarkable experiences of patients and families in the modern patient safety movement & how they are contributing to practice change, shaping policy and shifting our social understanding of accountability for harm.

Hatlie currently is CEO, Project Patient Care, the Chicagoland safety and quality improvement coalition, which is dedicated to using the voice of the patient to improve care. He also is President of Partnership for Patient Safety (p4ps), a patient-centered initiative dedicated to advancing the reliability of healthcare systems worldwide. Hatlie is a co-developer of the H2Pi – Healthcare & Patient Partnership Institute suite of tools for enaging patients and families in improvement work.

In 2003, Hatlie co-founded Consumers Advancing Patient Safety (CAPS), a 501(c)(3) organization dedicated to fostering the role of consumer as proactive partner, where he currently serves as Program Chair. He also serves on the World Health Organization’s Patients for Patient Safety Steering Committee, the Advisory Board of Parents of Infants and Children with Kernicterus, the Joint Commission’s Patient Safety Advisory Group and Leapfrog Group Board of Directors.
The Smart Family Foundation is based on the success of the business enterprises of David and Alfred Smart. The Smarts had originally been an immigrant family who had come to the United States from Russia and settled in Omaha, Nebraska. In 1990, the family moved to Chicago and like many other struggling newcomers, settled on the West Side in a blue-collar neighborhood. David and Alfred built a highly successful magazine publishing business in the 1930’s. (This included Esquire Magazine).

In an effort to use their success for philanthropic ends, the Smart Foundation was established in 1951. After the deaths of Alfred and David, Esquire INC. began a period of expansion and diversification under the leadership of John Smart and Abe Blinder, John Smart along with his wife, Gwen Meyerson Smart, also born to immigrant parents, were a dynamic combination.

Since 2003, the Smart Family Foundation has generously supported the Buehler Center’s mission through annual gifts that have funded pilot projects, provided integral bridge funding for larger projects as well as for the continued growth of our academic and public profile by supporting events such as the Smart Symposium.
In 2012 the City of Chicago (through the Mayor’s office) received the designation of an age-friendly city. The concept of age-friendliness has been globally coined by the World Health Organization (WHO) to give value to the physical, social and environmental factors which can promote or hinder older residents’ ability to age in place in cities. Age-friendly cities can benefit not only older adults, but also their families and their communities. Cities which ostensibly rate quality of life are more likely to achieve economic sustainability. The city wide initiative was spearheaded by the City of Chicago in partnership with the Buehler Center on Aging, Health, and Society. A core aim was to present older Chicagoans views and opinions of Chicago as an enabling and disabling environment. Findings and opinions were gathered through a series of eight focus groups with 106 adults conducted at various regional senior centers throughout the city of Chicago. Today is the first presentation of the findings and the first opportunity to discuss age friendliness with professional and community stakeholders.

We invited discussants David Marquez, Cheryl Irmiter, and Christina Ferraro to join us for this roundtable discussion. They will share what they see as priorities for age friendliness in Chicago, how their work relates to the Age Friendly Initiative and how they plan to help sustain Chicago as an age friendly community.
**Interactive Booths**

**Rush University Medical Center, Rush Health and Aging**
Rush Health and Aging (RHA) offers innovative programs and services designed to measurably improve health and quality of life. From direct care coordination to health promotion and disease prevention to research and education, our mission is to promote wellness by improving access to psychosocial and medical resources for patients, those who care for them and the community.

**Contact:** Michelle Hochwert, MPH  
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**Cognitive Neurology and Alzheimer’s Disease Center, Northwestern University**
The CNADC is a multi-departmental freestanding component of the Feinberg School of Medicine. We specialize in the clinical care and scientific study of neurological diseases that interfere with cognition and behavior. Areas of clinical emphasis include age-related memory impairments, dementia, Alzheimer’s disease, frontotemporal degenerations, primary progressive aphasia, and related neurodegenerative conditions. Our three interacting missions are to investigate the causes and clinical characteristics of neurodegenerative diseases, to ensure that our patients are the beneficiaries of the latest advances, and to explore the neural foundations of behavior and cognition in health and disease.

The interactive booth of the CNADC will be offering brief, non-diagnostic memory screenings administered by research coordinators. The screenings are intended to bring awareness of memory and cognitive health, as well as to provide a worksheet that may elicit conversation about memory health with a primary care physician. In addition, information on clinical services, support groups and research opportunities will also be made available.

**Contact:** Darby Morhardt, MSW, LCSW  
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**University of Illinois Chicago**
The Center for Research on Health and Aging (CRHA) was established in 1997. CRHA is directed by Susan L. Hughes, PhD, Professor in the Division of Community Health Sciences (CHS) in the School of Public Health. CRHA is comprised of 18 other faculty members across the University, representing 5 Schools and 8 Departments including Public Health, Medicine, Nursing, Applied Health Sciences, and Urban Planning and Public Affairs. The Center conducts rigorous applied research on health promotion for older adults including group facility based programs, environmental audits, and policy recommendations. The Center is the recipient of three consecutive NIH/National Institute on Aging Roybal Center awards. These awards support the translation of theories about health promotion into actual programs that improve the functioning of older adults CRHA provides consultation and service to multiple external communities (local, regional, national and international).
Fit and Strong! is an award winning, evidence-based exercise and health behavior change program that improves the functioning and quality of life of older adults with lower extremity osteoarthritis. Tested with funding from NIH and easy to implement, this 8-week program improves strength and mobility out to 18 months.

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University of Illinois at Chicago
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Website: http://www.fitandstrong.org/

**Buehler Center on Aging, Health, & Society, Northwestern University**
The Buehler Center on Aging, Health and Society is committed to improving the quality of life and quality of care for older people, the terminally ill, and other vulnerable populations through education and research. It seeks to achieve this mission by conducting clinical, applied, and policy research; disseminating education and implementation programs; and supporting community outreach. It works in partnership with other Institute centers to address aging-related issues in the US population.

The Buehler Center’s booth will offer aging simulation exercises to demonstrate the effects of aging on the 5 senses. In addition, participants will be able to participate in our Age Friendly Chicago Initiative by completing a brief survey on the age friendliness of the city. Attendees who are interested in signing up for our research registry will find sign up forms at the booth as well.

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**IntelliStretch**
The IntelliStretch is an invention for motor function training of upper or lower extremity on neurological disorders or musculoskeletal injuries (e.g. Stroke, Traumatic brain injury (TBI), Cerebral Palsy etc.). It comes with safe and effective joint adaptive passive stretching and active assistive/resistance guidance functions with novel control method, and focuses on joint coordination, muscle weakness, selective motor control and abnormal muscle tone. The users will receive various fun training tasks by playing robotassisted games and gain their motor control ability.

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Email: l-zhang@northwestern.edu  
Website: http://www.rehabtek.com/#!intellistretch/vstc1=service-2
Aging and Social Science

1) **SuperAging Research Program-A Multidisciplinary Study of Extraordinary Seniors**
   Kristen Whitney B.S., Amanda Rezutek B.A., Adam Martersteck B.S., Tamar Gefen M.S.,
   Amanda Cook M.A., Stephanie Kielb M.H.S, Changiz Geula Ph.D, Sandra Weintraub Ph.D,
   M-Marsel Mesulam M.D., Emily Rogalski Ph.D

2) **Family strain and emotional health: Important midlife considerations for continued aging in place**
   Nicky Newton, Ph.D.

3) **Exploration of Physical Activity in Patients with Parkinson’s Disease**
   Amy Eisenstein, PhD; Tanya Simuni, MD; Mary Kwasny, ScD; Odinachi Oguh, MD; Brian Joyce, BA

4) **Community Participation after Spinal Cord Injury: Associations between Depression, Grief, Employment, and Mental Health Services**
   Alex Wong, PhD; Allen Heinemann, PhD; Catherine Wilson, PsyD; Holly Neumann, MPPA;
   Jesse Fann, MD; Denise Tate, PhD; Martin Forchheimer, MPP; Scott Richards, PhD; Charles Bombardier, PhD

5) **Targeted classical ballet instruction improves mobility in Parkinson’s disease**
   Citlali Lopez-Ortiz, MA, PhD; Wendolyn Gomez, BS; Ana Miskovic, MS; Santiago Toledo, MD; Mark Albert, PhD.

Age Friendly Communities

6) **Evidence to support the need to educate physicians and healthcare professionals about non-emergency medical transportation**
   Cheryl Irmiter, PhD, LCSW, CADC, Amy Eisenstein, PhD, Matthew Lee Smith, PhD, MPH, CHES,
   Thomas Prohaska, PhD

7) **Assessment of the Age-Friendliness of the City of Chicago**
   Rebecca Johnson Ph.D, Amy Eisenstein Ph.D, June M. McKoy MD, Katrina Marie Tulas, Joyce Gallagher, John Pfeiffer, Caroline Taromino MA

Caregiver

12) **Do perceptions of family-centered care differ in older and younger family caregivers?**
    Sherri LaVela, PhD, MPH, MBA; Tiffany Drinkwater, BS; Bella Etingen, MA; Scott Miskevics, BS.

13) **Caregivers of Persons with Spinal Cord Injuries**
    Sherri L. LaVela, PhD, MPH, MBA, Kelsie C. Landers, BS, Bella Etingen, MA, Scott Miskicks, BS, Vytas P. Karalius, MPH

14) **Professional Assessment of Family Caregiver Skill**
    Carol J. Farran; Judith J. McCann; Olimpia Paun; Caryn Etkin; K. Bharat Rajan; and Amy Eisenstein
Dementia & Alzheimer’s Disease

16) **Northwestern Alzheimer’s Disease Center Education Core 2012-2013**
Darby Morhardt, Mary O’Hara, Kristine Zachrich, Jaimie Robinson, Emily Rogalski, Kristine Lipowski, Christina Wiencke, Shannon Stone, SungJae Shin

17) **iILUMAnations: Results of a Museum based Art Program for Persons with Cognitive Impairment and Their Families**
Shannon Stone, SungJae Shin, Ann Meehan, Marlea Edinger, Mary O’Hara, Jaimie Robinson, and Darby Morhardt

18) **Dementia Patients Mentor Medical Students: A Multi-Site Study**
Darby Morhardt; Andrew Budson; Angela Jefferson; Elizabeth Daube; Robert Santulli; and Andrea Denny

19) **Korean American Alzheimer Research and Education (KARE)**
SungJae Shin; Mi Young Seo; Jeong Hwan Yi; Sun Young Balan; Darby Morhardt

20) **Episodic memory performance is associated with neuropathology in Primary Progressive Aphasia**
Stephanie Kielb, MHS; Amanda Cook, MA; Christina Wiencke, BA; Alfred Rademaker, PhD; Bing Bing Weitner, PhD; M-Marsel Mesulam, MD; Emily Rogalski, PhD; Sandra Weintraub, PhD

21) **Northwestern Alzheimer’s Disease Center (NADC) Clinical, Data Management and Biostatistics Cores**
Mallory Swift Ward BA, Laura Martindale BA, Alejandra Balen BA, Alfred Rademaker PhD, Saman Ahmadian MD, Borna Bonakdarpour MD, Shoib Memon MD, HyungSub Shim MD, Mary O’Hara MSW, Darby Morhardt MSW, M-Marsel Mesulam MD, Sandra Weintraub PhD

22) **Neuropsychological Performance of Cognitive SuperAgers: Preliminary Findings from a Longitudinal Study of Extraordinary Seniors**
Tamar Gefen, MS., Emily Shaw, John Stratton, MA., Kristen Whitney, Sandra Weintraub, PhD., Mesulam, M.-M and Emily Rogalski, PhD.

23) **Latin Dance and Health Education: Influence on Cognitive Function**
Susan Aguiñaga, MS; Priscilla Vásquez, MPH; Robert S. Wilson, PhD; Louis F. Fogg, PhD; JoEllen Wilbur, PhD; Susan L. Hughes, PhD; David X. Marquez, PhD

24) **Development and Implementation of a Multi-Component Lifestyle Physical Activity Intervention for Family Caregivers of Persons with Alzheimer’s Disease**
Carol J. Farran, DNSc, RN, FAAN, Caryn D. Etkin, PhD, MPH, Judith J. McCann, PhD, RN, Amy R. Eisenstein, PhD, Kumar Bharat Rajan PhD, Cynthia Castro, PhD, Abby C. King, PhD

25) **Evaluation of a Multimodal Intervention to Promote Cognitive Health among Older Adults**
Catherine O’Brien, MPH, MA
Palliative & End-of-life Care

31) Engaging new media to drive advance care planning
Dimensions and Mediators of Surrogate Trust in the Intensive Care Unit
Paul J. Hutchison MD, MA; Katie McLaughlin; Thomas Corbridge MD; Megan Crowley-Matoka PhD

32) Dimensions and Mediators of Surrogate Trust in the Intensive Care Unit
Paul J. Hutchison MD, MA; Katie McLaughlin; Thomas Corbridge MD; Megan Crowley-Matoka PhD

33) Workings of the Human Spirit in Palliative Care Situations: a Consensus Model from the Chaplaincy Research Consortium
Linda Emanuel; MD, PhD

34) Patient-powered Spirituality-and Quality-of-life-focused Advanced-illness Research-network
Linda Emanuel, MD, PhD; George Handzo, MDiv; Regina Greer-Smith, MPH, FACHE

35) Staking a Claim: Setting the Strategic Research Agenda for Chaplaincy Care in Health
Rev. George Handzo, MDiv, BCC; Linda Emanuel, MD, PhD, MA; Robert Wolf, JD; Rev. Eric Hall; Rev. Walter J. Smith, SJ, PhD

36) Education in Palliative and End-of-Life Care
Linda Emanuel, MD, PhD; Joshua Hauser, MD; Michael Preodor, MD; S. Lawrence Librach, MD; Jamie VonRoenn, MD; Frank Ferris, MD, PhD; Charles von Gunten, MD; Arthur Derse, MD; Tammie Quest, MD

Geriatric Health Outcomes

26) Geriatric Patient Healthcare Control Through the Use of PROs
Jason Raad, PhD; Julie Schwertfeger, PT, MBA; Allen Heinemann, PhD, ABPP (RP), FARCMP

27) Colpocleisis: A Safe Minimally Invasive Option for Pelvic Organ Prolapse
Margaret G Mueller, MD, Chandy Ellimootil, MD, Melinda G Abernethy, MD, MPH, Elizabeth Mueller, MD, MSME, Samuel Hohmann, PhD, Kimberly Kenton, MD, MS

28) Age, Attitudes Toward Technology, and Technology Utilization in the ENGAGED Weight Loss Study
Sara Hoffman, BA; Jennifer Duncan, Psyd; Christine Pellegrini, PhD; Bonnie Spring, PhD

29) “Ideal Cardiovascular Health” and Healthy Aging
Norrina B. Allen, PhD, MPH; John Wilkins, MD; Laura Rasmussen-Torvik, PhD; Mark Huffman, MD; Martha Daviglus, MD, PhD; Kiang Liu, PhD; Donald Lloyd-Jones, MD

30) Re-Connecting Substance Abusers with HIV Back to Care
Hannah Park, BA, Robert R. Turrelli, Jr., MD, Jessica L. Dubar, LPC, Mitesh B. Rao, MD, MHS

47) Older adult beliefs and perceived barriers toward living donor kidney transplantation
Kelsey Kaneshiro

48) Assessing Seniors’ Normative Beliefs and Sharing of Health Information about Pneumococcal Vaccination
Crystal Doan, BA, Shira N. Goldman, MPH; Ji Young Lee, MS; Stephen D. Persell, MD, MPH; David W. Baker, MD, MPH

49) Pain in Parkinson disease and its impact on functional mobility
Christina Marciniak MD, Reid J Johnson BS
8) **Emotional Biopsy: How Cancer Patients Adjust**
Max Vergo MD, Lynne Wagner MD, Linda Emanuel MD, PhD, Celia Berdes PhD, William Small MD, Caroline Taromino MA

9) **Cognitive Function in Older Adults Prior to Hematopoietic Stem Cell Transplantation (HCT)**
Mandy W M Fong, MS, MSocSc; Andrew Artz, MD; Maureen A Lacy, PhD

10) **Preparing for Paralysis - Rehabilitation for A Rare Metastatic Meningioma: A Case Report**
Sangeeta Patel MD MPH, Gayle Spill MD

11) **Immune dysregulation is associated with sexual dysfunction and bother among advanced prostate cancer survivors following androgen deprivation treatment**
Molly Hermiller, BA; Catherine Benedict, PhD; Frank Penedo, PhD
Quality Improvement & Patient Safety

37) Using In Person and Video Observations to Assess Safety Vulnerabilities in Living Donor Liver Transplantation
Arianna F Yanes, Lisa M McElroy MD, John Joseph BS, Jane L Holl MD, MPH Donna M. Woods PhD, Daniela P Ladner MD, MPH

38) Seasonal Variation in Liver Transplantation
Zachary A Abecassis, BS, Lisa M McElroy, MD, Amna Daud, MD MPH, Attasit Chokechanachaisakul, MD, Daniela P Ladner, MD MPH

39) Probabilistic Risk Assessment of Pneumonia after Deceased Donor Liver Transplantation
Zachary A Abecassis, BS, Lisa M McElroy, MD, Rebeca Khorzad, MS, Sanjay Mehrotra PhD, Jane Holl, MD, Daniela P Ladner, MD MPH

40) Deficiencies in Postoperative Handoffs Following Living Donor Liver Transplantation

41) Detection of Medical Errors in Kidney Transplantation: A Pilot Study Comparing Proactive Clinician Debriefings to a Hospital-Wide Incident Reporting System
Lisa M McElroy MD, Amna Daud MD, MPH, Brittany Lapin MPH, Donna M Woods, PhD, Anton Skaro, MD, PhD, Michael M Abecassis MD, MBA, Jane L Holl MD, MPH, Daniela P Ladner MD, MPH

42) Complications of Deceased Donor Liver Transplant: A Meta-Analysis of Reported Incidences
Lisa M McElroy MD, Amna Daud MD, MPH, Ashley E Davis PhD, Brittany Lapin MPH, Talia Baker MD, Michael M Abecassis MD, MBA, Jane L Holl MD, MPH, Daniela P Ladner MD, MPH

43) Daily Forecasting of Inpatient Length of Stay
Vikram Kilambi, PhD, Sanjay Mehrotra, PhD, Danny Sama, MBA

44) Cost-Effectiveness of Minimally Invasive Versus Open Surgery for Adult Degenerative Deformity
Omar Uddin, BA; Raqeeb Haque, MD; Tyler Koski, MD; Richard Fessler, MD, PhD

45) The Patient Safety Education Program - Canada
Richard Bell, MD; Linda Emanuel, MD,PhD; Joshua Hauser, MD; Laurel Taylor, PhD; Abigail Hain, MScN; Mitesh Rao, MD,MHS; Amy Eisenstein, PhD; Joan Fernandez, RN, BA, BScN, MPH ; Lara Boyken, BA; Brian Joyce, BA; Caroline Taromino, MA; Derek Jarvis, BS

46) The Patient Safety Education Program (PSEP)
Linda L. Emanuel, MD, PhD; Dave Lu, MD, MBE; Mitesh Rao, MD, MHS; Martin J. Hatlie, Esq; Derek Jarvis, BS
The Super Aging Research Program - A Multidisciplinary Study of Extraordinary Seniors

Full Authorship: Kristen Whitney BS, Amanda Rezutek BA, Adam Martersteck BS, Tamar Gefen MS, Amanda Cook MA, Stephanie Kielb MHS, Changiz Geula PhD, Sandra Weintraub PhD, M-Marsel Mesulam MD, Emily Rogalski PhD

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Background: While many people consider cognitive and functional decline to be an inevitable part of aging, some individuals remain cognitively stable or even exhibit above average cognitive functioning into old age.

Objective: The Super Aging study has identified a group of men and women over the age of 80 with exceptional memory and cognitive abilities that more closely resemble those of individuals 20-30 years younger.

Research Design/Methods: Participants are followed longitudinally, coming to the CNADC every 18 months for a comprehensive visit that includes neuropsychological testing, tissue collection for genetic testing and structural and functional MRI scans. SuperAgers also complete surveys investigating family history, personality traits and psychosocial factors. Currently in its sixth year, the Super Aging study has expanded to include a “Life Story” component, which is a guided interview that details participants’ life experiences. Life Stories are completed in collaboration with the Foley Center at Northwestern University’s Evanston campus. SuperAgers are enrolled in Northwestern’s Alzheimer’s Disease Center (ADC) Clinical Core and are invited to participate in the brain donation program, which provides researchers investigating aging and dementia with brain tissue for their studies.

Over 300 potential participants have been screened to date. To qualify as a SuperAger, individuals are required to perform at or above average normative values for individuals in their 50s and 60s on tests of episodic memory, and within one standard deviation of the average range for their age and education on non-memory cognitive domains according to published normative values. Two other participant groups are followed longitudinally, including middle age (50-64 years) and elderly controls average for their age (but not “super”) on memory and cognitive domains, as a basis for comparison.

Results: We have already demonstrated in a prior study that SuperAgers do not exhibit the cortical atrophy that is thought to be associated with normal aging. Additionally, one region of the SuperAgers brains, the anterior cingulate gyrus, was found to be thicker than in the younger, cognitively matched control group.

Conclusions: Interest and enrollment in the Super Aging study has greatly increased this year, after the study was featured on multiple local and national media sources. The SuperAging study is the only study of its kind that looks at exceptional memory performance in elderly adults through neuropsychological testing and neuroimaging. The study seeks to identify factors that promote resistance to age-related cognitive changes in the structure and function of the brain.

Keywords: Aging; Alzheimer’s Disease; Dementia; MRI
Title: Family strain and emotional health: Important midlife considerations for continued aging

Full Authorship: Nicky Newton, PhD

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Background: Many of the resources and contexts that promote and predict successful aging are already in place during midlife, such as health, family roles, and social support. Additionally, these factors are often related. For example, health problems in midlife are associated with psychosocial factors, including negative social support and strain (Ryff, Singer, & Palmersheim, 2004) or social roles, such as whether one is a parent or not (Umberson, Pudrovska, & Reczek, 2010). Equally important to consider in studies of negative social support and health are race and gender (Walen & Lachman, 2000).

Objective: The current study brings together these factors by examining the relationship between family strain and emotional health among individuals who are parents, grandparents, or have no children, through the lenses of race and gender.

Research Design/Methods: Using a sample of middle-aged (55-57), African American and White men and women (N = 158).

Results: Results revealed that the overall amount of family strain did not differ by gender or status as a parent. However, there were differences by race in the relationship between negative family support and emotional health, such that African Americans exhibited lower emotional health associated with family strain (β = -.83, p < .05).

Conclusions: These findings have implications for care provision, particularly for African Americans, given that both family support and personal health – separately, or taken together – feature prominently in decisions concerning aging in place.

Keywords: Family Strain, Family support, midlife, aging
Title: Exploration of Physical Activity in Patients with Parkinson’s Disease

Full Authorship: Amy Eisenstein, PhD; Tanya Simuni, MD; Mary Kwasny, ScD; Odinachi Oguh, MD; Brian Joyce, BA

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Background: Physical activity has been hypothesized to reduce the impact of Parkinson’s disease (PD), and improve the physical functioning of PD patients. However, there is limited data on the exercise habits of PD patients. Use of the National Parkinson’s Registry data allowed us to analyze variables that correlate with the exercise habits in a large cohort of PD patients across the disease severity followed at a number of centers across US.

Objective: The primary purpose of this exploratory analysis was to describe the cohort of PD patients who exercise and the degree to which they report exercising. Our secondary aim was to explore whether regular physical activity is associated with disease-related QoL and caregiver burden. Finally, we conducted a preliminary assessment of follow-up data to begin looking at whether regular physical activity is associated with a slower decline of disease severity and function.

Research Design/Methods: This study included all PD patients enrolled in the NPF registry. We examined factors associated with exercise among demographics and disease symptoms/stages using Chi-square, ANOVA, and Kruskal-Wallis testing. The association between exercise and disease-related QoL (measured by the PDQ-39) was tested using Spearman’s rank correlation. Multiple regression models controlled for disease duration, severity, age, gender, and cognition status.

Results: The population reflected a standard population of Parkinson’s patients, with 63% male, and an average age of 67 years. Men were more likely than woman to report regular exercise. There was very little difference in exercise reported by age and by care partner. Based on cross-sectional analysis, those who reported regular exercise had significantly better QOL, physical function, and less caregiver burden. After controlling for disease duration and severity, age, gender, and cognition status, greater levels of exercise still predicted higher quality of life, physical function, and caregiver burden. In this exploratory analysis, using physical activity data at baseline and health outcomes at 1-year follow-up, we found greater levels of activity at baseline predicted better QOL, mobility, and physical function one year later. Those who reported greater exercise at baseline had less progression of disease, caregiver burden and cognitive decline 1 year later, even after controlling for age and gender.

Conclusions: This study provides important preliminary evidence of the beneficial effects of moderate exercise in the early post-diagnostic period for Parkinson’s Disease patients. Future work should attempt to rigorously replicate these results using a prospective study design that minimizes the burden of data collection on subjects and reduces the frequency of loss to follow up among subjects with worse physical functioning.

Keywords: Parkinson’s disease, physical activity, quality of life, caregiver burden.
Title: Community Participation after Spinal Cord Injury: Associations between Depression, Grief, Employment, and Mental Health Services

Full Authorship: Alex Wong, PhD; Allen Heinemann, PhD; Catherine Wilson, PsyD; Holly Neumann, MPPA; Jesse Fann, MD; Denise Tate, PhD; Martin Forchheimer, MPP; Scott Richards, PhD; Charles Bombardier, PhD

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Background: Spinal Cord Injury (SCI) is a life-altering –event that occurs among healthy persons of all ages. SCI can have lasting emotional consequences including increasing the risk of major depressive disorder and other mood disorders. These disorders can limit a person’s function, community participation, and quality of life. Demographic and injury characteristics are not always good predictors of these outcomes. Instead, outcomes are strongly influenced by psychosocial variables. To improve the community participation of persons with SCI, it is important to understand how potentially malleable psychosocial-related factors contribute to participation.

Objective: To evaluate a structural equation model predicting community participation in persons with SCI from depression severity, grief, employment, and depression treatments; and to evaluate how demographic and injury characteristics moderate the relationship between these variables.

Research Design/Methods: Study sample was drawn from a multi-site, randomized control trial of Venlafaxine extended release for Major Depressive Disorder in persons with SCI. Data were collected via structured interviews that were conducted in person or by telephone as part of the comprehensive screening protocol. Participants (N=522) were on average 42 years old, 75.6% male, 64% white, and 36.2% at least high education. Measures included the Community Participation Indicators, Patient Health Questionnaire-9, and other variables were based on self-report and confirmed with medical record reviews as pertinent.

Results: The final model provided a good fit to the data: CFI= 0.939, TLI= 0.894, RMSEA = 0.066 (90% CI: 0.043-0.089), explaining 31.8% of the variance in community participation. Depression severity and employment were direct predictors of community participation. Grieving the loss of a loved one and use of antidepressant or counseling were indirectly related to community participation mediated by depression severity. Testing of multi-group invariance indicated the final model is valid for SCI patients with varying gender, marital status, severity and level of injury.

Conclusions: Findings demonstrate that a complex interplay between various factors predicts community participation after SCI and provide evidence for the importance of tailoring rehabilitation to the individual’s needs. The final model may be useful to guide clinical intervention designed to improve the community participation of persons living with SCI.

Keywords: Spinal Cord Injury, Community Participation, Depression, Structural Equation Model
Title: Targeted Classical Ballet Instruction Improves Mobility in Parkinson’s Disease

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Background: Parkinson’s disease (PD) affects over four million adults in the world. Individuals with PD suffer from tremor, rigidity, poor balance, stooped posture, difficulty turning, slowness of movement, impaired gait, frequent falls, and low physical activity levels. Exercise classes have demonstrated significant improvements in PD symptoms, with dance classes increasingly being considered as a more enjoyable variant of exercise therapy.

Objective: We present a pilot study of a targeted classical ballet-based intervention involving five participants with PD to assess the clinical improvements in mobility over a period of eight months.

Research Design/Methods: Five subjects participated in a one-hour class twice per week over a period of eight months with a minimum attendance rate of 75%. Uniquely to the design of this classical ballet PD class, each exercise was selected or adapted to counter specific mobility deficit in Parkinson’s disease. Our mobility measures were the 10 meter walk test, the five times sit to stand test, the 360 degree turn test and the composite Timed Up and Go (TUG) calculated from the previous measures. All test were performed at the beginning of the first and last class.

Results: Significant differences were found in the 10 meter walk test ($p<0.005$, paired t-test), the five times sit to stand test ($p<0.016$) and the composite TUG test ($p<0.004$). The timed 360 degree turn test demonstrated a decrease that was not statistically significant ($p<0.0229$).

Conclusions: To our knowledge, this pilot study is the first to report improvements on motor scores in a targeted classical ballet-based dance class for subjects with PD.

Keywords: Parkinson’s disease, dance, mobility.
Title: Evidence to support the need to educate physicians and healthcare professionals about non-emergency medical transportation

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Background: A critical component to maintaining the health and well-being of older adults in the community is their ability to access health care. Lack of access to non-emergency medical transportation (NEMT) is a critical barrier to the management of chronic illness and disabilities. Approximately 3.6 million American adults living in the community fail to obtain health care due to a lack of transportation and that these individuals are more likely to be older adults who find it difficult to perform activities involved in transporting themselves to medical appointments. Transportation is critical for access to health care. NEMT is a valuable service that clinicians could help their patients benefit from as an alternative form of transportation.

Objective: Cognitive impairment or degenerative chronic conditions often require older adults (OAs) to cease driving, yet it is unclear: (a) Who and what transportation services are OAs likely to need* (b) What is physician confidence to assess, counsel, and address transportation needs for OAs.

Research Design/Methods: Findings from two studies will be presented regarding (a) when OAs are likely to need transportation services and (b) physician confidence to assess, counsel, and address transportation needs for OAs. The first study utilized 2010 data from Delaware statewide brokered transportation services. The second study examined the impact of an educational program to help healthcare providers council older drivers (ODs) about driving cessation.

Results: In the first study, among the 16,195 NEMT Delaware users, 2,467 are age 65 and older. The majority of trips for older NEMT users were: (1) ambulatory (58.3%), but this type of service decreased with age; and (2) patients requiring dialysis (67%, n=22,368 trips) with older women more likely to use NEMT for dialysis treatment than older men. Almost 11% of OAs used NEMT for mental health services, although almost none of these trips were for individuals aged 75+. Almost a third of NEMT services for older adults involved the use of or accommodation of a wheelchair. In the second study, upon completion of the program, self-efficacy to assess, counsel and treat ODs about driving retirement and options improved among 93% of the providers. Additionally, 90% increased their knowledge and level of confidence about OA driving and laws.

Conclusions: These concurrent findings suggest there are opportunities for healthcare professionals to better understand transition options and provide referrals for OA subgroups to use NEMT for specific health issues.

Keywords: Transportation, Non-emergency medical transportation, physician education, older adults
Title: Assessment of the Age-Friendliness of the City of Chicago

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Background: The Buehler on Aging Health and Society and has partnered with the City of Chicago (recently designated an Age-Friendly city by the World Health Organization (WHO)) to conduct an independent assessment of the city’s age-friendliness. Now, along with 35 other cities across the world, Chicago is working to maintain that designation by routine assessments, evaluations, and strategic improvements of its age-friendly environment.

Objective: The goal of this project is to explore with older adults their experiences of living in the city. This information will help the city create age friendly indicators in preparation for the upcoming demographic imperative of the aging population.

Research Design/Methods: This project emphasizes listening to and learning from residents, and will identify community leaders and innovations capable of driving continuous improvement. Eight focus groups have been conducted throughout the city (1 with the city advisory committee, the remainder at senior centers, including one in Spanish and one in Polish) in order to explore older Chicagoans perceptions of 8 key areas outlined by the WHO: outdoor spaces and buildings; transportation, housing, social participation, respect and social inclusion, civic participation and employment, communication and information, and community and health services.

Results: Key themes from focus groups were gathered using NVIVO qualitative software, and culminated into a report to the City of Chicago. The Buehler center is currently in the active stages of the next phase, which includes interview with key community stakeholders.

Conclusions:

Keywords: Age Friendly, Chicago
Title: Do perceptions of family-centered care differ in older and younger family caregivers?

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Background: Patient-centered care (PCC) involves partnering with patients and families, engaging them in decisions, and providing needed support (LaVela 2012). In this context, PCC, which is sometimes referred to as patient/family-centered care (P/FCC) comprises 3 concepts: respect, collaboration, and support. Families/caregivers are integral to the delivery of care. Efforts to involve family caregivers and maintain their well-being need attention, as well (LaVela 2010). Young adult caregivers, in particular, tend to report a variety of unmet needs in helping the recipient with care needs, including issues obtaining medical help, information, and needing help with shared decision-making (Levine 2005).

Objective: Our objective was to examine family perceptions of P/FCC overall, and compare by age.

Research Design/Methods: We conducted a mailed survey with family members of Veterans who received care at 8 Veterans Affairs facilities. We collected family member’s demographic information (the family member’s relationship to the patient, gender, age, race/ethnicity, education, marital status). Using the Family-Centered Care Survey, we measured respect (6 items, such as “I feel like a visitor rather than a relative when I attend the unit”), collaboration (9 items, such as “The staff give me honest information about the care that my relative may need”), and support (5 items, such as “All team members listen to my concerns”). All items asked how often a stated event occurred; response options range from 1 (never) to 4 (always). This 4-point scale was used to calculate mean subscale scores. Data analyses included bivariate comparisons of demographics and P/FCC constructs: respect, collaboration, and support.

Results: Family members/caregivers (n=2082) aged 60 and older group vs. those 59 and younger were more likely to be spouses of the Veteran patient (76% vs. 54%, p<0.0001) and white race/ethnicity (74% vs. 49%, p<0.0001). There were no differences in gender in the older and younger caregiver cohorts. The older cohort of family caregivers of Veterans, compared with the younger family caregivers, reported higher respect (3.36 vs. 3.22, p<0.001), collaboration (3.14 vs. 2.98, p<0.0001), and support (3.07 vs. 2.88, p<0.0001) values of family centered care.

Conclusions: As health care organizations endorse modern models of care, recognizing the important role of the family caregiver is key. In general, at VA facilities, family members of Veterans perceive relatively high levels of P/FCC. Overall, family caregivers of Veterans report highest on the respect scale and lowest in the area of support. The higher subscale scores reported by older adult family caregivers indicate perceptions of higher levels of family-centered care compared with younger family caregivers. Although VA is doing very well in the area of providing P/FCC, additional efforts may be aimed toward younger family caregivers and at addressing issues related to ‘support.’

Keywords: Caregiving, Patient Centered Care, Aging, Veterans, Health Care Delivery
Title: Caregivers of Persons with Spinal Cord Injuries

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Background: Adults with SCI require continuous support more than 2x as often as do aging persons in the general population and require personal care assistance up to 7x more often. The unique challenges of caring for an adult with SCI may place their caregivers at increased risk of negative outcomes.

Objective: To describe outcomes of caregivers of persons with SCI relative to individuals caring for adults with other conditions, and to determine if caregiving for SCI is associated with poor health status and chronic conditions.

Research Design/Methods: Secondary data from the BRFSS 2009/2010 national cross-sectional survey were used. Measures included caregiving role factors, sociodemographics, lifestyle behaviors, chronic conditions, health status, perceived emotional support, and life satisfaction. Analyses included descriptive statistics, bivariate comparisons, and multivariate regression.

Results: Demographic characteristics and lifestyle behaviors did not differ in caregivers of adults with SCI and caregivers of adults with other neurological conditions (except for younger average age in SCI caregivers 53 years vs. 57 years, p=0.05). Greater proportions of caregivers of adults with SCI vs. caregivers of other neurological conditions combined (MS, TBI, PD, stroke, dementia) had coronary heart disease (12% vs. 6%, p=0.06, marginal), and were obese (43% vs. 28%, p=0.03). Frequent mental distress was experienced by 18% of caregivers of adults with SCI vs. 13% of other caregivers, p=0.29. Frequent physical distress was experienced by 20% of caregivers of persons with SCI vs. 12% of other caregivers, p=0.09. A greater proportion of caregivers of adults with SCI experienced frequent insufficient sleep (47% vs. 30%, p=0.008) and days without enough sleep (13 vs. 9 days, p=0.008) than caregivers of adults with neurological conditions overall (and independently with the exception of TBI caregivers). Regression analysis identified several variables associated with being a caregiver of an adult with SCI relative to caregivers of adults with other neurological conditions, including being younger, caregiver of a spouse, having CHD, and being obese.

Conclusions: Caregivers of adults with SCI self-report similar mental health status, but appear to have more physical distress and frequent insufficient sleep than caregivers of individuals with other neurological conditions do. Caregivers of adults with SCI have increased odds of coronary heart disease and obesity. Interventions to improve sleep and physical distress may help to lower CHD, and obesity in this caregiver group.

Keywords: Caregiving, Spinal Cord Injury, Sleep, Coronary Heart Disease, Obesity
Title: Professional Assessment of Family Caregiver Skill

Background: Family caregiver studies frequently note that skill building interventions are more effective than psycho-educational interventions but few studies assess targeted skills pre and post-intervention. Investigators’ research has focused on developing a broad-based conceptualization of caregiver skill and testing alternate skill assessment methods such as caregiver self-report and professional assessment.

Objective: This presentation will report results concerning the development and testing of the Professional Assessment of Family Caregiver Skill. Study data are part of an ongoing randomized clinical trial of family caregivers of persons with Alzheimer’s disease/related dementias which tests the effectiveness of a lifestyle physical activity intervention to increase physical activity in comparison to a standard caregiver skill building intervention (n=202).

Research Design/Methods: Caregivers provide care to their impaired family member in home settings. Measures include a broad range of stressor, resource, intervention implementation, physical activity and mental and physical health variables. The Professional Assessment of Family Caregiver Skill is a 28-item measure that addresses seven aspects of caregiver skill: knowledge and attitudes toward learning, personal qualities, relationships that support skill, person-centered care, management of emotions, management of resources and overall effectiveness. Measurement assessments are completed at baseline, 3, 6, 9, 12 and 18 months. Caregiver participants are primarily female (82%), married (64%), well-educated (77% have some college/college graduates), are Caucasian (66%) and almost equally divided between being spousal or adult child caregivers. Their care recipients have moderate levels of cognitive impairment, instrumental/personal activities of daily living dependencies and behavioral symptoms.

Results: Results will focus on baseline psychometric properties of the Professional Assessment of Family Caregiver Skill, including construct validity and internal consistency. Longitudinal analyses will determine measurement stability and sensitivity to change over time, using caregiver characteristics, stressors, resources, mental and physical health and intervention variables as covariates.

Conclusions: Conclusions will focus on the feasibility and sensitivity of this measure for future use in clinical and research settings.

Keywords: Caregiver
Title: Northwestern Alzheimer’s Disease Center Education Core 2012-2013

Full Authorship: Darby Morhardt, Mary O’Hara, Kristine Zachrich, Jaimie Robinson, Emily Rogalski, Kristine Lipowski, Christina Wieneke, Shannon Stone, SungJae Shin

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Introduction: Education Core specific aims are: 1) to optimize recruitment and retention; 2) target outreach and education to raise awareness in underserved communities; 3) develop and evaluate Quality of Life (QOL) enrichment programs; and 4) support professional staff and faculty development.

Methods: The Education Core works closely with all cores to fulfill aims. While the search for new treatments continues, the Education Core is committed to the development and evaluation of programs targeted at improving daily life for patients and families, providing support and promoting social engagement.

Results: 79 new subjects were recruited into the clinical core this past year for a total of 466 active research subjects (minority 15%). Underrepresented community outreach efforts continue through work with the Atlas Senior Center and the Korean American Community Services (see separate abstract). On a national level, a collaborative partnership with the NIA and Administration for Community Living aging resources has identified areas of synergy to help persons with cognitive impairment and their caregivers access resources for education, services, evaluations, and research. Locally, Northwestern and Rush Core E leaders along with the Illinois Aging Network and Alzheimer’s Association chapters formed the Illinois Cognitive Resource Network (ICRN), a state group to implement a statewide collaboration.

We continue to offer several caregiver support groups and other Quality of Life Enrichment programs; i.e., The Early Stage Group, The Memory Ensemble in collaboration with Chicago’s Lookingglass Theatre, ILLUMAnations in collaboration with The Loyola University Art Museum (LUMA) (see separate abstract) and The Buddy Program. These patient and family-oriented services leverage the ability of the Education Core to support the recruitment and retention of research participants. The “Care Pathway Program” a neurocognitive profile approach to care continues to offer a unique clinical service that emphasizes non-pharmacological interventions to support quality of life.

Two annual educational conferences, Alzheimer Day and the FTD/PPA Caregiver and Professional Conference attract hundreds of clinicians, professionals and families. A CNADC newsletter is distributed annually and a physician newsletter is sent to referring physicians. The Education Core is pivotal to dementia-related education of trainees and fellows. The CME-accredited AD seminar series is a successful intramural educational program. Nine seminars were held during 2012-13 and attended by 552 clinicians/basic scientists and students in aging and dementia research.

Conclusion: The CNADC Education Core continues to increase public awareness of dementia and treatment using community outreach, the training of scientists and clinicians, and the provision of programs and support services for diagnosed persons and families.

Keywords: Dementia and Alzheimer’s Disease
Title: iLUMAnations: Results of a Museum based Art Program for Persons with Cognitive Impairment and Their Families

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Background: There is growing evidence that creative engagement can improve overall health and a sense of purpose. There is increasing research demonstrating the positive impact of engagement with the arts on persons with cognitive impairment.

Methods: The Cognitive Neurology and Alzheimer’s Disease Center (CNADC) and Loyola University Museum of Art (LUMA) developed a pilot program to evaluate the efficacy of art exploration in facilitating communication between persons with dementia and their care partners entitled iLUMAnations, The program was modeled on New York City’s Meet Me at MOMA.

During four 90-minute sessions, four specially trained docents guided small groups of persons with cognitive impairment and their care partners around museum exhibits, exploring the art in a manner that encouraged meaningful interaction and open expression. The sample included 7 diagnosed persons, 5 friend/family care partners and 1 paid caregiver. Participant ages ranged from 66 to 80. Diagnoses included Alzheimer’s disease, mild cognitive impairment, primary progressive aphasia, and Lewy body dementia. Quantitative and qualitative observations were recorded including: participant responses to the docent, conversation between the person with cognitive impairment and their care partner, use of laughter and humor and instances of affectionate touch between the person with cognitive impairment and care partner. Each session concluded with time for participants to socialize with each other, the docents, and the researchers. After each session, a focused discussion was held among the docents, the researchers, and LUMA curator of education, which allowed for the collection of additional data and ideas for program improvement. At the conclusion of the program, a focus group was held with participants.

Results: Focus group feedback and post-session discussions revealed members (1) found the program to be cognitively stimulating, (2) enjoyed the social engagement, (3) found comfort in the small group size and intimate setting, and (4) felt inspired to seek out new opportunities for life enriching activities. However, observational data revealed interactions among the participants, docents, and dyads declined over the course of the 4 meetings.

Conclusion: iLUMAnations is a feasible and promising arts-based program with multiple perceived benefits. Further research is needed to continue to evaluate the impact of iLUMAnations on individuals living with cognitive impairment and their families.

Keywords: Dementia, Alzheimer’s Disease, Arts
Title: Dementia Patients Mentor Medical Students: A Multi-Site Study

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Background: While there is evidence that teaching interventions in geriatrics can improve knowledge, skills and attitudes of medical students, few interventions include specific learning outcomes relevant to dementia, nor do they address the lack of trained professionals who simultaneously understand the strengths, limitations, and needs of persons with memory impairment and dementia.

Objective: The NU Buddy Program (Morhardt, 2006) provides opportunities for first year medical students and persons diagnosed with early dementia to participate in an experiential learning program. Goals are to: 1) educate medical students about Alzheimer’s disease (AD) by increasing their knowledge base, heightening their awareness of skills and strengths that remain in persons with AD, and familiarizing them with care/support issues and effective communication skills; 2) introduce students to research and practice opportunities in fields related to aging and dementia; 3) provide persons living with dementia an opportunity to serve as a mentor to a future doctor.

Research Design/Methods: First year medical students are selected based on interest and willingness to commit to program requirements: 1) attendance at two 90-minute orientation sessions and monthly process meetings, 2) four hours per month in activity with their buddy for one academic year, and 3) submission of a semi-structured journal report following each visit. A pre/post dementia knowledge test assesses student’s objective learning and student journal entries are qualitatively analyzed for themes. Longitudinal data on students’ residency choice are maintained. The program has been successfully replicated at Boston University, Dartmouth College and Washington University.

Results: The Buddy Program has paired 167 students and persons with dementia over 16 years. The replicating programs have paired 133 students and mentors. Test scores across all sites demonstrate improved student knowledge and analysis of qualitative data yield themes that include heightened sensitivity and empathy toward persons with AD and increased recognition of remaining strengths.

Conclusions: This analysis of the buddy program and its replications at multiple sites demonstrates the program’s effectiveness in enhancing medical and allied health education. Results reveal improvement in dementia knowledge, change in attitudes toward individuals with dementia, enhanced communication skills and appreciation for the challenges faced by persons with dementia and their families.

Keywords: Medical student education, dementia knowledge/attitudes
Title: Korean American Alzheimer Research and Education (KARE)

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Background: Research shows stigma and shame are attached to Alzheimer’s disease, particularly among ethnic minorities and are barriers to early detection and timely intervention. Korean Americans are the fourth largest Asian American subpopulation, one of the fastest growing immigrant populations in the U.S., and have the largest number of Korean older adults who are limited English-language proficient. Research has shown the overall prevalence of dementia in the Korean population to be higher (6.4%–10.8%) than that reported from Western as well as other Asian populations. Considering the high prevalence of dementia, the rapidly growing size of the Korean American elderly population in the greater Chicago area (6.8% in 2000 and 11% in 2010), and the projected growth of the local aging population, a significant number of Korean American families are expected to be affected by Alzheimer’s disease.

Objective: After a year of partnership building using community-based participatory research (CBPR) principles, Korean American Community Services (KACS) and the Cognitive Neurology and Alzheimer’s Disease Center (CNADC) of Northwestern University’s Feinberg School of Medicine received seed grant funding to implement a research project exploring AD related-knowledge, cultural factors and help-seeking patterns among the Chicago Korean-American community.

Research Design/Methods: The methodology includes focus groups and individual interviews of stakeholders (Korean American older adults, family caregivers of persons with AD, and community personnel working with Korean-American older adults with AD). The KARE project received IRB approval and held interview and focus group training for interviewers. The KARE team is recruiting subjects via a local newspaper and conducting interviews and focus groups.

Results: This project is currently ongoing. Research results will be shared in the community and used to develop service and education tailored to the communities’ needs. Additional funding will be sought to implement next steps.

Keywords: Korean-American, dementia, stigma
Title: Episodic memory performance is associated with neuropathology in Primary Progressive Aphasia

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Background: Primary Progressive Aphasia (PPA) is an aphasic dementia syndrome commonly caused by frontotemporal lobar degenerations (FTLD). However, 30-40% of PPA cases are caused by atypical Alzheimer’s disease (AD) neuropathology where neurofibrillary tangles show greater leftward asymmetry and less entorhinal prominence (Rogalski & Mesulam, 2008; Gefen et al., 2012). Episodic memory is impaired in dementia associated with typical AD neuropathology, and thus might represent a clinical marker of AD versus FTLD neuropathology in PPA.

Objective: To describe differences in performance on a memory test (Three Words Three Shapes) in patients with PPA and AD neuropathology versus FTLD neuropathology at post mortem.

Research Design/Methods: This study is an archival analysis of performance on the Three Words Three Shapes Test in a sample of PPA patients with post mortem AD (PPA-AD, N=14) or FTLD neuropathology (PPA-FTLD, N=8). The test assesses verbal and nonverbal copy, recall, and recognition in the visual modality. Recall is tested under conditions of effortless encoding and after effortful learning trials and a delay. Data were analyzed using ANOVAs with neuropathology diagnosis as the between-subjects variable and material (words vs. shapes) as the within-subjects variable.

Results: PPA-AD and PPA-FTLD groups did not differ significantly based on age at test, education, symptom duration, age at death, or activities of daily living (all ps > 0.05). Consistent with previously reported findings in a living sample (Weintraub et al., 2013), all patients had better recall of shapes than of words following effortless encoding (p < 0.001) and delayed recall (p < 0.05). However, word recall in both conditions was better for PPA-FTLD than for PPA-AD patients (effortless encoding, p < 0.05; delayed recall p < 0.05).

Conclusions: FTLD neuropathology was associated with greater capacity for both online storage (effortless encoding) and long-term storage and retrieval (delayed recall) of words than AD neuropathology in patients with clinical PPA. Findings suggest that PPA-AD patients show more amnestic features than PPA-FTLD patients on an episodic memory test.

Keywords: episodic memory, dementia, neuropathology
Background: The Northwestern Alzheimer’s Disease Center (NADC) was established with funding from the National Institute on Aging (NIA) and the Illinois Department of Public Health in 1996.

Objective: The primary goals of the center are to 1) provide state-of-the-art care to patients with Alzheimer’s disease and related disorders, and 2) support clinical and basic research on memory and aging through the collection and storage of clinical data and brain tissue from research participants. Clinical data and tissue are distributed to collaborators throughout Northwestern, as well as to other Alzheimer Disease Centers. The NADC is comprised of five Cores: Clinical, Administrative, Neuropathology, Data Management and Biostatistics, and Education. Over the past year, the Clinical and Data cores have worked closely with the Education and Neuropathology cores to recruit and enroll subjects, facilitate brain donations, support investigations of dementia and aging, and educate the public on effectively coping with these illnesses.

Research Design/Methods: The Clinical Core recruits cognitively healthy individuals and patients with different forms of dementia (e.g. AD, PPA, FTD) and cognitive impairment. These subjects are followed clinically, many for the remainder of their lifetime, after which brain donation provides tissue for investigators on well-characterized individuals. Participation entails an annual examination according to the methods of the Uniform Data Set (UDS) of the NIA ADC program. The Data Core receives all data collected on these participants, makes the data available to approved studies, and also contributes them to the National Alzheimer’s Coordinating Center (NACC) database. The Education Core assists with subject recruitment and retention by meeting with the participant and maintaining contact with those no longer able to visit.

Results: From 1996-2013 the Clinical Core has enrolled more than 1,765 participants, and the current active cohort is 466. In the past year, the Clinical Core supported over 25 different projects being conducted in the areas of cognitive neuroscience, clinical trials, neuroimaging and neuropsychology (See tables). A total of 31 publications have been supported by Core data from 2012-2013.

Conclusions: The Clinical and Data Management/Biostatistics Cores of the NADC together have facilitated research on Alzheimer’s and related disorders and have promoted collaborative efforts at Northwestern and nationally.

Keywords: Dementia, Alzheimer’s Disease, Aging
Title: Neuropsychological Performance of Cognitive SuperAgers: Preliminary Findings from a Longitudinal Study of Extraordinary Seniors

Full Authorship: Tamar Gefen, MS, Emily Shaw, John Stratton, MA, Kristen Whitney, Sandra Weintraub, PhD, Mesulam, M.-M and Emily Rogalski, PhD

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Background: The elderly frequently complain of declining episodic memory. Such complaints are so widespread that they have led to the belief that a gradual loss of cognition is part of normal aging. Recent data from the Northwestern University SuperAging study, suggests it is possible for some individuals to maintain memory at the level of individuals 20-30 years their junior. SuperAgers are defined as individuals over age 80 with memory scores at least average according to 50-65 year-old normative scores, and whose scores in other cognitive domains are at least normal for their age.

Objective: This study examined longitudinal neuropsychological data from SuperAgers at baseline (T1) and at 1.5 year follow-up (T2) to determine whether memory and other cognitive domains remain stable or decline over time.

Research Design/Methods: To date, of 27 total SuperAgers studied at T1, 18 had neuropsychological data available from T1 and T2. Scores from SuperAgers were compared to well-established demographically adjusted 50-65 year-old norms to determine SuperAgers' longitudinal performance on tests of memory and cognition relative to that of individuals 20-30 years their junior.

Results: Of 18 SuperAgers (Age Range: 80-88), 16 maintained memory scores at least average for 50-65 year-old norms at T2. Furthermore, when compared to 50-65 year-old norms, the vast majority (at least 66.7%) of SuperAgers remained within the average to superior range over the 1.5 year interval on tests of attention, executive function, and language.

Conclusions: Such high cognitive performance by a majority of SuperAgers is impressive given the high prevalence of Alzheimer’s dementia over age 80, and provides further support that a unique trajectory of cognitive aging is possible. Although their preservation of cognitive performance over 1.5 years is intriguing, it must be evaluated relative to the rate of decline in elderly persons cognitively normal for age tested over the same time interval.

Keywords: Aging, cognition, longitudinal
Title: Latin Dance and Health Education: Influence on Cognitive Function

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Background: Disparities exist between Latinos and non-Latino whites in cognitive function, putting Latinos at increased risk for dementia and disability. Physical activity (PA) can improve aspects of cognition and protect against disability. However, older Latinos are not physically active at recommended levels. Dance is a culturally appropriate form of PA for older Latinos that challenges individuals both cognitively and physically.

Objective: A pilot randomized controlled trial used a subsample of the official Spanish version of the Uniform Data Set (UDS) of the National Institute on Aging Alzheimer’s Disease Center Program to test the impact of the BAILAMOS® dance intervention on cognition.

Research Design/Methods: Participants were randomly assigned to the 4-month, twice-weekly dance intervention; or to a health education control group.

Results: Participants were low active, older, Spanish-speaking Latinos, N=44, M(SD) age=64.9 (5.9), 81.8% female, 81.8% Mexican, Years in US=31.2 (16.8), years of education =7.0 (4.3). A repeated measures multivariate ANOVA revealed an overall multivariate effect F(11,32) =3.54, p<.05. Follow-up univariate analyses found an effect for several measures of cognition, including a Logical Memory test (p<.05), in which the dance group improved significantly more than the health education group; and Digit Modalities test in which both groups significantly improved over time (p<.05).

Conclusions: Results indicate that participation in regular dance has the potential to improve aspects of cognitive functioning. It is possible that regular dance may have improved episodic memory (Logical Memory test) and psychomotor speed and visuospatial function (Digit Modalities test) as dancing requires participants to recall and execute a dance sequence in a timely manner and in response to others’ actions. Both conditions were exposed to structured and routine learning, which may have influenced cognitive function. Future studies should examine these relationships in a larger trial.

Keywords: physical activity, Latinos, cognition
Development and Implementation of a Multi-Component Lifestyle Physical Activity Intervention for Family Caregivers of Persons with Alzheimer's Disease

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Background: Alzheimer's disease currently affects 5.5 million Americans and is the sixth leading cause of death in the United States. Since there are no treatments that reverse the progressive loss of cognitive function associated with Alzheimer's, interventions have focused on reducing family caregiver stress and burden as one way of minimizing the suffering of persons with Alzheimer's and their caregivers. The purpose of this randomized clinical trial, Telephone Resources and Assistance for Caregivers (TRAC), was to test a 12-month multi-component lifestyle physical activity intervention with strained and sedentary caregivers and determine their ability to increase lifestyle physical activity. Caregivers were randomly assigned to either the Enhancing Physical Activity Intervention (EPAI: treatment) or the Caregiver Skill-Building Intervention (CSBI: control). Data were collected at baseline, 3, 6, 9, 12 and 18 months.

Objective: The EPAI will be more effective in improving caregiver lifestyle physical activity than the CSBI. The secondary hypothesis was: The EPAI will be more effective than the CSBI in changing the following secondary caregiver outcomes: mental health, physical function and self-reported physical health

Research Design/Methods: All caregivers were enrolled in the home- and phone-based intervention in which they received 20 intervention contacts from a trained Telephone Counselor over 12 months. The EPAI goal was to increase lifestyle physical activity and incorporate caregiving-related concerns that often create barriers to increasing physical activity. The CSBI sought to help caregivers understand how to meet basic dementia care-related needs. Caregiver self-report and direct observational methods assessed lifestyle physical activity in all participants.

Results: This poster will report preliminary baseline, three- and six-month outcomes and issues faced during TRAC implementation. The process of EPAI intervention goal setting and attainment; and challenges faced in assisting caregivers to increase physical activity will be addressed. Preliminary physical activity, physical and functional outcomes will be reported.

Keywords: Caregiver, physical activity, intervention
Background: Lack of effective treatments have prompted a growing body of research examining behavioral strategies that may delay onset of Alzheimer’s Disease symptomology. At the 2012 Alzheimer’s Disease Summit, one of the key recommendations called for the combining of behavioral, lifestyle, and environmental interventions with pharmacological treatments to maximize the potential for benefit (NIA, 2012). Even a modest reduction in disease progression would have a significant societal impact by: reducing the rate of institutionalization, decreasing the physical and emotional burden felt by caregivers, and mitigating the financial impact of the disease on the healthcare system and the workplace. Evidence supporting behavioral interventions is preliminary but sufficient to warrant additional study. Moreover, lifestyle behaviors that seem to be good for the brain (e.g., physical activity, eating healthy foods, maintaining high levels of social and cognitive engagement, stress reduction) are recommended behaviors with numerous known benefits for health in general. Identifying behavioral interventions that delay the onset of AD symptoms would make a significant contribution toward addressing a major public health problem.

Objectives: 1. Examine data for potential associations between program participation and an increase in “brain-healthy” behaviors, and cognitive performance 2. Determine the feasibility of implementing a new brain fitness program with older adults in the Chicagoland area.

Research Design/Methods: This study uses a randomized controlled trial with a sample of 96 older adults in the Chicagoland area. Participants completed an 8-week intervention consisting of education on 1) lifestyle factors (e.g. physical activity, intellectual engagement), 2) memory strategies, and 3) online memory training. The evaluation included objective cognitive assessments and surveys completed at baseline and post-intervention time points.

Results: Completion rate for the course was 86.2%. Participants demonstrated small improvements on behavioral and cognitive measures, but these differences were not statistically significant. In addition, an assessment of program feasibility was conducted wherein participants reported a high level of satisfaction with course contents and the online training component. Lessons learned from this pilot study are being utilized in a second study being conducted this year.

Conclusions: Older adults were receptive to a brain fitness program promoting lifestyle factors, memory strategies and online training. The fact that this program did not demonstrate significant change in behavioral and cognitive intervention components may be due to: inadequate dose and duration of behavioral instruction, a lack of precise measures of the dose and duration of intervention components, and insufficient attention to behavior change strategies. Future iterations of this program should incorporate these elements.

Keywords: brain fitness, cognitive health, older adults
Background: Though Congress enacted the Patient Self-Determination Act in 1991, only 18-36% of Americans have completed an advance directive. Less than half of severely ill patients had an advance directive in their medical record, only one in three with a chronic illness completed an advance directive, and studies suggest that two-thirds of physicians whose patients had advance directives were unaware of the existence of the documents. The Act required healthcare facilities to provide written information on rights to make treatment decisions and to make information available to patients who did not have an advance directive. There was a mandate directing HHS to conduct an awareness campaign about advance directives. The low acceptance of the directives demonstrates a failure to educate patients about their rights.

Objective: A patient-centered approach to end of life issues will generate better communication and result in greater acceptance of advance directives- achieving the goals of the Patient Self-Determination Act.

Research Design/Methods: A survey of 196 people showed that 67.7% felt that end of life issues were not covered enough in the media. We created a Newswire using WordPress and posted an average of three news stories weekly on topics pertaining to end of life. Posts were generated from existing media coverage and original reporting. The topics included culture, society, politics, healthcare, caregiving, law, advance care planning, hospice, and palliative care services. We tracked the number of views, the most viewed reports, monthly traffic and referral sources. We established Facebook, Twitter, and Pinterest accounts. We tracked followers, likes, re-tweets, pins, and shares.

Results: From 8/2012 through 2/2013, the number of views increased from 566 to 2,452 with a peak of 3,809 in 11/2012. The most viewed day was 11/7/2012, the day following Election Day. The most viewed reports to date have been “Caregiver Discrimination Against LGBT Seniors,” “Psychedelic Drugs at the End of Life,” and “POLST Moving Forward in Illinois.” The referral sources in descending order are Facebook, Twitter, and Yahoo.

Conclusions: We demonstrated that there is an interest in patient-centered topics pertaining to the end of life and that social media drives interest, education and conversation.

Keywords: advance directives, advance care planning, end of life, social media
Title: Dimensions and Mediators of Surrogate Trust in the Intensive Care Unit

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Background: Surrogate trust of intensive care unit (ICU) clinicians is an important factor in avoiding conflict in end-of-life decision-making. While some data exist regarding distrust of the healthcare system and trust in the outpatient setting, little is known about trust in the intensive care unit and how its affects shared decision-making.

Objective: This pilot study utilizes qualitative methods to identify domains of trust and factors that promote its formation in the ICU.

Research Design/Methods: We are conducting in-depth, semi-structured interviews with surrogate decision-makers in a closed-model medical ICU. Questions target surrogates’ general ICU experience, staff and institutional qualities integral to trust, and components of trust unique to the ICU. Interviews are audio recorded and then transcribed. Transcripts have been analyzed using a modified grounded-theory approach.

Results: Preliminary data demonstrate surrogates’ strong emphasis on nursing care when describing their experience in the ICU. The constant activity and focus of nurses in patient rooms strengthens trust and reassures surrogates that their loved ones will receive good care even at times when they are not present. Surrogates frequently mention coordinated and thorough nursing care at the time of ICU admission as a relevant factor in establishing trust. In contrast, many surrogates admit to blind trust in the ICU physicians, which may be affected by institutional reputation. When describing physician activities that increase trust, surrogates commonly cite honesty and bluntness when delivering bad news. They also value physicians’ ability to communicate with lay language and to exhibit personal, humanistic qualities when interacting with surrogates.

Conclusions: Our results support the following conclusions regarding surrogate trust in the ICU: 1) Strong nursing care, especially upon ICU admission, is essential to establishing trust and to maintaining a working relationship with surrogates; 2) Physician trust is most closely tied to the style and content of their communication with surrogates; 3) Interventions aimed at increasing trust should be role specific, since surrogate expectations are different for physicians and nurses with regard to behaviors relevant to trust.

Keywords: Trust, End-of-life care, Intensive care unit
Title: Workings of the Human Spirit in Palliative Care Situations: a Consensus Model from the Chaplaincy Research Consortium

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Background: Our approach is consensus based; that is, all members felt they could live with the content although not all would have stated everything exactly as it is in their own words. The Chaplaincy Research Consortium is convened by the HealthCare Chaplaincy and is a community of researchers and scholars. The group is all involved in a three year Templeton Foundation grant to foster palliative care chaplaincy research.

Objective: Our purpose is to create a model of the human spiritual processes and needs in palliative care situations in order that researchers in spiritual aspects of palliative care can locate their hypotheses in a common model. This model is intended as one that will evolve with each relevant research finding.

Research Design/Methods: We proceed from consensus definitions of spirituality, sacredness, and existentiality to base our model upon three fundamental precepts: A greater existence (with which humans interact), connectedness (a fundamental link between humanity’s inner spirituality and the greater existence), and human mediators of the spiritual experience (the sense of spiritual well-being that is the focus of much chaplaincy work, both within and without of palliative care practice).

Results: The mathematical model depicts interacting components but not process or mechanism for the interaction. A greater understanding of what happens in the processes of the human spiritual ‘apparatus’ is provided by Pargament’s model of discovery, conservation, and transformation, which, with some adaptation, we adopt. As presented here, the states are four, and the movement between states is unconstrained. Spiritual processes entail movement between these states in a recursive processing of spiritual experience entailing four distinct states and distinct types of outcome. All states can lead to any other state in this model and there is not an irrevocable one way movement or an exclusive starting point for spiritual experience. These four stages are: Discovery, Dialogue, Struggle, Arrival/disconnection.

Conclusions: The main purpose of the model is to provide a working understanding of the ‘physiology’ of the human spirit in palliative care settings so that it can aid in the generation of hypotheses for study and aid in assessing the state of research so that gaps can be more readily noted and responded to. Similarly, the validity of the model can be somewhat assessed by mapping on to it existing studies to assess the goodness of fit with the way researchers are asking questions about human spirituality. In the end, the model must be able to evolve in response to empirical findings. A test of the quality of this model will be how well it evolves over time. We look forward to many empirical studies that will result in its evolution.

Keywords: Spirituality, end of life, psychology
**Title:** Patient-powered Spirituality-and Quality-of-life-focused Advanced-illness Research-network

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**Background:** The advanced illness patient population includes people of all ages and ethnicities. With a high burden of illness and short life span, they face daunting challenges in learning about their options and expressing their values. Yet they are under-represented in research, and their spiritual care needs and quality of life demand far greater attention.

**Objective:** A group of committed patients, family caregivers and organizations have united under the umbrella of the HealthCare Chaplaincy (HCC) to propose a unique, ambitious, and cross-cutting group known as PSQAR (Patient-powered Spirituality- and Quality-of-life-focused (QOL) Advanced-illness Research-network). 27 partners represent patient and family caregiver (FCG) groups, most of the spirituality- and QOL-focused advanced illness researchers and advanced illness organizations in the U.S., and several health systems. Envisioned as an open community that supports and engages patients and FCGs as well as inviting their participation in research through health information giving.

**Research Design/Methods:** Because of the burden of illness and short life span, PSQAR relies on healthcare chaplains, family caregiver (FCG) groups, and advanced illness researchers and organizations to help structure and sustain the network. PSQAR will: represent diverse advanced illness patients; unite patients and FCGs with one another and stakeholders through a single virtual site, where they freely access resources, and join an on-line community; offer patients and FCGs voluntary contribution of their health information for research; establish a governance structure built on respect and reciprocity, with a Patient Led Advisory Council and Research Open Circle; contribute new standards for measuring spirituality and QOL among standard health care indicators; create a standardized database that links patients and FCGs, of self-reported, EHR, and biospecimen data; and harness scalable technology.

**Results:** In May 2013 PSQAR was launched and has been meeting weekly or more since then, to articulate and materialize its mission to create a patient-powered comprehensive and integrated research network by partnering with existing groups, filling gaps in spirituality and QOL matters, and supporting patient and FCG linked research in the interconnected aspects of advanced illness.

**Conclusions:** PSQAR will be an era-defining, patient-powered resource for spirituality and QOL research in advanced illness.

**Keywords:** Spirituality, Quality of Life, Advanced Illness, Patients, Caregivers, Research Open Circle
**Title:** Staking a Claim: Setting the Strategic Research Agenda for Chaplaincy Care in Health

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**Background:** Despite their central role in the care of patients who are suffering and patients’ consistent endorsements of its importance to them and to their loved ones, professional chaplaincy still remains a marginalized, non-essential service in much of health care even to some extent in palliative care. To be included in the evolving 21st century health care paradigm, a discipline or service must have a body of evidence that drives its practice and validates its value. Very little empirical research in spiritual care has been done and much of it has been limited by application of weak methods, poorly-designed interventions, and imprecisely-defined outcome measures. It is necessary to develop the field of chaplaincy care into a professional discipline that is defined, empirically grounded, and coordinated with other aspects of care.

**Objective:**
1) To create a sustainable, critical mass of researchers who are capable of posing and addressing the big questions that arise from spirituality in health and health care. 2) To produce an integrated body of seminal models, methods and measures for the profession of health care chaplaincy. 3) To establish a mentoring/consulting network to help manage and co-ordinate the ongoing efforts and continuing skills development of the selected chaplaincy researchers. 4) To build the future research capacity for professional chaplaincy by further developing the practical research skills of chaplains via a multi-disciplinary team of skilled researchers/teachers.

**Research Design/Methods:** Phase 1: HCC will convene its Ad Hoc Advisory Group of 9 members, including the 2 HCC project team leaders to develop the request for funding proposals (RFP); Phase 2: Issue the RFP and consult/mentor interested applicants as they prepare proposals. Proposals must have paired co-principal investigators: a board-certified chaplain and an experienced behavioral or social science researcher; Phase 3: Representatives from the Ad Hoc Advisory Group will select finalists from those who responded to the RFP. The finalists will present oral presentations to the representatives. Six research projects will be selected for funding; Phase 4: Selected projects will carry out their research. During this time, the faculty will be available for telephone and video conference consultations and mentoring; and Phase 5: Evaluate research outcomes, plan for dissemination, and create guidebook based on research. Convene 4-day conference to present completed work and plan next steps.

**Results:** The project has completed phases one through three and is currently implementing phase four. After the release of the RFP, 72 proposals were submitted from institutions throughout North America, demonstrating significant interest in furthering professional health care chaplaincy as an evidence-based clinical field. Six grants have been selected for funding.

**Conclusions:** HCC expects roughly 40 new chaplaincy researchers will be formed and empowered as a result of this grant; this will be measured by their successful delivery of the objectives of their funded research projects and their attendance at the program meetings.

**Keywords:** Chaplaincy, Palliative Care
Title: Education in Palliative and End-of-Life Care

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Background: The Education in Palliative and End-life Care (EPEC) program was developed in response to calls from the Institute of Medicine and the National Cancer Policy Board, that palliative care must be integrated into the care of all patients with cancer and other life-threatening illnesses. This is important because nearly 1 in 3 Americans will receive a diagnosis of cancer in their lifetime. This means that every physician practicing in the US needs a basic understanding of core principles of palliative care. EPEC has evolved from a grant-funded project into an ongoing, self-sustaining educational program that has been molded by the needs of the health care workers who have participated in EPEC conferences. The program has undergone modifications and adaptations in order to meet the needs and goals identified by the participants.

Objectives: 1. Disseminate palliative care competence in the US using a curriculum-driven, training model that starts with establishing 1,200 new EPEC-Trainers by their attendance at ‘Become an EPEC Trainer’ conferences. 2. Advance a curriculum-driven faculty development approach to enhance and sustain the effectiveness of EPEC Trainers. 3. Maintain the currency of the EPEC Curriculum via a systematic review process that incorporates principles of best evidence medicine and best evidence medical education.

Research Design/Methods: Participants learn palliative care skills and competencies and are introduced to effective teaching methods through a high impact high dissemination curriculum at ‘Become an EPEC Trainer’ conferences and Professional Development Workshops. For those not able to attend conferences, distance learning modules have been created. In recent years, the EPEC has actively collaborated with many partners to create adaptations of the original curriculum. Recently, EPEC has incorporated a powerful set of methods and tools for implementing change, clinical practice improvement (CPI), which derives from rigorous disciplines such as systems theory, human factors design and statistics. CPI methods are designed to tailor interventions to specific systems.

Results: The EPEC core curriculum currently has 5 full specialty adaptations; EPEC-India, EPEC-Oncology, EPEC-Emergency Medicine, EPEC for Veterans, and EPEC-Pediatrics, as well as many other modular and cultural adaptations. Today there are more than 2,000 EPEC Trainers in the United States and 25 other countries that are disseminating the various adaptations.

Conclusions: EPEC continues to support the efforts of its Trainers, adapt and expand the curriculum to fit the needs of interdisciplinary audiences, and evaluate and measure the impact of EPEC training on the experiences of patients and families.

Keywords: Palliative Care, High impact, High dissemination
Title: Geriatric Patient Healthcare Control Through the Use of PROs

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Background: Research demonstrates that there are health benefits to giving choices to a person. This concept is applied, contrasted and complimented in literature review and novel data collection of a sample clinician group working with geriatric persons.

Objective: To assess the use of Patient Reported Outcome measures (PROs) in comparison to objective and physiological outcome measures. Implications and limitations are also discussed.

Research Design/Methods: Data were collected at 38 healthcare faculties across Chicago and surrounding suburbs. The sample included 212 clinicians representing various clinical specialties. Comparative analysis of the survey’s results was conducted.

Results: Results suggest that the use of objective and physiological outcome measures is greater than the use of PRO across locations and clinical specialties.

Conclusions: PROs provide clinician’s with unique information that may enhance patient involvement and influence treatment plans, however, this research suggests that PROs are not commonly used in clinical settings. Prior research suggests that the PROs may also provide unanticipated benefits in that the use of these measures may indirectly increase patient perceptions regarding autonomy and agency.

Keywords and terms: Adult, Geriatric, Patient Reported Outcome (PRO), Validated Measures, bias, measurement, error, autonomy, control
Title: Colpocleisis: A Safe Minimally Invasive Option for Pelvic Organ Prolapse

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Background: Pelvic organ prolapse (POP) affects many women and will increase by 46% from 3.3 million to 4.9 million US women over the next 40 years. With our aging population, it is inevitable that a larger percentage of women will present for management of prolapse later in life. Despite the overwhelming need for surgical repair, the optimal approach to treat POP still remains unclear, especially in the elderly. Colpocleisis, an obliterative vaginal procedure, was initially described by Leon LeFort in 1877. This procedure, in which the anterior and posterior wall are denuded and sewn together at the introitus, is an effective surgical treatment for POP in women who are no longer sexually active, with high satisfaction and low levels of regret.

Objective: To describe the morbidity and mortality associated with colpocleisis and factors associated with improved outcomes.

Research Design/Methods: We utilized University HealthSystem Consortium (UHC) database, which included in-patient data from US hospitals. We included all women who underwent colpocleisis from 2002 to 2012. Centers were categorized geographically and by annual case volume. Cases were grouped by age and provider specialty. Outcome and readmission data from participating hospitals were compared between groups by analysis of variance and Tukey statistics. Average length of stay (LOS), Intensive Care Unit (ICU) admission rate, complication rate, mortality rate, and readmission rate were calculated for each hospital and compared.

Results: 4776 colpocleisis procedures were performed at 145 US medical centers. 43% of procedures were done on women >80yr, 52% on women 60-79yr, 3% on women 40-59yr, and 0.9% on women 20-39yr. Overall, rates of complications, ICU admission and mortality were low with average rates of 6.82%, 2.80%, and 0.15% respectively. High volume centers had lower ICU admission and complications rates as well as a shorter length of stay. Younger women had higher ICU admission and complication rates as well longer LOS. Stratification by provider specialty demonstrated higher ICU admission rates among cases performed by urologists as compared to cases performed by urogynecologists and general OB/GYNs. Complication rates were also higher among OB/GYNs and urologists as compared to urogynecologists. LOS was significantly longer when colpocleisis was performed by urologists rather than a urogynecologist.

Conclusions: Colpocleisis is safe minimally invasive procedure and outcomes are influenced by provider specialty and hospital volume.

Keywords: colpocleisis, pelvic organ prolapse, aging
Title: Age, Attitudes Toward Technology, and Technology Utilization in the ENGAGED Weight Loss Study

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Background: Currently, only 18% of those over 65 own smartphones, as compared to 39% of adults 55-64 and 79% of adults 18-24 (Smith, 2013). Age-related differences in smartphone ownership may reflect variation in attitudes toward technology and willingness to use smartphones and their applications for health promotion. Smartphones were utilized to self-monitor diet and physical activity in one arm of the ENGAGED 6-month behavioral weight loss trial.

Objective: To examine relationships among age, technology anxiety and acceptance, and adherence to using a smartphone and accelerometer for self-monitoring in the ENGAGED weight loss trial. We hypothesized that age would be: (a) positively associated with initial anxiety about using self-monitoring technologies and (b) negatively associated with acceptance of the technologies. We also expected greater technology anxiety and lesser technology acceptance to correlate with poorer adherence to using a smartphone to self-monitor diet and wearing an accelerometer to monitor physical activity.

Research Design/Methods: Data from the ENGAGED Study’s Technology [TECH] arm (n= 32) were analyzed [87.5% female, 40.6% Black or African-American, mean age= 40.4 years (SD=10.7), mean BMI= 34.8 (SD= 2.8), mean weight= 208.9 (SD= 25.5)]. Participants attended 8 in-person group sessions, received regular coaching calls, self-monitored diet and activity using the ENGAGED smartphone application, and wore an accelerometer (ShimmerTM) to objectively measure physical activity. Technology anxiety was assessed at baseline; technology acceptance was assessed after 3 and 6 months of enrollment in the trial.

Results: The predicted positive correlation between age and technology anxiety was observed (r = .420; p = .017), indicating that older individuals reported higher levels of technology anxiety. However, being older was not associated with having lower technology acceptance. Greater technology acceptance and a perception of fewer barriers to technology use were associated with greater adherence to wearing the ShimmerTM for more days (r = .393; p = .032) and longer hours (r = .519, p = .003) at 6 months. No significant relationships were observed between technology anxiety or acceptance and use of the smartphone dietary self-monitoring application.

Conclusions: Results showed that although older age was associated with greater anxiety upon first encountering new technologies, experience with the devices erased age-related differences in technology acceptance. Spring et al. (2013) demonstrated that older adults are able to use mobile technology and coaching calls to achieve significant weight loss. The success of our technology-supported intervention with older participants is likely attributable to individualized in-person training, as well as ongoing telephone support. Mobile technology remains a promising intervention delivery channel for older adults. The mechanisms that convert initial technology anxiety to technology acceptance warrant further investigation.

Keywords: Health Outcomes, Technology, Smartphones, Weight Loss, Older Adults
Title: “Ideal Cardiovascular Health” and Healthy Aging

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Background: Cardiovascular disease (CVD) is the leading cause of death and disability in men and women. The number of people with CVD will increase dramatically over the next two decades, during which time annual direct expenditures on CVD are expected to triple, from $273 billion in 2010 to $819 billion in 2030. Thus, we must find a new paradigm to bend the curve of the CVD epidemic.

Objective: We recently hypothesized that having a package of all ideal health factors and health behaviors might be a powerful means for abolishing risk for CVD and for achieving healthy longevity.

Research Design/Methods: Beginning in 1999, faculty in Preventive Medicine and Cardiology began to explore the implications of having simultaneous ideal levels of all CVD risk factors, defined as ideal CV health: (1) total cholesterol <200 mg/dL, (2) blood pressure <120/<80 mm Hg, (3) no diabetes, (4) non-smoking, (5) ideal body weight, (6) physically active, and (7) healthy diet. Research has focused on identifying the prevalence of ideal CV health in the population, the impact of ideal CV health on outcomes including cardiovascular disease and cancer incidence, healthcare utilization and costs, development of atherosclerosis, cognition and determining lifestyle and genetic predictors of maintaining ideal CV health throughout the lifetime.

Results: Research within our department has found that although we are all born with ideal CV health, we lose it quickly through childhood and young adulthood because of environmental and behavioral factors. Once CV risk factors develop, it is difficult to restore low risk, suggesting that interventions to maintain CV health may be easier than to improve CV health once it’s lost. The ideal cardiovascular health pattern is minimally heritable, but pursuit of healthy lifestyles through young adulthood preserves ideal CV health. Ideal CV Health when present in childhood, young adulthood, or middle age is associated with dramatically lower risks of total mortality, CVD, coronary and stroke mortality, non-fatal and fatal CVD events, incident cancer, better quality of life at older ages, better cognitive function at older ages, lower healthcare costs and lower atherosclerotic burden in children and young adults.

Conclusions: Based in large part on these findings from the Department of Preventive Medicine, in 2010, the American Heart Association (AHA) adopted the Ideal CV Health concept as the cornerstone of its new definition of “cardiovascular health.” The AHA aims improve the cardiovascular health of all Americans by 20% in the current decade. Northwestern researchers are working with policymakers to define strategies that will improve the cardiovascular health of our Chicago-land communities and of the nation as a whole.

Keywords: cardiovascular disease; healthy aging
Title: Re-Connecting Substance Abusers with HIV Back to Care

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Background: HIV infection has become a chronic condition that can be effectively managed with regular monitoring and appropriate medical care. However, most HIV-positive individuals remain either undiagnosed, unconnected to medical care, or have less optimal patterns of healthcare utilization. Prior research has shown that substance abusers have lower levels of engagement in HIV care than other risk groups. With primary care shortages in the US, Emergency Departments (ED) represent an important gateway for community health access. One solution for more efficient use of ED resources may lie in the creation of care-linkages with community-based organizations.

Objective: The overarching goal of this study is to develop and test a unique ED-based and community-engaged care linkage program designed to reconnect HIV-positive substance-abusers to both clinical care and community-based social supports, with the goal of improving clinical and care retention outcomes.

Research Design/Methods: Through a partnership between Northwestern Memorial Hospital Emergency Department and Chicago House, a dedicated and mobile Care Coordinator (CC) will provide an intensive, patient-centered, and counseling-based intervention to connect patients with various healthcare and social services through Chicago House referrals. Enrolled patients will be evaluated for one year after enrollment, with measures of CD4 count and HIV viral load being measured in the established clinic setting at intake and every three months for one year. Also, surveys incorporating patient reported outcomes will be administered at these intervals by the CC to measure changes in quality of life.

Results: Of the nine patients enrolled in a pilot over the last six months, 67% had not seen a physician for over a year before enrollment, and after enrollment, 78% of these individuals have been re-linked into the care via scheduled and completed appointments for HIV management with most completing their first medical appointment within 30 days of enrollment. 86% of these re-linked patients have been provided and filled prescriptions for antiretroviral therapy (ART), linked to needed psychosocial supports, and remained in coordinated communication with the CC. 57% have already demonstrated a decrease in viral load.

Conclusions: Preliminary results from the pilot phase indicate that a substantive yet practical effort to address the lack of medical support and community-based care coordination for substance-abusing known HIV-positive or newly diagnosed adults can improve their adherence to care plans and augment both their clinical condition and quality of life.

Keywords: Linkage, Retention, Community Engagement, Care Adherence, Substance Abuse, Patient-Centered Care
Background: Kidney transplant in older adults with end-stage renal disease (ESRD) reduces morbidity and mortality, improves quality of life, and is more cost-effective compared to other renal replacement options such as hemodialysis. Living donor kidney transplantation (LDKT) is a good option for older adults who are disadvantaged by the long waiting time and ethical allocation principles involved in cadaveric donation. Although older adults represent a large and growing proportion of patients with end stage renal disease (ESRD), they do not pursue LDKT to the same extent as younger cohorts.

Studies have shown that older adults are also less likely to be kidney donors, although research shows that kidneys from older donors can still be highly therapeutic for recipients, and can even match the benefits of a standard criteria donation. Additionally, even when older kidneys provide less benefit than standard criteria donations, recipients still achieve great advantages over remaining on dialysis. Donations from older adults can address the donor shortage and may especially benefit other older adults.

The causes underlying the low rates of LDKT and kidney donation in older adults are largely unexplored. No prior research has elicited opinions directly from members of this age group.

Objectives: To examine older adults’ beliefs and perceived barriers towards LDKT from both the recipient and donor perspectives.

Methods: In-depth telephone interviews were conducted with adults ages 65 and older. Subjects were interviewed using both Likert-scale and open-ended questions on their beliefs toward kidney transplantation and perceived barriers. The survey lasted 30-45 minutes. Participants were not compensated for their participation.

Participants: 30 English-speaking older adults over 65 years old who are current patients in geriatric practices within the Northwestern Medical Faculty Foundation (Chicago IL, USA).

Results: Participant’s concerns regarding their age and health were the main reasons cited for why they would not pursue LDKT (reason cited by 71% of participants) AND also the main concern mentioned when patients considered whether they would be a donor for someone else (50% of participants). Asking for a kidney donation was also identified as a barrier to pursuing LDKT; 41% reported that they would not ask anyone for a kidney even if they needed one. Older adults increasingly considered LDKT in the scenario where they were offered a kidney and did not have to ask a donor.
Title: Assessing Seniors’ Normative Beliefs and Sharing of Health Information about Pneumococcal Vaccination

Full Authorship: Crystal Doan, BA, Shira N Goldman, MPH; Ji Young Lee, MS; Stephen D Persell, MD, MPH; David W Baker, MD, MPH

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Background: In 2012, 59.9% of senior citizens were vaccinated against invasive pneumococcal disease, despite the Healthy People 2020 goal of 90% vaccination coverage. In prior research, physician recommendation and patient attitudes were found to be more powerful predictors of receipt of pneumococcal vaccination (PnVx) than access to medical services.

Objective: It remains unclear how normative beliefs, defined as perceptions of others’ behaviors and judgments associated with those behaviors, toward PnVx influence decisions to get vaccinated. As part of a larger study assessing the implementation of a clinical decision support tool and patient education video, we sought to understand older adults’ normative beliefs about PnVx, as well as what information about PnVx adults sought and shared.

Research Design/Methods: Patients age 65 or 66, with no documentation of receipt or refusal of PnVx, who received care at an academic general internal medicine clinic, were eligible. One week following their appointments, we contacted patients for participation in a telephone survey consisting of qualitative and quantitative items. Measures include patients’ normative beliefs, if they sought or shared information about PnVx, and self-report of vaccination. For the full study, we will assess the relationship of normative beliefs and receipt of PnVx (verified by medical record review).

Results: In progress. Preliminary descriptive results provided in poster.

Conclusion: To be determined.

Keywords: Feasibility study, Patient Education, Electronic Health Record, Vaccine, Decision Support Systems, Pneumonia, Pneumococcal, Health Behavior
Background: The progressive neurodegeneration characterizing Parkinson disease (PD) leads to significant motor and non-motor disturbances. A common non-motor complaint of PD patients is pain. Pain specific to PD, while quite common, remains a relatively under-studied topic. In one study, of 176 home-living PD patients, 83% (146) reported pain that they felt attributable to their disease. Pain associated with PD is a common complaint – that has been previously understudied – opening ample opportunity to add to the PD treatment knowledge base.

Objective:
• Characterize the frequency, location, and severity of PD-related pain
• Analyze how said pain impacts functional mobility
• Assess pain’s impact on both functional mobility and various quality of life issues (QOL) – including sleep, relationships, and work. Use impact on motor function + QOL to assess globally how PD-associated pain impacts overall patient quality of life.

Research Design/Methods: This study consists of a retrospective chart review of 200 patients seen at the Rehabilitation Institute of Chicago’s (RIC) Movement Disorder Clinic. Patients self-reported pain location, severity, and impact on QOL on the Brief Pain Inventory. The impact of pain location/severity on functional mobility will be assessed by analyzing performances on timed tests of functional mobility, completed by therapists at RIC. Statistical analyses comparing pain and functional mobility impact will include use of chi-squared, one-way ANOVA, and ANCOVA testing.

Results: Initial results reveal women participants experiencing pain at greater levels and with more impact on overall QOL than their male counterparts.

Additional findings discovered an association between distal leg pain (particularly foot/ankle pain) and more disturbed performance on tests of functional mobility. A final initial finding includes a ubiquitous decline in functional mobility associated with an obese BMI (BMI > 30 kg/m^2) in all aspects of functional mobility. Further data collection and statistical analysis will be required to finalize the results of the study.

Conclusions:
• PD patients frequently experience pain that impacts their motor function and QOL
• It is critical for physicians to assess and treat this pain
• Physicians should encourage responsible life choices and emphasize maintenance of healthy weight as an effective means to ensure improved patient motor function

Keywords: Parkinson disease, Movement disorders, Functional mobility, global quality of life, aging, palliative care, analgesia
Title: Emotional Biopsy: How Cancer Patients Adjust

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Background: A diagnosis of cancer, or any serious illness, brings a multitude of difficult decisions that greatly affect an individual’s long-term health and quality of life. Although this has a profound effect on all domains of a person’s life, there are few conceptual models that deal specifically with patient adjustment, particularly as it relates to guiding how clinical assessments and interventions are presented. In the absence of both theoretical and empirical work in this context, a comprehensive psychological processing model for adaptation, termed the Reintegration Model, was developed by Sara Knight, PhD, and Linda Emanuel, MD, PhD.

Objective: There are three primary aims in this study:
Establish feasibility of collecting qualitative and quantitative data in real time (EMA) focusing on cognition, affect, and behavior.
Examine the processes of psychological adjustment to a cancer diagnosis, particularly as it relates to medical decision making and fertility preservation.
Assess content of psychological adjustment as compared with the reintegration model, including staging and temporal facets.

Research Design/Methods: Men and women between the ages of 21 and 45 years of age are approached as soon after diagnosis as possible in order to capture the initial stages of their response. Ecologic Momentary Assessment (EMA) is conducted through daily diary entries and recorded responses that take place over a one month period. Participants are given a diary containing a series of daily questions about thoughts or conversations they had or decisions they made related to their diagnosis, as well as a weekly HRQL SF 12 (physical and mental health) questionnaire

Results: 18 participants have completed the diary and recordings. All participants have rated their participation as somewhat to moderately helpful for their own needs. Qualitative analysis has shown that patients are experiencing the three distinct psychological processes.

Conclusions: These results support a more thorough understanding of response to a difficult diagnosis and may suggest the need for new methods to assist informed decision making in overwhelmed populations.

Keywords: Cancer, Decision making, psychological adjustment.
Background: Cancer increases in prevalence with age; it predominantly affects individuals over the age of 55. Hematopoietic stem cell transplantation (HCT) has been increasingly performed on older adults given the advent of nonmyeloablative preparative regimens. Previous studies documented a consistent finding of cognitive impairment in patients prior to HCT. However, most research on cognitive functioning prior to the transplant procedure involves younger adults. Data are scarce in older adults planned for HCT although they may be at greater risks.

Objective: The objective of the study is to expand current evidence-based research to older adults with cancer by characterizing cognitive dysfunction in older cancer patients prior to HCT. It is hypothesized that older patients with cancer exhibited significant cognitive impairment on various domains prior to HCT.

Research Design/Methods: Participants were patients 60 years or older with a diagnosis of hematologic malignancy. They are scheduled for routine pre-allogeneic HCT neuropsychological assessment at a medical center prior to starting HCT induction regimens. A battery of neuropsychological tests measuring various cognitive domains including memory, executive functions, language, visuospatial functions, psychomotor functions, and mood was administered.

Results: The sample consisted of 27 older HCT recipients, with a mean age of 66.59 (SD = 4.29). The majority of patients showed no impairment on a standardized cognitive screening measure (Mini Mental State Exam = 28.5; SD = 1.2), with only 11 percent (n = 3) displaying gross impairment. However, detailed neuropsychological assessment revealed a high rate of impairments. Specifically, 48% showed mild cognitive impairment of a prominent memory profile (Hopkins Verbal Learning Test Delayed Free Recall z score ≤ -1.5), a third displayed executive dysfunction (Wisconsin Card Sort Test Error = 33%; Phonemic Fluency = 32%), and 17% had gross cortical dysfunction (Boston Naming Test).

Conclusions: The results showed a high rate of occult cognitive deficits for medically cleared HCT recipients 60 years and older which are consistent with previous findings. The current findings suggested that the use of only a brief screening measure for cognitive functioning in this population might not capture subtle cognitive impairment. Detailed neuropsychological assessment revealed more individuals with cognitive impairment in various domains.

Keywords: Cognitive function, Stem cell transplant, Cancer
Preparing for Paralysis - Rehabilitation for A Rare Metastatic Meningioma: A Case Report

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Background/Case Description: The patient is a 61 year-old male with a rare metastatic anaplastic meningioma, a malignancy with an annual incidence of 0.17 per 100,000 people. Through the continuum of this patient’s disease progression, rehabilitation interventions were instituted to improve his functional status and quality of life.

Results/Clinical Course: The patient, with known diagnosis, was initially seen by the cancer rehabilitation consult service when he was admitted to the acute care setting with recurrent falls. An ankle-foot orthosis and walker were recommended after exam findings were notable for right dorsiflexor weakness. The patient was discharged home modified-independent with ambulation.

He was re-admitted with worsening lower extremity weakness and found to have recurrence of tumor at T11 with severe cord compression. He was not a surgical candidate. He was transferred to inpatient rehabilitation knowing that he would progress to complete T11 paraplegia.

As expected, he progressed to complete paraplegia within three weeks. The rehabilitation team coordinated care with Neuro-oncology and Palliative Care to maximize function and control symptoms, especially the patient’s severe anxiety. At discharge, he was modified-independent at the wheelchair level. Two months later, the patient was re-admitted with progressive upper extremity weakness. A day rehabilitation program was instituted for a motorized wheelchair and acquiring activities of daily living (ADL) aids such as a universal right hand cuff so he could continue to play the guitar, his passion. Due to these interventions, the patient was able to live a higher quality of life through his transition to home hospice and subsequent passing six months later.

Conclusions: This is an unusual case not only in its rare diagnosis but also in the way rehabilitation medicine was integrated into the patient’s care throughout his disease progression to maximize function and promote quality of life.

It demonstrates how the emerging field of Cancer Rehabilitation can add value to comprehensive oncologic care even in the face of disease progression.

Keywords: Cancer, Rehabilitation, End of Life Care
Immune dysregulation is associated with sexual dysfunction and bother among advanced prostate cancer survivors following androgen deprivation treatment

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Advanced prostate cancer (APC) is associated with disruptions that compromise health related quality of life (HRQOL). Treatment typically includes androgen deprivation therapy (ADT) which often results in multiple chronic and debilitating symptoms, including sexual dysfunction, which further impacts HRQOL. Previous work has shown that inflammatory cytokines exacerbate lower urinary tract symptoms. To this date, very limited work has reported links between cytokines and lower sexual dysfunction and bother in APC.

This study evaluated relationships two markers of systematic inflammation (IL6 and TNF-alpha) and sexual dysfunction and bother.

Participants ≥ 50 years of age (n=43) and ethnically diverse (41% Non-Hispanic White, 17% Black, 42% Hispanic) were part of a larger NCI-funded study that evaluated the effects of a psychosocial intervention among APC survivors (stage III or IV) who had undergone ADT. Sexual side effects were assessed using the Expanded Prostate Cancer Index Composite (EPIC), which can be subdivided into dysfunction and bother subscales. Proinflammatory measured from stimulated peripheral blood monocular cells via ELISA kits. Zero-order and partial correlations controlling for age, medical comorbidities, and months since diagnosis evaluated associations among cytokines and sexual dysfunction and bother.

Eight-six percent of men reported an ongoing sexual relationship prior to their PC diagnosis. At the time of assessment, 84% of men reported that they have not had sexual intercourse in the past month. Initial analyses evaluated bivariate correlations among sexual side effects and inflammatory cytokines. TNF-alpha was negatively associated with the EPIC composite (r=-.42, p=.01) and analyses of subscales demonstrated that the sexual dysfunction subscale was significant related (sexual dysfunction, r=-.37, p=.02), though the sexual bother subscale only trended toward significance (r=-.27, p=.08). Partial correlations were run controlling for age, months since diagnosis, and number of comorbid medical conditions. TNF-alpha remained negatively associated with the EPIC composite (r=-.38, p=.02). However, with the inclusion of the control variables, the cytokine-EPIC subscale associations dropped to a trend (sexual dysfunction, r=-.31, p=.06; sexual bother, r=-.28, p=.09). IL-6 was not significantly associated with either the EPIC composite or subscales; however, a trend emerged with sexual bother (r=-.31, p=.07).

TNF-alpha exhibited a stronger relationship than IL-6 with EPIC composite scores. When analyzing the EPIC subscales, TNF-alpha appears to have a stronger relationship with bother compared to dysfunction. This indicates that TNF-alpha may be more a prominent correlate of with dysfunction and bother. These results serve as preliminary data for future studies investigating the relationship between HRQOL symptoms/side effects and biological factors.

Keywords: sexual dysfunction and bother, prostate cancer, quality of life
**Title:** Using In Person and Video Observations to Assess Safety Vulnerabilities in Living Donor Liver Transplantation.

**Full Authorship:** Arianna F Yanes, Lisa M McElroy MD, John Joseph BS, Jane L Holl MD, MPH Donna M. Woods PhD, Daniela P Ladner MD, MPH

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**Background:** Over the past decade, research has been aimed at reducing medical error and improving the quality and safety of clinical processes. Prospective studies allow for better understanding of safety vulnerabilities before adverse events occur. Observations, either video recorded or in-person, have been successful in identifying areas for improvement in patient safety, including team dynamics, leadership styles, communication methods, and technical processes.

**Objective:** To identify failures in the process of living donor liver transplant (LDLT) that lead to medical errors and preventable complications.

**Research Design/Methods:** We combined in person observations with videotaping of all of the processes of care during the operative processes of LDLT surgery. Using human observers and video cameras, the entire operative process, from the transfer of the patient to the pre-operative area to the transfer of the recipient to the intensive care unit, was observed. The videos were reviewed and coded independently using the WHO International Classification for Patient Safety.

**Results:** A total of 13 (7 donor, 6 recipient) surgeries were observed, 6 using human observers and 7 with video recordings. A total of 154 safety issues were observed (26 Contributing Factors and 128 Safety Incidents), 13 of which occurred during the postoperative handoff. Of the 314 Safety Incidents, one resulted in patient harm.

**Conclusions:** In person and video observations are powerful techniques for studying process vulnerabilities and identifying threats to patient safety before they cause patient harm. While this is a novel and still unconventional approach to clinical research, similar studies in industrial, aviation, and other high-risk domains have led to major system redesigns and improvements in safety and performance. Areas for further investigation include the postoperative handoff.

**Keywords:** Liver Transplantation, Observation, Error Detection, Patient Safety
Seasonal Variation in Liver Transplantation

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Background: Liver transplant recipients are complex and require excellent post-operative care to ensure good outcomes, thus variations in care can impact both patient and graft survival. Prior studies have identified variation in care based on time of year for several surgical specialties. Our study aimed to identify seasonal variation in liver transplantation.

Objective: We conducted a secondary data analysis of the United Network of Organ Sharing or Organ Procurement and Transplantation Network database to determine whether seasonal variation exists in liver transplantation.

Research Design/Methods: We performed a secondary database analysis of the United Network of Organ Sharing/Organ Procurement and Transplantation Network database of adult primary liver transplant recipients from 2002 to 2010. Patients were grouped according to the month of transplant: 1) February-April, 2) May-July, 3) August-October, and 4) November-January. Patient and graft survival were estimated using Kaplan-Meier survival analysis and differences between seasons were analyzed using a log-rank test. Unadjusted and adjusted Cox proportional hazards regression models were used to assess patient and graft survival by season.

Results: From 2002 to 2010, 55,695 liver transplants were performed in the United States, and 36,983 transplant recipients were included in our final analysis. Patients transplanted November-January had higher rates of graft loss (HR = 1.09; 95% CI: 1.02, 1.16), and patients transplanted May-July had higher rates of graft loss (HR = 1.12; 95% CI: 1.05, 1.19) and mortality (HR = 1.11; 95% CI: 1.04, 1.19).

Conclusions: These data demonstrate seasonal variation in liver transplant outcomes, potentially due to winter holidays and trainee turnover in July. Further research is needed to determine the significance of this variation with respect to complications, and identify solutions.

Keywords: Mortality, Outcomes, Graft Survival, Liver
Title: Probabilistic Risk Assessment of Pneumonia after Deceased Donor Liver Transplantation

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Background: Pneumonia is one of the most common infections occurring in deceased donor liver transplant recipients. Post-operative pneumonia significantly increases the cost of the hospital stay, and results in worse patient outcomes. In addition to pathophysiologic factors, system level factors also contribute to the development of post-operative pneumonia.

Objective: We applied Fault Tree Analysis, a common system engineering mechanism of risk assessment, to determine the interaction of contributing factors in the development of pneumonia after a deceased donor liver transplant.

Research Design/Methods: A systematic literature review was performed of all studies examining pneumonia in deceased donor liver transplant recipients using the terms “liver transplantation [MeSH]”, “postoperative complications [MeSH]” and “pneumonia [MeSH]”. From these studies, various risk factors were identified and a fault tree was created to visually identify the risks within the system. Within the fault tree, OR gates denote causative factors which can independently lead to pneumonia, whereas AND gates denote causative factors that must occur together to lead to pneumonia.

Results: At total of 17 deceased donor liver transplant studies were identified examining the prevalence of pneumonia in transplant recipients. Six primary faults, only one of which had dual sub-faults, and 13 secondary faults, one of which had dual sub-faults, were identified from the literature. In total, 2 AND gates and 12 OR gates were incorporated in the fault tree.

Conclusions: Based on preliminary findings, further investigations are needed to understand how postoperative pneumonia develops in the early postoperative period. The majority of the gates (12; 85.7%) are “OR” gates, indicating that a single process failure can result in pneumonia. This is in contrast to other high risk industries such nuclear power or aviation which contain redundant systems that require multiple failures within the system to result in an adverse event. Our next step will be to integrate the numbers from the literature in order to identify the key faults that occur the most frequently and may have actionable resolutions that can be immediately applied to the system.

Keywords: Outcomes Assessment, Risk, Engineering, Adverse Effects, Risk Assessment
Title: Deiciencies in Postoperative Handoffs Following Living Donor Liver Transplantation


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Background: Medical error is the third leading cause of death in medicine, with an annual cost of over 17 billion dollars. Patient handoffs, which involve either the physical transfer of patients or handing over their care from one person or team to another, have been identified as a frequent source of medical error. Living Donor Liver Transplantation is a complex procedure involving debilitated patients who are at increased risk of complications from medical error, as well as living donors who assume a large amount of risk with no medical benefit.

Objective: To identify errors associated with the postoperative handoff of living donor liver transplant patients from the operating room (OR) to the intensive care unit (ICU) or post-anesthesia care unit (PACU).

Research Design/Methods: Our assessment was conducted over 4 years (2008-2012) at 4 high volume transplant centers, which performed ¼ (252) of all LDLT’s nationally during the study period. Our methods of assessment included: medical record review, in-person and video observations of the donor and recipient surgeries, web-based clinician debriefings of all clinicians involved in donor and recipient surgeries. We recorded all detectable errors including incomplete documentation, miscommunication, technical or procedural errors and equipment malfunction.

Results: We conducted a total of 60 medical chart reviews, 14 in-person and video-recorded observations and clinician debriefings of 108 surgeries. In total, 260 medical errors were detected involving the postoperative patient handoff, 34 of which resulted in patient harm. The most common errors during handoff involved communication (80/260), Medications (58/260) and Patient Monitoring (19/260). The most common errors resulting in patient harm involved the Respiratory (10/34) and Cardiovascular (6/34) systems.

Conclusions: The postoperative handoff of both donors and recipients after living donor liver transplantation is a process of care that is highly vulnerable to medical error. Medication administration and both written and verbal communications were both the most frequently found error and the errors with the greatest likelihood to cause harm to the patient. Given that 40% of complications can be prevented, a more focused assessment of the postoperative handoff is warranted to identify handoff related preventable errors, determine which markers are suitable as indicators of handoff quality and develop interventions aimed at reducing medical errors and improving patient outcomes.

Keywords: Liver Transplantation, Postoperative Complications, Deceased Donor, Patient Outcomes
Title: Detection of Medical Errors in Kidney Transplantation: A Pilot Study Comparing Proactive Clinician Debriefings to a Hospital-Wide Incident Reporting System

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Background: Rates of medical errors and adverse events remain high for kidney transplant patients, who are particularly vulnerable due to the complexity of both their disease and the kidney transplant procedure. Although hospitals around the country utilize institutional incident reporting systems, they often fail to capture a substantial proportion of medical errors.

Objective: To assess the ability of a proactive, web-based clinician safety debriefing to gather additional information about safety vulnerabilities in kidney transplantation.

Research Design/Methods: Within 24 hours of completion of kidney transplant surgeries between April 2010 and April 2011, emails were sent to all individuals listed in the operating room nursing personnel report requesting participation via a hyperlink to the debriefing. Incident reports were obtained for the same time period. The World Health Organization International Classification for Patient Safety was used to classify issues reported in incident reports and debriefing responses.

Results: A total of 270 debriefings were submitted reporting 334 patient safety issues (179 safety incidents, 155 contributing factors); 57 incident reports were filed reporting 92 patient safety issues (56 safety incidents, 36 contributing factors). Debriefings and incident reports were completed primarily by nursing staff (40.3% and 77.2% respectively), but increased participation by attending physicians occurred in debriefings vs. incident reports (31.1% vs. 3.5%). Debriefings captured up to 11 patient safety issues per response compared to incident reports, which captured up to 3 issues per report. Among debriefings, the most common incident class reported was Resources/Organizational Management (49/179; 27.4%), of which Human Resources/Staff Availability/Adequacy was the most common subcategory (26/49; 53.1%). Among incident reports, the most common incident class reported was Medical Device/Equipment (16/56; 28.6%), of which Failure/Malfunction was the most common subtype (9/16; 56.3%).

Conclusions: This study demonstrates the ability of a proactive, web-based clinician debriefing to augment a traditional incident reporting system in gathering information about safety risks in kidney transplantation. The debriefings demonstrated multiple advantages, including increased information, multiple perspectives of a single safety issue or incident, increased focus on contributing and mitigating factors and increased breadth of participants, including attending physicians. Future research by this group is aimed at expanding the web-based tool to capture safety risks throughout the course of the hospital stay along with integration into the electronic hospital records, including the incident reporting system.

Keywords: Medical error, adverse event, patient safety, kidney transplantation, data collection
Complications of Deceased Donor Liver Transplant: A Meta-Analysis of Reported Incidences

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Background: Among liver transplant recipients, postoperative complications lead to increased length of stay, and decreased graft and patient survival. The incidence of complications in transplant recipients is not known, and the quality of the data reported from single-center studies are variable. This results in a limited ability of transplant centers to accurately inform their patients about the risks of transplantation, and a decreased ability to measure the effect of any intervention.

Objective: To understand the magnitude of the burden of postoperative complications on liver transplant recipients.

Research Design/Methods: A systematic review of the literature was performed to identify studies that reported incidence of postoperative complications in deceased donor liver transplant recipients. Articles were selected for inclusion if they reported an incidence of postoperative complications in deceased donor liver transplant recipients based on human studies. Articles were excluded if they were not available in English, were published prior to January 1, 2002, or originated from a location other than the United States, Australia, Canada or the United Kingdom. Data from the selected manuscripts were independently extracted from each study by 3 reviewers (LM, AD, AED). Disconcordant decisions were solved by a consensus among the investigators with guidance from a fourth reviewer (DPL). Incidence rates were calculated as percentages, and heterogeneity was assessed using the Cochran Q chi-square test and the I2 statistic.

Results: Our original search criteria returned 8159 studies. After preliminary exclusions and supplemental searches, 134 studies were selected for full text review. In total, our meta-analysis includes 29,227 deceased donor liver transplant recipients from 75 studies performed between 2002 and 2012. The pooled incidence rate of biliary leak and stricture was 0.079 (95% CI = 0.055 to 0.107) and 0.125 (95% CI = 0.099 to 0.154) respectively. The pooled incidence of hepatic artery thrombosis was 0.045 (95% CI=0.031 to 0.062), and postoperative hemorrhage was 0.083 (95% CI = 0.046 to 0.131). The estimated mean incidence of acute renal failure was 0.299 (95% CI = 0.220 to 0.385). The pooled incidence of intra-abdominal abscess was 0.044 (95% CI = 0.019 to 0.078). We found evidence of statistically significant heterogeneity for all but one complication (Q statistic, p<0.001; I2 range 80.1-99.0%).

Conclusions: Our results show that although the absolute incidence of major postoperative complications varies, further efforts are needed to standardize the monitoring of postoperative morbidity in liver transplant recipients. Improved knowledge of the incidence of these complications will allow for more accurate estimation of the effect of interventions aimed at improving patient safety.

Keywords: Liver Transplantation, Postoperative Complications, Deceased Donor, Patient Outcomes
Title: Daily Forecasting of Inpatient Length of Stay

Full Authorship: Vikram Kilambi, PhD, Sanjay Mehrotra, PhD, Danny Sama, MBA

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Background: The patient-care process for hospitals is an interaction of patient characteristics, comorbidities, and dynamic changes in health-status and hospital procedures – and length of stay (LOS) is the essential performance measure. Improved prediction of LOS enables better management of hospital resources. However, recent studies seldom forecast LOS either daily or hospital-wide.

Objective: The objectives of this study are to implement a real-time predictive model of LOS that includes both patient- and service-related factors and assess the relative contribution of service factors to LOS.

Research Design/Methods: Using electronic records, we collected daily encounter data for all non-obstetric and non-psychiatric inpatients at Northwestern Memorial Hospital. Data consisted of patient demographics, mode of admission, patient health characteristics, and service attributes that changed as the encounter progressed. We employed generalized linear random-effects regression model to model the data and assess the relative importance of procedural attributes.

Results: The coefficient of determination, R2, was 0.7737, and the absolute mean and median prediction errors were 4.9 and 2.8 days respectively. Procedural factors and patient health characteristics were the most significant drivers of LOS. The influence of the procedural factors varied and the accuracy of the model increased as the encounter progressed.

Conclusions: Procedural factors are important determinants of LOS and warrant closer investigation to improve scheduling of services. Real-time forecasting of LOS aids coordination of patient care and hospital resource management.

Keywords: Length of stay (LOS); predictive model
Title: Cost-Effectiveness of Minimally Invasive Versus Open Surgery for Adult Degenerative Deformity

Full Authorship: Omar, Uddin, BA; Raqeeb, Haque, MD; Tyler, Koski, MD; Richard, Fessler, MD, PhD

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Background: Back pain is an increasing concern for the aging population. Minimally invasive spine surgery has been associated with reduced dissection of muscular fascia, blood loss, complications, and total hospital charges for 1 and 2-level surgeries in comparison to open surgery. However, there have been no published studies that have compared both functional outcomes and costs between multilevel MIS and open surgery for the treatment of adult spinal deformity.

Objective: This study aims to evaluate if minimally invasive surgery presents cost-effective attributes compared to open surgery in treating adult degenerative deformity.

Research Design/Methods: Seventy-one patients with adult degenerative scoliosis received two-stage, multilevel surgical correction through either an MIS approach with posterior instrumentation (n=38) or an open midline approach (n=33). Costs were derived from hospital and rehabilitation charges. Length of stay, blood loss, and radiographic outcomes were obtained from electronic medical records. Functional outcomes were measured with Oswestry Disability Index (ODI) and Visual Analogue Scale (VAS) surveys.

Results: Patients in both cohorts were similar in age (AgeMIS=65.68, AgeOpen=63.58, p=0.28). Mean follow-up was 18.16 months and 21.82 months for the MIS and Open cohorts (p=0.34). MIS and Open cohorts had an average of 4.37 and 7.61 levels of fusion, respectively (p<0.01). Total inpatient charges were lower for the MIS cohort ($269,807 vs $391,889, p<0.01) and outpatient rehabilitation charges were similar (41,072 vs $49,272, p=0.48). MIS patients experienced reduced hospital stay (6.16 days vs 12.39 days, p<0.01) and blood loss (EBLMIS = 470.26 mL, EBLOpen=2872.73mL, p<0.01). Baseline ODI was lower in the MIS cohort (40.03 vs. 48.04, p=0.03) and both cohorts experienced similar 1-year improvement (ΔODIMIS=-15.98, ΔODIOpen= -21.96, p=0.25). Baseline VAS scores were similar (VASMIS = 6.56, VASOpen= 7.10, p=0.32) but MIS patients experienced less reduction after 1 year (ΔVASMIS = -3.36, ΔVASOpen=-4.73, p=0.04). Pre-operative SVA were comparable (Preop-SVAMIS=63.47 mm, Preop-SVAOpen=71.3mm, p=0.60) but MIS patients had larger post-operative SVA (Postop-SVAMIS=51.17mm, Postop-SVAOpen=28.17mm, p=0.03).

Conclusions: Minimally invasive surgery demonstrated reduced costs, blood loss, and hospital stay while open surgery exhibited greater improvement in VAS scores, deformity correction, and sagittal balance. Additional studies with more patients and longer follow-up will determine if MIS presents cost-effective benefits for certain subsets of patients with adult degenerative scoliosis.

Keywords: Minimally Invasive Spine Surgery, Adult Degenerative Scoliosis, Adult Degenerative Deformity, cost-effectiveness analysis, cost-utility analysis, quality of life, complications, blood loss
Title: The Patient Safety Education Program - Canada

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Background: The Patient Safety Education Program (PSEP)TM addresses the gaps between the training medical team members receive and the continued need for improvement in patient safety. The Canadian National Steering Committee on Patient Safety, convened in 2002, published a report recommending the establishment of a Canadian Patient Safety Institute (CPSI). CPSI works to inspire improvement in patient safety and quality through its support of best practice implementation and awareness campaigns.

Objective: Beginning in 2010, PSEP and CPSI faculty and staff collaborated to create PSEP - Canada. PSEP - Canada is a comprehensive curriculum in patient safety developed for Canadian providers and mapped to Canadian healthcare standards. 8 ‘Become a Patient Safety Trainer’ (BPST) conferences have since been held. CPSI has engaged numerous partners in conference hosting. 423 Trainers from 86 healthcare organizations have graduated.

Research Design/Methods: Participant attitudes towards the conference are assessed using a standardized evaluation form consisting of 11 Yes/No questions and two six-item Likert scale questions. Patient safety knowledge change is assessed through the administration of pre- and post-test questions by curriculum module. For Likert items (scale 1 = Very Likely to 6 = Very Unlikely) we calculated descriptive statistics (mean, SD). For each Yes/No item on the overall conference evaluation, we report the percent of ‘Yes’ responses. For each pre- and post-test, we calculated summary scores for each participant by counting the number of correct answers, and then subtracted participant pre-test scores from post-test scores to calculate the change in score per participant. We performed analyses of the post-pre change in score using Wilcoxon signed-rank tests.

Results: Of participants who responded to the 11 Yes/No questions, 98% reported that they felt they had learned how to teach others as a result of the conference, 95% that they had learned how to implement safety improvement projects, and 94% that they had learned how to contribute to their entire organization’s patient safety. Of participants who responded to the Likert scale questions, the average score for both questions was between ‘Very Likely” and “Likely”, with 62% of participants reporting that they were very likely to encourage others to participate and 72% reporting that they were very likely to teach others as a result of attending the PSEP – Canada conference. Analysis of pre- and post-test results revealed statistically significant improvement in participants’ knowledge as a result of their participation in the conference.

Conclusions: PSEP - Canada is a successful and sustainable patient safety curriculum and conference model.

Keywords: Patient Safety
Title: The Patient Safety Education Program (PSEP)

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Background: Managing patients’ risk for injury while they are receiving care in healthcare organizations is a national priority in the U.S. While this has been true for several years - ever since the National Academy of Sciences’ Institute of Medicine (IOM) reported that medical errors were the 4th to 8th largest cause of preventable death - not much progress has been made preventing them.

Objective: The Patient Safety Education Program (PSEP) is utilized by organizations to better design their safety and quality improvement efforts and transform their organizational culture through a high-impact, high dissemination implementation model.

Research Design/Methods: PSEP is a comprehensive, end-learner friendly, high quality, patient safety curriculum. It also uses an approach adapted from the Education in Palliative and End-of-life Care (EPEC) Program that is grounded in adult learning methodology to teach content. Its framework for the curriculum design came from the Australian Council for Safety and Quality in Health Care and uses a collaborating approach. The curriculum consists of four plenaries, nine small group modules that describe the core competencies of patient safety, and clusters of modules addressing key clinical safety issues in intensive care, chronic care, and interventional care settings.

However, PSEP is more than just a curriculum. It identified skills, knowledge and behaviors/attitudes in a framework to guide patient safety education for healthcare workers at all levels. The inaugural ‘Become a PSEP Safety Trainer’ event was held in Pittsburgh, Pennsylvania in May 2008. Since 2008, PSEP has trained over 500 individuals from over 100 organizations in the United States and abroad. 37 Master Facilitators from various countries and background serve as the faculty for PSEP and its adaptations.

Keywords: Patient safety, PSEP, education
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