WISH 2017 @ AMIA Morning Program

08:00 AM

Opening Remarks

Lauren Wilcox, PhD

08:05 AM

Opening Keynote

Bongshin Lee, PhD

Bongshin Lee is a Senior Researcher in the EPIC group at Microsoft Research. Lee explores innovative ways for people to create visualizations, interact with data, and share data-driven stories. The recent focus of her research is on helping people explore data about themselves and share meaningful insights with others by leveraging visualization. Lee recently served as a General Co-Chair for IEEE PacificVis 2017, and served as Papers Co-Chair for IEEE InfoVis 2015 and 2016. She currently serves as an Associate Editor for IEEE TVCG. She earned both her MS and PhD degrees in Computer Science from the University of Maryland at College Park in 2002 and 2006, respectively.

08:55 AM

Morning Panel

Good Intentions Are Not Enough: Health Informatics Interventions That Worsen Inequality

Tiffany C. Veinot MLS PhD, Jessica S. Ancker MPH PhD, Courtney Lyles PhD, Andrea G. Parker PhD, Katie A. Siek MS, PhD

09:45 AM

Lightning Talks: Research Highlights

Investigating Support Seeking from Peers for Pregnancy in Online Health Communities

Xinning Gui MA, Yu Chen PhD, Yubo Kou PhD, Kathleen H. Pine PhD, Yunan Chen PhD

“Let Me Know If You Need Anything”: Support Realities of New Mothers

Annu S. Prabhakar, Lucia Guerra-Reyes, Anne Effron, Vanessa M. Kleinschmidt, Maggie Driscoll Charles Peters, Vanessa Pereira, Majdah Alshehri, Tom Ongwere, Katie A. Siek

Opportunities and Design Considerations for Peer Support in a Hospital Setting

Shefali Haldar, Sonali R. Mishra, Maher Khelifi, Ari H. Pollack MD, Wanda Pratt PhD

Help-Seeking & Technology: Perceptions of Adolescents & Young Adults

Maria Carpenter RN BSN, Connie Kerrigan RN BSN MBA, Michael J. Mirro MD FACC FACP Tammy Toscos PhD
We report a study of peer support in online health communities for pregnancy care along three gestational stages (trimesters) to investigate how pregnant women seek and receive peer support during different stages of pregnancy.

Research Setting: BabyCenter.com

Methodology: a grounded theory research design with the primary data collection and analysis being qualitative content analysis

Findings:

1) limited access to healthcare professionals; 2) frustration with their own healthcare providers; 3) limited access to offline support; and 4) mismatch between information obtained online or from books and their own experience.

Types of questions asked throughout the three trimesters: advice, formal pregnancy-related knowledge, informal pregnancy-related knowledge, reassurance, and emotional support.

Question topics at different stages: Although the types of online peer support pregnant women sought on the three Mommy Mentor forums were relatively consistent across the three trimesters, the specific content of the concerns expressed varied across the three trimesters:

First trimester: seeking support for a "tentative pregnancy"
Second trimester: caring for two
Third trimester: preparing for birthing

Replies from peers: Peers shared their own experiential knowledge, the advice they received from healthcare providers, medical information, and sometimes encouraged the poster to see healthcare professionals in situations that are perceived to exceed the capacity of the mommy mentor forums. The pregnant women who asked for support in turn used peers' experiential and clinical knowledge to evaluate healthcare services they had received or were going to receive.

Discussion and Design Implications

Stage-based, timely, continuing care
From fetus-centered to women-centered care
Integrating experiential and medical knowledge

Contributions:

Our study contributes to the field of women’s health and HCl as well as health informatics more broadly by identifying the temporal, women-centered, and holistic demands in prenatal care and reflecting upon the design of health services and technologies.
“LET ME KNOW IF YOU NEED ANYTHING”: SUPPORT REALITIES OF NEW MOTHERS

Annu S. Prabhakar, Lucia Guerra-Reyes, Anne Effron, Vanessa M. Kleinschmidt, Maggie Driscoll, Charles Peters, Vanessa Pereira, Majdah Alshehri, Tom Ongwere, Katie A. Siek

RESEARCH DETAILS

Aim
Investigate support needs and support sources of pregnant women and new mothers.

Participants
48 participants:
10 first time pregnant, 20 pregnant mothers, 18 new mothers

Method
Asynchronous, Remote, Community (ARC) method
- 3 closed Facebook groups
- 19 activities
- 8 weeks

Activities
- Discussions
- Surveys
- Validated instruments
- Social support circle diagram

Findings
- Support needs and support sources of women evolve as they go through pregnancy, childbirth, and stages of motherhood

Proposed Support Design Framework
Evolving Ecology of Support (EES)
Opportunities and Design Considerations for Peer Support in a Hospital Setting
Shefali Haldar*, Sonali R. Mishra, Maher Khelifi, Ari H. Pollack, Wanda Pratt

To understand the previously unexplored needs, barriers, and design opportunities for peer support tools in the hospital environment

PURPOSE

A survey asking patients and caregivers about their advice for peers
Semi-structured interviews with patients and caregivers about their thoughts on interacting with peers during their hospital stay

METHOD

KEY NEEDS FOR PEER CONNECTIONS IN THE HOSPITAL

Ask Questions
Learn about Providers
Report and Prevent Medical Errors
Exchange Support
Manage Time

DESIGN OPPORTUNITIES

Leverage the EHR to match peers
Accommodate for a patient’s dynamic peer support needs and interaction preferences throughout their hospital stay


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The Question:
What are the perceptions of using technology to meet the mental health needs of adolescents and young adults?

Three-quarters of mental health disorders begin before the age of 24; however, only 1 out of every 5 of those youth receive mental health treatment. Technology has the potential to serve as a supplement or alternative to traditional mental health care, which is especially relevant considering that a large majority of today’s youth go online daily and use technology as a primary means of communication. In a study funded by the Robert Wood Johnson Foundation, Tammy Toscos, Ph.D.; Maria Carpenter, RN, BSN; Michael Mirro, M.D., FACC, FHRS, FAHA; and Connie Kerrigan, RN, BSN, M.B.A. of Parkview Health in Fort Wayne, Indiana are leading a team of researchers and community experts to uncover the local community’s perceptions of using technology to meet the mental health needs of a general population of youth ages 14-24.

In this mixed-methods study, researchers began with a series of online surveys to understand the perceptions of a diverse panel of experts. The findings were used to guide focus groups conducted with clinicians, educators, parents and youth ages 14-24. In the final phase of the study, a general population of high school students were surveyed during interactive events using polling technology. College students (ages 18-24) took part in an online survey. Technologies such as websites, apps, social media, text messaging, online chat and video chat were explored, including resources involving licensed mental health professionals, trained non-professionals, peer support and self-help applications.

The Implications:
Technology is an important part of the pathway to meet the mental health needs of adolescents and young adults.

Preliminary results indicate that technology can be a viable avenue for adolescents and young adults to receive mental health support, but it is not the sole solution to connecting this population with resources that meet their individual mental health needs and preferences. Experts agreed that technology may be used in a variety of beneficial ways to help youth ages 14 to 24, but many felt that technology cannot and should not serve as a replacement for in-person, face-to-face communication with a mental health professional.

Youth preferences for how they communicate with trusted sources about their stress or problems varied; while some prefer to use a form of technology, over half would rather talk to someone face-to-face. When given examples of mental health resources provided through technology, the large majority of youth reported not having utilized these types of resources. Findings show significant relationships between youth characteristics and preferences for various technologies, including: depression/anxiety screening results, prior thoughts of suicide, and self-reported stress levels.

Contact Us
For more information on the results from this grant, please visit the project website at www.parkview.com/mechanicsofmind, or contact the principal investigator Dr. Tammy Toscos (tammy.toscos@parkview.com).

If you would like to learn more about other related work, please contact: Megan Collado, M.P.H., Director, AcademyHealth | megan.collado@academyhealth.org
WISH 2017 @ AMIA Morning Program

10:05 AM
Coffee Break and Poster Viewing

10:35 AM
Morning Technical Session
Comparison of Participant Demographics and Yield of Recruitment Strategies in a Study of Men Who Have Sex with Men (MSM) in Metropolitan Detroit
Bradley E. Iott MPH MS, Tiffany C. Veinot MLS PhD, Jimena Loveluck MSW, Erin Kahle PhD, MPH, Leon Golson, Akilah Benton MPH

Where am I?" Finding Patients in the Process of Navigating a Complex Clinical Information Space
Tera L. Reynolds MPH MA, Emma McGregor BSE, Kai Zheng PhD

Comparing Qualitative Evaluation Methods for Improving User Engagement with Mobile Health Applications
Katherine S. Finnerty, Carolina Ruiz PhD, Bengisu Tulu PhD, Qiaoyu Liao BS, Jessica Oleski MA, Sherry Pagoto PhD

11:35 AM
Lunch and Poster Viewing
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Posters Original Research

A Comparative In-Situ Study of Two Medication Reconciliation Interfaces in Pre-Operative Nurse Assessments
Benjamin Duncan MS, Andrew Solomon MS, Bradley Doebbeling MD MSc
David Kaufman PhD

Achieving Problem–Solution Fit in Digital Health Implementation
Magdalene Au BHS, Sabrina K. Tang BASc MHSc, Payal Agarwal, BASc MD, Jay Shaw PT PhD, Daniel Cornejo Palma MD, Laura Desveaux PT PhD, Illaha Tahir HBSc MMI, Onil Bhattacharyya MD PhD

Alexa, Start Living Healthy!
Omar Metwally MD, Blake Gregory MD

Biobank Participants’ Preferences for Research Updates: Tailoring Communication Services
Lochan Shah BS, Casey L. Overby PhD

Considerations for Using the Asynchronous Remote Communities (ARC) Method in Health Informatics Research
Julia C. Dunbar, Ciabhan L. Connelly, Juan F. Maestre MS, Haley MacLeod MS, Katie Siek PhD
Patrick C. Shih PhD

Decision Making In Online Health Communities: What Can We Learn From Member Choice Inquiries
Jing Zhang MS, Jina Huh PhD

Dementia Caregivers’ Engagement of Informal and Formal Supports and the Potential Role of Consumer Health Information Technology
Anna Jolliff, Andrea Gilmore-Bykovskyi PhD RN, Laura Block BS, Nicole E. Werner PhD

Designing Health Information Technologies to Support Integrated Care
Karina Caro PhD, Kenneth B. Nimley MS, Allison N. Spiller BS, Nicole Tomy BS, Gabriela Marcu PhD

Developing an Interactive Social Network Analysis Tool to Explore Activity Patterns on an Online Health Knowledge Sharing Platform
Danny T.Y. Wu PhD MS, Wu-Chen Su MS, Paul Murdock, Divyay Gupta, Aniket Mahurkar, Nameeta Raj, Supraja Sivaramakrishnan, Daniel J. McLinden EdD, Dong-Gil Ko PhD

Development and Preliminary Evaluation of a Patient Portal Messaging for Research Recruitment Service
Kelly T. Gleason, RN BSN PhD(c), Daniel E. Ford MD MPH, Diana Gumas MS, Maureen Meyer BS, Cheryl R. Dennison Himmelfarb RN ANP PhD FAAN

Evaluation of Different Modalities for Self Measuring Impulsivity
Jason Waterman PhD George Whiteside, Hongyi Wen, Dylan Horowitz, JP Pollak PhD, Deborah Estrin PhD
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Posters Original Research

Exploring New Design Factors for Electronic Interventions to Prevent College Students from Excessive Drinking by Using Personal Breathalyzers
Aehong Min MS, Patrick C. Shih, PhD

Interactive Systems in Mental & Behavioral Health
Jessica A. Pater MS, Tammy Toscos PhD, Nazanin Andalibi MS
John Torous MD

Investigating Unintentional Medication Non-Adherence to Inform Technology Design
Clara Caldeira BS, Sripriya Komarlingam Natarajan MS, Yunan Chen PhD

Just-in-Time Design: In Situ Methods for Capturing and Articulating Adolescents’ Illness Experiences
Matthew K. Hong MS, Udaya Lakshmi BS, Lauren Wilcox PhD

Listening to Users: Older Adults Have Ideas on How to Improve Patient Portals
Yuqi He MLIS

Mobile Technologies for Grief Support: Prototyping an Application to Support the Bereaved
Anna N. Baglione BS, Maxine M. Girard, Meagan Price, James Clawson PhD, Patrick C. Shih PhD

Patient–Provider Communication: Improving Patients’ Comprehension of Their Care
Ji Youn Shin, John Marshall, David Bozaan, Franc Nunoo-Quarcoo, Sun Young Park

Perceived Usefulness and Acceptance of Telestration in Laparoscopic Training
Yuanyuan Feng MS, Jatin Chhikara MS, Jordan Ramsey BS, Helena M. Mentis MS PhD

Small Data Privacy Protection: An Exploration of the Utility of Anonymized Data of People with Rare Diseases
Haley MacLeod MS, Jacob Abbott MS, Sameer Patil PhD

Too Many Conditions, Too Little Time: Designing Technological Intervention for Patients with Type-2 Diabetes and Discordant Chronic Comorbidities
Tom Ongwere, Gabrielle Cantor, Sergio Ramirez Martin, Patrick Shih, James Clawson, Kay Connelly

Turning to Bioethics to Inform the Design of Health Technologies
Amanda Lazar PhD

Understanding Informal Caregiver Needs for the Development of a Care Coordination Tool
Portia E. Singh PhD, Payaal Patel MA, Mladen Milosevic PhD
Posters

Research Highlights

Comprehensive Process Model of Clinical Information Interaction in Primary Care: Results of a “Best-Fit” Framework Synthesis
Tiffany C. Veinot MLS PhD, Charles R. Senteio MBA MSW PhD, David Hanauer
Julie C. Lowery MHSA PhD

Developing Visual Thinking in the Electronic Health Record
Andrew Boyd, Christine D. Younga, Margret Amatayakulb, Michael G Dietera
Lawrence M Pawolaa

Narratives of Older Adults with Mild Cognitive Impairment and Their Caregivers
Galina Madjaroff

Self-Tracking for Fertility Care: Collaborative Support for a Highly-Personalized Problem
Mayara C. Figueiredo MS, Clara Caldeira BS, Tera L. Reynolds MS, Sean Victory, BS
Kai Zheng PhD, Yunan Chen PhD

The Use of High Fidelity Scenario Based Mockups in Formative User Testing and Requirements Gathering for a Clinical Decision Support Intervention for Whole Exome Sequencing
J. W. Pennington, Dean J. Karavite, E. M. Krause, J. Miller, B. A. Bernhardt
R. W. Grundmeier

Understanding Exergames as an Approach to Health and Wellness Activities for Older Adults
Christina N. Harrington PhD, Wendy A Rogers PhD
WISH 2017 @ AMIA Afternoon Program

12:40 PM

**Afternoon Panel**

Cinnamon Rolls Cure Diabetes: Deception, Disinformation, and Controversy in Online Health Information

David Kaufman PhD, Catherine Arnott Smith PhD, Alla Keselman PhD, Anita Murcko, MD, FACP

01:30 PM

**Afternoon Technical Session**

Virtualizing Homes to Study Health Decisions

Catherine Smith RN PhD, Gail Casper RN, PhD, Kevin Ponto PhD

Utilizing Multi-Modal Personal Health Tracking and Health Affordances of the Built Environment

Clayton Feustel MS, Lauren Wilcox PhD

Development of a Decision Support System to Generate Data-Powered Personalized Nutrition Recommendations for Diabetes Self-Management

Marissa Burgermaster PhD, Matthew E. Levine BA, David J. Albers PhD, Jung H. Son MD, Daniel J. Feller BA, Patricia G. Davidson PhD RD, Arlene M. Smaldone PhD RN, Lena Mamykina PhD

An Enterprise Approach to Designing Patient-Reported Outcomes (PROs) Systems: Diverse Perspectives Across a Large Healthcare Organization

Elizabeth Austin MPH, Cynthia LeRouge PhD, Andrea Hartzler PhD, Danielle Lavallee PharmD PhD

William Lober MD MS

02:30 PM

**Coffee Break and Poster Viewing**

03:00 PM

**Lightning Talks: Research Highlights**

Mobile App Review for Epilepsy Self-Management

Cam Escoffery, Robin McGee, Jonathan Bidwell, Christopher Sims, Eliana Kovitch, Cherise Frazier

Elizabeth D Mynatt

Plansourcing: Generating Behavior Change Plans with Friends and Crowds

Elena Agapie, Lucas Colusso, Sean Munson, Gary Hsieh

“Move into Another World of Happy”: Insights for Designing Affect-Based Physical Activity Interventions

Sonali Mishra, Predrag Klasnja
Mobile App Review for Epilepsy Self-management

Cam Escoffery, PhD¹, Robin McGee, PhD¹, Jonathan Bidwell², Christopher Sims³, Eliana Kovitch³, Cherise Frazier³, Elizabeth D Mynatt²

¹Emory Rollins School of Public Health, Atlanta, GA; ²Georgia Institute of Technology, Atlanta, GA, ³Children’s Healthcare of Atlanta, Atlanta, GA

Research Aim

Mobile health app developers are increasingly interested in supporting the daily self-care of people with chronic conditions.

In this study, we reviewed mobile applications (apps) for epilepsy self-management (SM).

Method

We examined 149 apps from the Apple App Store in terms of

- 11 Adult Self-Management Measurement Instrument (AESMMI) SM domains
- Mobile App Rating Scale (MARS) and the
- Michie et al. Taxonomy of behavioral change strategies

Findings

- Mobile apps had low MARS ratings for user engagement and information provision.
- None of the apps provided a comprehensive coverage of all SM categories in this review.
- None of the apps provided evidence of their effectiveness or employed behavior change strategies to promote long-term engagement.

These findings highlight the need for epilepsy SM mobile apps that promote greater patient engagement, facilitate a broader coverage of SM domains and provide a more robust evaluation of behavior change strategies.
Plansourcing: Generating Behavior Change Plans with Friends and Crowds

Elena Agapie, Lucas Colusso, Sean A Munson, Gary Hsieh (garyhs@uw.edu)
Human Centered Design and Engineering, University of Washington

Research Questions
1. Can friends and crowd members generate plans that support behavior change?
2. What benefits and costs do friends offer for the creation of behavior change plans for individuals?
3. What benefits and costs do crowdworkers offer for creating behavior change plans for individuals?

Tailored Crowdsourced Recommendations

How likely is the current plan to help the person improve their physical activity level? (expert evaluation)

- Friends: 57%
- Strangers: 91%

How well would you say this plan fits with your life? (participant evaluation)

- Friends: 78%
- Strangers: 57%

Friends
+ Knows preferences, goals, routines and constraints
+ More conservative with the plans generated
+ Enables additional social interactions opportunities in the future

Strangers
+ Can infer (some) preferences, goals, routines and constraints
+ Added more diverse activities to plans; provided novelty
+ Less concerned about being judged by strangers; more disclosure

Future Work
Create systems to support behavior change with the help of others (crowds, peers, friends, experts).

This research was in part funded by NSF Grant #1348543.
We thank the Prosocial Computing Group, Daniel Epstein and Jared Bauer for their feedback on this project.
“Move into Another World of Happy”
Insights for Designing Affect-Based Physical Activity Interventions
Sonali R. Mishra
Predrag Klasnja

RESEARCH QUESTION
We know exercise leads to affective benefits (feeling good):

But how do we use those benefits to PROMOTE activity?

METHODS
158 survey responses about:

- What affective benefits people experienced from exercise
- What about the exercise made them feel that way
- How experiencing affective benefits affected their future exercise

RESULTS
- Affective benefits motivate exercise
- Individuals experience a variety of affective benefits
- Different people enjoy different aspects of physical activity
- People value sharing information about affective benefits

INSIGHTS
Affect-based physical activity interventions:
- Have potential for meaningfully impacting behavior
- Can make affective benefits more salient
- Can make activity recommendations based on what people enjoy
- Should support sharing information about affective benefits with others in ways that must still be explored
Closing Keynote

Sally Okun, RN

Sally Okun is Vice President for Advocacy, Policy and Patient Safety at PatientsLikeMe. Sally ensures the patient voice, represented in PatientsLikeMe’s member community, is heard, collected and disseminated for better treatment, services, and care. She actively participates in national and international policy discussions on the benefits of sharing health data and ensuring patient perspectives are at the forefront of health and healthcare.

Sally oversees PLM’s Research Collaboration Agreement with the FDA and the company’s role with the Participant Technology Center for the NIH All of Us Research Program. Sally joined PLM in 2008 to oversee the medical ontology, curation of patient data and development of the Drug Safety platform. She regularly participates in policy workshops and forums and has contributed to numerous peer-reviewed publications, discussion and white papers including Vital Signs, a consensus report of the National Academy of Medicine.

Her expertise is frequently sought on topics ranging from empowering patient partnerships to advancing the science of patient-generated health data. A registered nurse for over four decades, she specialized in palliative and end-of-life care. In addition to her nursing education, she completed her graduate work at Brandeis University’s Heller School for Social Policy and Management and was a NLM Fellow in Biomedical Informatics.

Closing Remarks

Suzanne Bakken PhD, RN, FAAN, FACMI, Lauren Wilcox PhD
WISH 2017 @ AMIA Committee

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