Families and Chronic Illness
Officers Club – South Conference Room
Nice to meet you!

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Areas of Interest:
• Identifying and leveraging family behaviors affecting adults’ ability to manage type 2 diabetes
• Intervening to improve family contexts in which adults manage type 2 diabetes while also seeking to prevent diabetes-related risk in other family members
Findings thus far

• Describe population & family

• **Type** mattered more than degree of family member involvement

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<tr>
<th>Independent effects of supportive and obstructive family behaviors on adherence to self-care behaviors among adults with type 2 diabetes.</th>
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<td>N=192</td>
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<td>Adherence to self-care behaviors (SDSCA)</td>
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<tr>
<td>General Diet</td>
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<td>Specific Diet</td>
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<td>Exercise</td>
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<td>SMBG</td>
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<td>Diabetes Medications</td>
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* p<.05, ** p<.01, *** p<.001. Adjusted for age, gender, race, education, diabetes duration, insulin status, & insurance status.

Unique variance explained = incremental $R^2$

Subgroups more vulnerable to obstructive behaviors:

• Limited health literacy

• Moderate-severe depressive symptoms

• High rates of socioecological stressors

• Obstructive behaviors were associated with A1C, but only in the context of low supportive behaviors (adjusted interaction effect = -.22, p<.001).
Next Steps: Develop 3 month intervention & Test for usability

At enrollment & monthly, phone counselors work with patients to identify:

- A measureable, concrete goal to improve adherence to self-care.
- On-going supportive family behaviors relevant to the identified goal.
- Supportive behaviors family members could do to aid the participant in meeting the identified goal.
- Family members’ behaviors that may sabotage or interfere with the participant’s ability to meet the goal.
- Family members’ nagging/arguing behaviors that may decrease the participant’s motivation to meet the goal.
- Strategies for the participant to ask for desired behaviors and redirect undesired behaviors.

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<th>Family-focused intervention components &amp; content examples.</th>
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<tr>
<td><strong>Component</strong></td>
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Text messages to participants & family members to support goals set during phone counseling:
Profile

Jakob D. Jensen, Ph.D.
Associate Professor, Department of Communication
Member, HCI, Cancer Control & Population Science

Health communication expert interested in interventions/campaigns designed to improve individual/family health outcomes across the lifespan. Past work has focused primarily on cancer prevention and detection (colorectal, skin, breast, prostate), but Dr. Jensen is interested in other health outcomes as well.
Colorectal Cancer Prevention/Detection

- Designed/Evaluated a worksite RCT comparing colorectal cancer screening interventions that were (a) tailored or (b) narrative. Published in Social Science & Medicine.

- Surveyed 1,000 adults nationwide to assess knowledge, attitudes, behaviors concerning low-dose aspirin as a means of colorectal cancer prevention.

- Interested in helping families identify and initiate optimal health behaviors for reducing cancer risk.
Skin Cancer Prevention/Detection

- Designed/Evaluated a series of experiments comparing skin cancer screening interventions.


- Working with rural adults to develop evidenced based strategies for managing skin cancer risk.

- Launching a project that will evaluate a skin cancer prevention intervention designed for rural/frontier Utah children aged 10 – 12.
Consortium for Families and Health Research
Health Behaviors... after Knee Replacement

Julie Fritz
Robin Marcus
Paul LaStayo

Rehab Services
Physical Activity
Knee Replacement

Department of Physical Therapy
College of Health

Consortium for Families and Health Research
Physical Inactivity, Obesity and Arthritis

Following Knee Replacement and PT/Rehabilitation

Physical activity fails to improve (or diminishes) in a surprising number of patients de Groot, 2008 and many patients continue to gain weight. Zeni, 2010
Our overall goal is to shift the prevailing knee replacement rehabilitation paradigm from a narrow focus on the surgical knee to a wellness-based (± family-based?) approach that capitalizes on the opportunity afforded by pain relief to introduce healthy lifestyle modifications (and incorporate the powerful influence of the family in sustaining effective health behaviors?) aimed at improving physical activity and weight management.

Can the family system/methods be utilized?
...to help identify and overcome barriers to the adoption, integration, and sustainability of evidence-based wellness interventions as part of rehabilitation programs designed to reduce health risks associated with {insert health condition(s) here}. 

Before

After
Exercise Research: 
Across Disciplines, 
Across Family Constellations, 
Across the Life Span

Tom Meyer, PhD
Biostatistics and Health Psychology
Past Research Areas

- Multidisciplinary Meta-Analysis of Controlled Studies of Psychosocial Interventions with Cancer Patients.
- Psychometrics: Penn State Worry Questionnaire.
- Teenage Pregnancy in Appalachia.
- Prevention of Health Problems in Latino Adolescents.
- Sociocultural Context of Household Smoking.
- PTSD and HIV Infection in Methadone Patients.
- Using Biological Examples in Physics Teaching.
Present and Future Interests

• Exploring and possibly synthesizing exercise research across disciplines (medical/ nursing/ PT, mental health, HPER, nutrition), family constellations, and the life span. Meta-analysis as appropriate?

• Issues in existing exercise research to explore/include targeting introverts vs. extraverts, financial and geographical access, developing habits vs/and special events (e.g., 5K), support during family transitions.

• Relevance of smoking reduction successes.

• Willing to work as a statistical/ methodological volunteer on a few small health or LGBT projects.
YELENA WU

DEPT. OF FAMILY & PREVENTIVE MEDICINE; HUNTSMAN CANCER INSTITUTE
PAST WORK: PEDIATRIC HEALTH

Risk and resilience factors
- Family collaboration
- Mental health (dep, anx)
- Clinician’s decision-making

Adaptation to chronic health conditions
- Adherence
- Interventions

Health outcomes
- HbA1C
- Seizures
CURRENT WORK:
Adherence to medical recommendations across the cancer control continuum

Prevention
- BRIGHT Kids (p16 carriers, melanoma)
- SPARK: Melanoma prevention behavioral intervention

Cancer treatment
- SoMO: Social media use parents of pediatric cancer patients
- A/YA Smartphone Medication Reminder

Survivorship
- CASH: A/YA health behavior intervention preferences
- Care planning (Kirchhoff)
- Social support and medical appointment follow-up (CCSS)
FUTURE DIRECTIONS & COLLABORATIONS

- Adherence and self-management promotion interventions targeted towards individuals at risk for illness or have illness
  - Behavioral interventions
  - Family-focused interventions
  - Healthcare provider interventions
- Tailoring of risk communication strategies to children across developmental levels
- Adherence measurement
- Survey methods, design
- Family management of illness
Maija Reblin, PhD
Research Assistant Professor, College of Nursing
HCI Investigator
Health Psychologist: Relationship Quality & Health

Relationship quality in 2 dimensions (Uchino et al, 2001)
Program of Research

• How does advanced cancer caregivers’ social context impact their health?
  – Identify relationship and communication characteristics associated with increased advanced cancer caregiver psychological and physical stress
    • Use this information to target at-risk individuals or couples for intervention

• Ongoing Research
  – Focus on *spouse/partner* in American Cancer Society Mentored Research Scholar Award
  – Focus on *broader social network* in pilot work with neuro-oncology caregivers
Exciting Results

• Relationship quality categories are associated with different communication patterns
  – Reblin, Uchino & Smith, 2010

• Relationship quality categories in hospice spouse/partner caregivers are consistent with proportions seen across lifespan & in non-caregiving samples

• At enrollment to home hospice, RQ is related to cg burden
  – Reblin et al, under review
Internet Mediated Social Support

Jude P. Mikal
Research Assistant Professor, Psychology Dept.
Research Development Consultant, CSBS
Internet Mediated Social Support (IMSS)

Background:

- Early research on IMSS conceived of as superficial due to (1) limited emotional and social cues, (2) inability to communicate material support, (3) absence of physical presence.
- Early research conceptualized support networks as (1) inferior, (2) weaker, (3) less sustainable, and (4) more easily exitable.
- Individuals relying on IMSS were characterized as (1) socially reclusive and anxious, (2) having difficulties in FTF communication, (3) at increased risk for depression, anxiety and social isolation.
- Theoretical limitations, along with the widespread use and availability of Internet technology has shifted research ideologies, and later research associated an active online social life with a more active social life offline.
- Advantages of Social Support Communicated Online: (1) rapid reestablishment of new communities of support, (2) increased congruence with support needs, (3) diminished geographic and other barriers to communication, (3) increased control and increased privacy, and (4) reduced social obligation.
- Nevertheless, few contemporary studies conceive of social support networks as being maintained exclusively on, or offline, and most researchers acknowledge a fluidity between relationships maintained on and offline.
Internet Mediated Social Support (IMSS)

Past Research

- Mikal, et al (2013) models the role of Internet technology in responding changes to support needs: Following a transition, when individuals’ offline networks of support are in a state of flux, those individuals may benefit from the constancy and control of interacting online.

- Mikal, et al (2014 & in press) examines the possibility that specific sites become characterized by a “cultural identity” and that this can result in behavioral modification by individual members.

Future Research

- Can an effective support system created and maintained online buttress waning partner support during chronic illness?

- Alongside participation in synthetic, disease-specific environments, how does participation in online social environments change over time in response to transitions in health status?

- What is the perceived quality of support exchanged online? And does the quality of support change based on a sites “culture” – and an individual’s ability to fit within that culture?

- Population: Young Adults; Outcomes: Valence, RSA, Self-Reports
Consortium for Families and Health Research
Psychosocial Risk for Cardiovascular Disease:

Close Relationships as a Key Context

Timothy W. Smith
Department of Psychology
Marital Interaction and Atherosclerosis

Smith, Uchino, Berg et al. (2011). *Psychosomatic Medicine*
Individual Risk Factors for CHD are Related to Marital Processes

Smith, Uchino, Bosch, & Kent (2014) *Biological Psychology*

Caska, Smith, Renshaw, Allen, Uchino et al. (in press) *Health Psychology*
Dyadic Transactional Cycle and Coronary Risk Risk

Partner 1

**Covert Experience**
- appraisals
- representations
- expectations
- beliefs
- affect
- goals
- regulation

**Overt Behavior**
- affiliation
- control

Partner 2

**Overt Behavior**
- affiliation
- control

**Covert Experience**
- appraisals
- representations
- expectations
- beliefs
- affect
- goals
- regulation

**Physiological Mechanisms**
- CVR
- inflammation
- MetS
- hf-HRV

Atherosclerosis
- initiation
- progression

Acute CHD Events

Couple Psychosocial Context

**Physiological Mechanisms**
- CVR
- inflammation
- MetS
- hf-HRV

Atherosclerosis
- initiation
- progression

Acute CHD Events
Past Research on Children’s Socioemotional Well-Being & Family Relationship Quality and Interaction

Current Research: Strength-based, family-focused educational programming for youth on the autism spectrum

Reframing the child’s disability in 3 domains (Diener, Anderson et al., 2014; Diener, Wright et al., 2014; Diener, Dunn et al., 2014)
Children’s distress during hospitalization and IV insertion

- Use of treatment rooms to create psychological “safe space”
- Child life specialist role and strategies
- Child emotion regulation strategies
Child outcomes related to chronic health conditions, health disparities, reproductive technologies
- Infancy = difficult temperament, attachment security,
- Toddler/Preschooler = emotion regulation, emergent literacy skills
- Middle childhood = social and peer competence; academic competence; self-efficacy and self-esteem;
- Adolescence = social engagement; self-esteem

Processes involved in health outcomes – individual differences and mediators
- Parent-child interaction, marital conflict
- Coping, beliefs about emotional expression and emotion regulation
- Parenting stress, parent personality, social support

Indirect costs of health policies, chronic diseases
- E.g., parenting stress and CMV testing RO1 with Zick & Park
Intersections of Family & Organizational Systems

• Heather E. Canary, PhD
  – Associate Professor, Dept. of Communication
  – C-FAHR Executive Committee
  – Utah Center for Excellence in ELSI Research

• Communication Processes Within & Between:
  – Families of children with disabilities
  – Families with increased disease risk
  – Health organizations
  – Other relevant organizations

• Methodological Approaches:
  – Qualitative: Interviews, Observations
  – Quantitative: Surveys, Coding Systems
Current Projects

• Families of Children with Autism
  – With Dan Canary (U of U) & Danielle Jackson (Manchester U)
  – Decision-making for child treatment, education, etc.
  – Marital satisfaction and relational equity
  – Marital conflict and attributions

• Hospital Discharge Communication
  – With Victoria Wilkins & Paul Young (PCH)
  – Discharge experiences of parents, hospitalists, PCPs

• Colon Cancer Screening Interactions
  – With Anita Kinney (U of New Mexico)
  – Screening intervention conversations with people at increased risk for CRC; 9-month outcome data
  – Developing & applying new coding system, Resource-based Interaction Coding System
Common Theme in Findings

• Role of Missed or Negative Intersections
  – Family & Professional System Intersections Important to Family Processes & Outcomes
  – Families of Children with Autism:
    • Intersections with medical, education, & support systems frustrating, dismissal, often leading to adversarial attitudes
  – Hospital Discharge Communication:
    • “Care chasm” characterized by lack of connections between hospital care, primary providers, and home care; parents have clear ideas about what intersections would help
  – Colon Cancer Screening Interactions:
    • More references to positive intersections by completers than non-completers
    • Fewer references to ineffective/negative Intersections by completers than non-completers