ADVANCED CANCER AT HOME

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Stress: A Health Trade-off

- Sympathetic activation (fight/flight)
- Adaptive in short term
- Wear & tear over time

http://www.hakeem-sy.com/main/node/39518
• Physical Stress → Psychological Stress

• Psychological stress also activates sympathetic system

• Body’s response to psychological stress may not be metabolically appropriate: no short-term benefit, but long-term consequences
Cancer Caregiving is Physically and Psychologically Stressful

- Average 32.9 hours/week providing care
- More care tasks than non-cancer caregivers
  - Personal care, mobility, household activities
  - 72% assist with medical/nursing tasks (e.g. catheter care)
- Complex emotions: Fear, guilt, grief…
- Overwhelmed & underprepared

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Cancer Caregiving in the US, 2016; Health Affairs, 2017
Caregiving Impacts Health

- High caregiver burden/stress is related to worse caregiver health and worse patient outcomes

(Bevans & Sternberg, 2012; Pinquart & Sorensen, 2003; Adelman et al, 2014)
Social Support Can Help

- Having supportive people in your life can help you better cope with stress and reduce its physiological impact (Cohen & Wills, 1985)

- When we have support under stress, instead of threats, we see challenges
Low social support has about the same health risk as smoking 15 cigarettes/day and twice the health risk as being obese.
Communication and Relationship Quality are Intertwined

- Relationship quality is necessarily defined by the nature of communication (Montgomery, 1988)
- Relationship Intimacy Model of Couple Adaptation to Cancer (Manne & Badr, 2008) *cancer/relationship talk*

**Relationship-Enhancing Behaviors**
- Reciprocal self-disclosure
- Partner responsiveness
- Relationship engagement

**Relationship-Compromising Behaviors**
- Avoidance
- Criticism
- Pressure-withdraw

**Couples’ Relationship Intimacy**

**Couples’ Relationship and Psychological Adaptation**
Beyond Caregiver-Patient

• High quality relationships and effective communication are also important to establish with providers for family-centered care
  • “Working with patients and families, rather than just doing to/for them.” [http://www.ipfcc.org/about/pfcc.html](http://www.ipfcc.org/about/pfcc.html)

• Key tenets
  • Respect/Dignity—listening to/honoring family perspectives
  • Information Sharing—providing timely, complete, and accurate information
  • Participation—encouraging and supporting participation in care and decision-making to desired level
  • Collaboration— in policy and program development, research, education, and delivery of care
Research Question: Observation

What does communication look like for advanced cancer family caregivers?
Research at end of life

- Home hospice for cancer patients
  - Palliative care (focused on QOL) in last 6 months of life
  - Family provides 24/7 care, supported by nurse-led interdisciplinary team
  - Very little research on communication in this context
    - Program Project Grant NCI P01CA138317; PI Mooney/PL Ellington
Nurse-Caregiver Communication Study

- Observational, longitudinal study: enrollment in home hospice until patient death
- Multi-site study
  - 10 participating hospices in Boston and SLC
- Eligible participants
  - Hospice nurses
  - CGs
  - Home-based hospice cancer pt age > 45
- Data collection for home visits
  - Nurses wore digital recorders around their necks
  - Captured conversations in natural context

NCI P01CA138317; PI Mooney/PL Ellington
Reblin et al, Health Comm 2016
Sample Characteristics

- **Caregiver Patient Dyads**
  - Mean age = 66 (SD=10.2) (PT mean age =68)
  - 60% female caregivers
  - Most analyses: Spouses--35 years in relationship on average

- **Nurse**
  - Mean age = 42 (SD=14.6)
  - 92% female
  - 4.5 years as a hospice nurse; 14 years as RN on average
  - 68% had an Associates Degree or higher

- **Visit**
  - Visit length 40 minutes (SD=20.7; Range= 5-114 minutes)
  - Average 5 visits/patient (range coded: 1-10; range all 1-60+)
### Roter Interaction Analysis System:

<table>
<thead>
<tr>
<th>CODES</th>
<th>EXAMPLES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PHYSICAL CARE</strong></td>
<td></td>
</tr>
<tr>
<td>Information</td>
<td>I gave her 2 pills this morning.</td>
</tr>
<tr>
<td>Questions</td>
<td>How long has he been having this pain?</td>
</tr>
<tr>
<td>Partnering (nurse only)</td>
<td>What do you think this means? What I’ll do next is check out that bandage… Is this clear?</td>
</tr>
<tr>
<td><strong>LIFESTYLE/PSYCHOSOCIAL</strong></td>
<td></td>
</tr>
<tr>
<td>Information</td>
<td>I’ve been working out in the yard most days</td>
</tr>
<tr>
<td>Questions</td>
<td>Is your family coping okay for now?</td>
</tr>
<tr>
<td><strong>EMOTION</strong></td>
<td></td>
</tr>
<tr>
<td>Distress and Concern (PT/CG only)</td>
<td>I just can’t stand to see my wife in pain</td>
</tr>
<tr>
<td>Positive Affect Statements</td>
<td>Of course I love to talk about pooping, ha! You look wonderful today!</td>
</tr>
<tr>
<td>Emotional Response</td>
<td>I know it’s tough sometimes It’s ok for you to feel that way.</td>
</tr>
</tbody>
</table>
Mean Proportions of Total Visit Talk
101 cases (537 visits)

Caregiver: 27% Total Talk
- Physical Care
- Lifestyle/Psychosocial
- Positive Emotion
- Distress
- Emotional Response

Patient: 17% Total Talk
- Physical Care
- Lifestyle/Psychosocial
- Positive Emotion
- Distress

Nurse: 56% Total Talk
- Physical Care
- Lifestyle/Psychosocial
- Positive Emotion
- Emotional Response

Ellington et al, PEC 2018
Emotional deep dive: Distress

- Focus on caregiver and patient distress statements to determine:
  - What are caregivers and patients most concerned about?
  - What nurse communication strategies elicit expression of distress?
  - How do nurses respond to expressions of distress?
Methods

• Analyzed a subset of 31 visits
  • Identify caregiver/patient distress statements (n=268)
    • Qualitatively code distress statement into domain of care
  • Identify coded nurse statements that fall before and after distress statement
What is distressing?

- Caregivers and patients have at least one expression of distress per visit, usually addressing physical or psychological areas.
Nurse elicitation/response to distress

- Nurse statements with higher relative frequency (compared to whole visit)
  - Before pt/cg distress:
    - Emotional response (e.g. reassurance/validation)
    - Positive emotion
  - After pt/cg distress:
    - Emotional response
    - Physical question

### Table 1. Mean Frequencies and Relative Proportions of Nurse Communication Codes

<table>
<thead>
<tr>
<th>Code</th>
<th>Preconcern Nurse Speech</th>
<th>Postconcern Nurse Speech</th>
<th>Total Nurse Speech</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Relative Proportion</td>
<td>Frequency</td>
</tr>
<tr>
<td></td>
<td>X, SD</td>
<td>RP, SD</td>
<td>X, SD</td>
</tr>
<tr>
<td>Emotional response</td>
<td>1.03, 1.22</td>
<td>0.13*, 0.21</td>
<td>1.45, 2.08</td>
</tr>
<tr>
<td>Partnering</td>
<td>1.9, 2.15</td>
<td>0.2, 0.17</td>
<td>1.81, 2.12</td>
</tr>
<tr>
<td>Physical information</td>
<td>1.93, 2.02</td>
<td>0.2, 0.23</td>
<td>1.87, 2.01</td>
</tr>
<tr>
<td>Physical questions</td>
<td>0.68, 1.22</td>
<td>0.09, 0.18</td>
<td>0.71, 0.97</td>
</tr>
<tr>
<td>Positive emotion</td>
<td>1.68, 2.27</td>
<td>0.13*, 0.14</td>
<td>1.83, 2.31</td>
</tr>
<tr>
<td>Psychosocial or lifestyle information</td>
<td>2.26, 2.99</td>
<td>0.22, 0.26</td>
<td>2.42, 3.24</td>
</tr>
<tr>
<td>Psychosocial or lifestyle questions</td>
<td>0.61, 1.2</td>
<td>0.04, 0.04</td>
<td>0.61, 1.23</td>
</tr>
<tr>
<td>Total hospice nurse utterances</td>
<td>9.68, 9.91</td>
<td>--</td>
<td>10.33, 9.28</td>
</tr>
</tbody>
</table>

* p ≥ 0.1
RP — relative proportion

Note: RP is the mean frequency of a particular nurse communication code divided by the total number of nurse utterances in the section of interest.
Findings

• Patients and caregivers most frequently communicate distress to nurses about psychological or physical domains of care
  • Nurses may acknowledge psychological through emotional response and follow up physical by asking questions to address the concern

• Emotion begets emotion: nurse positive emotion or emotional response
  • Nurses may need to open the door to emotional disclosure through trust, relationship building
  • Normalization; may be easier with positive emotion
Emotional deep dive: Positivity

• Limited empirical research on caregiver positive emotions suggests it may be associated with improved well-being and health during care and into bereavement

• Broaden-and Build Theory (Fredrickson)
  • Positive emotions broaden an individual’s thought-action repertoire and thereby build physical, intellectual, and social resources.
    • Serves adaptive function
    • May undo effects of negative emotion and enhance recovery from stress
    • When shared, positive emotions create mutual enjoyment and social bonds

• Little is known about positive emotion expression or the role it plays at end-of life caregiving
Methods

- Use a subsample of coded visits to identify positive emotion talk and classify into different constructs
- 4 visits from 20 patient-caregiver-nurse triads (n=80)
## Constructs of Positive Emotion

<table>
<thead>
<tr>
<th>Construct</th>
<th>Definition</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connection</td>
<td>Fostering relationships, reassurance, endearment, affection</td>
<td>“You’ll be in my thoughts and prayers”</td>
</tr>
<tr>
<td>Savor/ Take Joy</td>
<td>Taking delight in life’s momentary pleasures and wonders. Being open to finding beauty, relishing ordinary experiences, and savoring those experiences with others.</td>
<td>“How beautiful the day is”</td>
</tr>
<tr>
<td>Gratitude</td>
<td>Counting blessings, appreciation of life circumstances and gratitude towards persons (thanking someone)</td>
<td>“I’m so glad to be home with my family”</td>
</tr>
<tr>
<td>Praise and Affirmation</td>
<td>Praising someone, providing support and affirmation (for the good work they’re doing); positive reinforcement</td>
<td>“You’re doing a 300% fantastic job”</td>
</tr>
<tr>
<td>Positive Focus</td>
<td>Optimism, encouraging others to focus on the positive</td>
<td>“He’s quieter, but think about how much more comfortable he looks compared to last week”</td>
</tr>
<tr>
<td>Humor</td>
<td>Joking, trying to be funny. Includes nervous humor, dark humor, funny stories, etc.</td>
<td>“When I was on the phone it sounded like goose honk”</td>
</tr>
</tbody>
</table>
Communication Results for Expression of Positive Emotions

- Humor: 26%
- Other (perfunctory): 20%
- Praise/Affirmation: 18%
- Gratitude: 11%
- Connection: 9%
- Savor/Take Joy: 9%
- Positive Focus: 7%
Proportion of Positive Emotion Talk by Speaker

<table>
<thead>
<tr>
<th>Speaker</th>
<th>Other (perfunctory)</th>
<th>Savor/Take Joy</th>
<th>Praise/Affirmation</th>
<th>Positive Focus</th>
<th>Humor</th>
<th>Gratitude</th>
<th>Connection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver</td>
<td>19.4%</td>
<td>12.8%</td>
<td>8.9%</td>
<td>4.8%</td>
<td>29.8%</td>
<td>12.4%</td>
<td>12.0%</td>
</tr>
<tr>
<td>Nurse</td>
<td>21.8%</td>
<td>6.7%</td>
<td>23.7%</td>
<td>9.2%</td>
<td>21.4%</td>
<td>8.8%</td>
<td>8.5%</td>
</tr>
<tr>
<td>Patient</td>
<td>18.7%</td>
<td>12.2%</td>
<td>10.1%</td>
<td>6.5%</td>
<td>35.5%</td>
<td>10.6%</td>
<td>6.5%</td>
</tr>
</tbody>
</table>

- **Total**
  - Caregiver: 25.6%
  - Nurse: 60.5%
  - Patient: 13.9%
Discussion

- Nurses make the majority of positive emotion statements, mostly praise and affirmation, followed by humor
  - Set the tone/normalize the act of dying
  - Help caregiver self-efficacy
  - Relationship-building

- Caregiver and patient most commonly express humor, followed by savor/take joy
  - Often dark humor; may divert from deeper emotions?
  - Notice and revel often in the simplicity of life—focus on priorities
Implications

• Positive emotion does happen in hospice, including humor and joking
  • Might be important to open the door to distress communication

• Need to understand the role of humor specifically
  • Adaptive or maladaptive coping?

• Opportunity to build on savoring small moments
  • Mindfulness?

• But so what??
How is emotion talk associated with outcomes into bereavement?

- Depression is common in short-term bereavement
- Emotion expression is linked to improved psychological outcomes in other populations
- Nurse emotional expression may be a key element of effective communication
  - Signal support, allows nurse to meet family needs

Reblin et al, under review
Methods

- **Caregiver questionnaire data**
  - Enrollment in hospice, 2, 6 and 12 months after patient death
  - Geriatric Depression Scale
  - HADS Anxiety Scale

- **Caregiver and Nurse coded communication data**
  - Positive emotion (CG & Nurse)
  - Distress (CG)
  - Emotional response (Nurse)

- **Multilevel modeling**
  - Communication predicting depression (controlling for anxiety) over time
Depression and anxiety over time

- Caregivers had moderate levels of depression and anxiety at study enrollment and throughout bereavement.
Communication effects

• No impact of caregiver distress on depression in bereavement
  • Distress is normative?
• Nurse emotional response associated with higher depression at enrollment
  • Nurses may be reacting to more depressed caregivers
  • No change over time
Communication effects

• Caregiver positive emotion communication associated with higher caregiver depression in bereavement
  • But at individual time points when anxiety is also low, positive emotion is associated with lower depression
  • Effect may depend on HOW positive emotion is used
    • Not powered to assess humor vs savor/take joy
    • Is positive emotion an adaptive coping strategy?
      • Processing emotion versus distracting
Stepping back: Emotion

- A lot of exploration into the emotional expression involved in nurse-caregiver-patient interactions
  - Much more than typical found in clinic-based interactions
  - Variety of emotion: distress and positivity
  - Emotional context of hospice care may have important impact on caregivers over time
- Still have a sticking point: the FAMILY context
Patients OR Caregivers

- Patients and Caregivers communicate together with the nurse in only 17% of nurse visits; Missing an important context

**Table 3: Visit Communication Patterns**

<table>
<thead>
<tr>
<th>Low distress Patient N = 109; 20% (Cluster 5)</th>
<th>Caregiver N = 124; 23% (Cluster 1)</th>
<th>Dyad N = 39; 11% (Cluster 6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient LifeStyle/psychosocial information</td>
<td>Patient Low talk</td>
<td>Patient LifeStyle/psychosocial information</td>
</tr>
<tr>
<td>Patient Physical care Information</td>
<td>Patient LifeStyle/psychosocial questions</td>
<td>Patient Emotional response</td>
</tr>
<tr>
<td>Patient Physical care questions</td>
<td>Patient Physical care information</td>
<td>Patient Positive emotion</td>
</tr>
<tr>
<td>Patient Positive emotion</td>
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<td>Patient Positive emotion</td>
</tr>
<tr>
<td>Caregiver Low talk</td>
<td>Caregiver Physical care information</td>
<td>Caregiver Emotional response</td>
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<tr>
<td>Caregiver LifeStyle/psychosocial questions</td>
<td>Caregiver Distress</td>
<td>Caregiver Emotional response</td>
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<td>Caregiver Distress</td>
<td>Caregiver Emotional response</td>
</tr>
<tr>
<td>Caregiver Positive emotion</td>
<td>Caregiver Distress</td>
<td>Caregiver Emotional response</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>High distress Patient N = 64; 12% (Cluster 6)</th>
<th>Caregiver N = 149; 28% (Cluster 2)</th>
<th>Dyad N = 32; 6% (Cluster 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Distress Emotion response</td>
<td>Patient Low talk</td>
<td>Patient Distress</td>
</tr>
<tr>
<td>Patient Physical care Information</td>
<td>Patient Low talk</td>
<td>Patient Emotional response</td>
</tr>
<tr>
<td>Patient Physical care questions</td>
<td>Patient Physical care information</td>
<td>Patient Positive emotion</td>
</tr>
<tr>
<td>Patient Positive emotion</td>
<td>Patient Physical care information</td>
<td>Patient Positive emotion</td>
</tr>
<tr>
<td>Caregiver Low talk</td>
<td>Caregiver Physical care information</td>
<td>Caregiver Emotional response</td>
</tr>
<tr>
<td>Caregiver Distress</td>
<td>Caregiver Distress</td>
<td>Caregiver Emotional response</td>
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<tr>
<td>Caregiver Emotional response</td>
<td>Caregiver Emotional response</td>
<td>Caregiver Emotional response</td>
</tr>
<tr>
<td>Caregiver Positive emotion</td>
<td>Caregiver Emotional response</td>
<td>Caregiver Emotional response</td>
</tr>
<tr>
<td>Caregiver Partnering</td>
<td>Caregiver Partnering</td>
<td>Caregiver Emotional response</td>
</tr>
</tbody>
</table>

Reblin, Clayton, Xu, Hulett, Latimer, Donaldson & Ellington; Psycho-Oncology, 2017
Communication at Home

- How do couples cope with cancer in real life?


ACS MRSG 13-234-01-PCSM PI Reblin
“Everyday” Communication

• Everyday communication
  • Provides a context/baseline for all other communication
  • May inform interventions: where are couples starting and what strengths can we build on?
• Little knowledge about how much couples actually talk in “real life” and about what
  • Especially couples coping with advanced cancer
  • Most research is self-report or analogue
• Invited manuscript (in press)
  • Innovations and Real World Applications in Relationship Research in Cancer, *Journal of Psychosocial Oncology*
Participants

• Patients and caregivers recruited from thoracic and gastrointestinal (GI) clinics
  • Age 18+, English-speaking/writing

• Patient eligibility criteria:
  • Stage III or IV Non-small cell lung or GI cancer
  • KPS score 70+
  • Prognosis > 6 months
  • Undergoing active treatment at Moffitt

• Caregivers were cohabitating spouses who self-identified as providing some care
Naturalistic ambulatory study

- Recording continuous CG-PT communication & CG ABP during waking hours
  - On “a day when you plan to be home together”
  - Mid-morning to bedtime

Reblin, Heyman, Ellington, Baucom, Georgiou & Vadaparampil; PEC, 2018
## Procedure: Data collection

<table>
<thead>
<tr>
<th>Task</th>
<th>Pre-task</th>
<th>Analogue: Baseline</th>
<th>Post-Baseline</th>
<th>Analogue: Cancer</th>
<th>Post-Structured</th>
<th>Free task</th>
<th>Debriefing &amp; Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Time</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within 2 hours of waking</td>
<td>10 min</td>
<td></td>
<td>10 min</td>
<td></td>
<td></td>
<td>12 hrs+ Until bed</td>
<td>Next morning</td>
</tr>
<tr>
<td><strong>Measure</strong></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- SRI</td>
<td></td>
<td>-Audio (RMICS)</td>
<td>-Post task qs</td>
<td>-Audio (RMICS)</td>
<td>-Audio (TT/TA)</td>
<td>-Materials collection &amp; verification</td>
<td></td>
</tr>
<tr>
<td>- BMI</td>
<td></td>
<td>-ABP (2 mins)</td>
<td></td>
<td>-ABP (2 mins)</td>
<td>-ABP (20 mins)</td>
<td>-Brief CG interview</td>
<td></td>
</tr>
<tr>
<td>- ABP calibration</td>
<td></td>
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</tr>
</tbody>
</table>

**Questionnaires:** e.g. Demographics, Relationship Quality, Cancer Concerns, Burden

**Analogue:** Cancer Stress

**Naturalistic:** “Day in the Life”
Coding

• Day-long audio recordings reviewed by coders to identify & categorize communication (Intimacy Model)
  • Relationship
    • Feelings about each other, positive/negative; relationship history; kissing
  • Cancer
    • Treatment; medication; feelings about cancer; symptom talk; appointments; what happens next
  • Other
    • Anything else with at least 3 exchanges (e.g. p:c:p) or >90 seconds: chit-chat; household tasks
  • Conversations broken by 30+ seconds of silence
• 20% Double-coded. Reliability >85%
## Communication Domains

<table>
<thead>
<tr>
<th>Domain</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship</strong></td>
<td>“I love you”  \n“Why do you have to argue with me all the time?”  \n“You always sound like you don't care.”  \n“Do you remember the first time we met?”  \n“No honey, I didn’t notice that. You are the only person I pay attention to.”  \n“I just wanted to let you know that I am so grateful for you.”</td>
</tr>
<tr>
<td><strong>Cancer</strong></td>
<td>“My brain is being cooked with radiation.”  \n“When was the last time I took my pain medication? Oh, an hour ago.”  \n“I'd rather have the pain than take those pills. I can’t stand being groggy”  \n“You’re always wiped out after a treatment day. We shouldn’t plan anything.”  \n“I'm going to be stuck at the clinic all day tomorrow.”  \n“My last visit to the clinic was very excellent. They always treat me well there.”  \n“When my mother had cancer, she didn't have the same symptoms as you.”</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>“What do you feel like for dinner?”  \n“Anything but leftovers!”  \n“I thought you liked leftovers?”  \n“Did you hear what happened to the neighbor’s dog?”  \n“No, what?”  \n“It escaped out the back gate and went on an adventure…”  \n“Can you help me move this table?”  \n“Where do you want to move it?”  \n“Just over so I can clean.”</td>
</tr>
</tbody>
</table>
Results: Demographics

• 83 heterosexual couples
  • Mostly Caucasian (93% of patients; 90% of caregivers)
  • Patients more likely to be male (71%) and older than caregivers (66.8 vs. 64.8 years)
  • Couples together for 35 years on average
## Psychosocial Questionnaires

<table>
<thead>
<tr>
<th></th>
<th>Patient</th>
<th>Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Anxiety (HADS; max=14)</strong></td>
<td>M=5 (SD=3.5)</td>
<td>M=8 (SD=4.5)</td>
</tr>
<tr>
<td><strong>Depression (HADS; max=14)</strong></td>
<td>M=5 (SD=3.0)</td>
<td>M=5 (SD=3.5)</td>
</tr>
<tr>
<td><strong>Relationship Satisfaction</strong></td>
<td>M=20 (SD=9.0)</td>
<td>M=20 (SD=16)</td>
</tr>
<tr>
<td>(CSI; max=24)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Objective burden</strong></td>
<td>--</td>
<td>M=22 (SD=4.0)</td>
</tr>
<tr>
<td>(max=30/”high”=23)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Stress burden</strong></td>
<td>--</td>
<td>M=14 (SD=2.5)</td>
</tr>
<tr>
<td>(max=20/”high”=13.5)**</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Demand burden</strong></td>
<td>--</td>
<td>M=12 (SD=3.0)</td>
</tr>
<tr>
<td>(max=20/”high”=15)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Top cancer concerns (Self-report)

<table>
<thead>
<tr>
<th>Patient</th>
<th>Patient Concerns</th>
<th>Caregiver</th>
<th>Caregiver Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of energy</td>
<td>22% severe</td>
<td>Worry about cancer</td>
<td>26% severe</td>
</tr>
<tr>
<td></td>
<td>61% somewhat</td>
<td></td>
<td>60% somewhat</td>
</tr>
<tr>
<td>Difficulty doing physical activity</td>
<td>15% severe</td>
<td>Lack of energy</td>
<td>14% severe</td>
</tr>
<tr>
<td></td>
<td>56% somewhat</td>
<td></td>
<td>62% somewhat</td>
</tr>
<tr>
<td>Not feeling sexually attractive/less sex</td>
<td>15% severe</td>
<td>Feeling overwhelmed</td>
<td>13% severe</td>
</tr>
<tr>
<td></td>
<td>52% somewhat</td>
<td></td>
<td>56% somewhat</td>
</tr>
<tr>
<td>Worry about cancer</td>
<td>14% severe</td>
<td>Difficulty sleeping</td>
<td>24% severe</td>
</tr>
<tr>
<td></td>
<td>48% somewhat</td>
<td></td>
<td>42% somewhat</td>
</tr>
<tr>
<td>Pain</td>
<td>14% severe</td>
<td>Difficulty talking with partner about EOL</td>
<td>19% severe</td>
</tr>
<tr>
<td></td>
<td>39% somewhat</td>
<td></td>
<td>43% somewhat</td>
</tr>
</tbody>
</table>

All participants reported at least 1 “severe” concern. Caregivers listed more “severe” concerns than patients. Low dyadic concordance.

Martinez, et al, under review.
Results: Observation

- **Audio-recorded Communication**
  - Median length of recording: 9.78 hours (range=1.35–16.0 hours)
  - Median total talk: 1.47 hours (range=3.37 minutes–6.56 hours)
  - Median 35.75 unique conversations between caregivers and patients (range=1–97)
    - Median 7.23 minutes each (range=9.31 seconds to 56.16 minutes)
Results

• Cancer talk: median 1.46 minutes
  • Range= 0-41.20 minutes
  • 22% couples: no talk
  • Median 2 discussions
Results

- **Cancer talk:** median 1.46 minutes
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  - 22% couples: no talk
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- **Relationship talk:** median 30 seconds
  - Range 0-19.87 minutes
  - 54% couples: no talk
  - Median 1 discussion
Results

• Cancer talk: median 1.46 minutes
  • Range = 0-41.20 minutes
  • 22% couples: no talk
  • Median 2 discussions

• Relationship talk: median 30 seconds
  • Range 0-19.87 minutes
  • 54% couples: no talk
  • Median 1 discussion

• Other talk: median 87.5 minutes
  • Range 3.37-338.28 minutes
  • Median 32 discussions
Results

- No difference between patients & caregivers (ps>.73)
- No significant relationship between amount of total observed communication and demographic/health factors (ps>.11)
Results

• Higher patient (but not cg) perceived relationship satisfaction predicts more time talking about cancer (p<.05)
• More perceived caregiver burden predicts less time talking about the relationship (p<.005)
Discussion

• Majority of communication outside of cancer and relationship domains
  • Routine aspects of daily life continue
  • May be due to timing in cancer/relationship trajectories

• Significant amount of variability
  • Context
  • Communication style
Discussion

• Relationships and cancer are tied together
  • Many top “cancer” concerns are relationship-focused
    • Sex, communication
• Patient relationship satisfaction sets “safe” context for cancer talk?
• Caregiver burden lowers bandwidth for relationship talk?
Limitations/Next Steps

- Mostly verbal communication
  - Non-verbal may be more meaningful?
- Capture what couples discuss, not how
  - Analysis underway
    - Traditional human coders
    - Behavioral Signal Processing/Acoustic Analysis
- Not yet linked to well-being
  - Analysis underway
    - Patient and Caregiver well-being
    - Caregiver cardiovascular health
    - Patient mortality
Implications

• Need to identify “right” amount of communication
  • May depend on the couple?
  • May depend on stage?
• Intimacy model built on cancer and relationship domain talk—more research to identify if framework holds for “other” talk
• Interventions may need to cue communication if it doesn’t naturally occur for some couples
Missed opportunities

• Many patients in our sample are at EOL
  • Planning, benefit-finding, meaning-making are beneficial for caregiver bereavement outcomes

• Could we encourage meaningful discussions and promote more use of positive emotions?
  • “Building blocks” of resilience
  • Some couples already go positive as a means to discuss stressful topics
Future Plans for Intervention Research

- Identify critical periods for family caregivers and provide psychological tools
  - Facilitating Communication
    - Caregiver-Patient-Provider-Social Network
  - Reframing
    - Focus on opportunities/positive aspects
  - Building on Existing Sources of Strength
    - Relationships & support
- Cancer and beyond
Thank you!

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Extra Thanks: Research Participants
Questions?