


ADVANCED CANCER AT HOME

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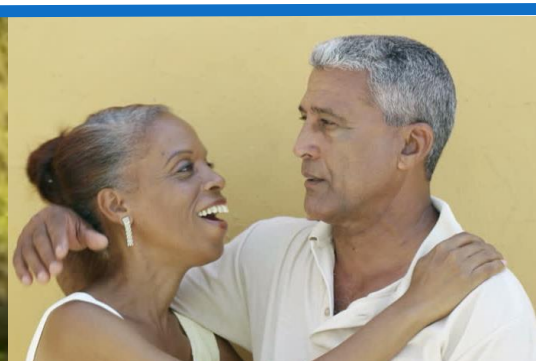
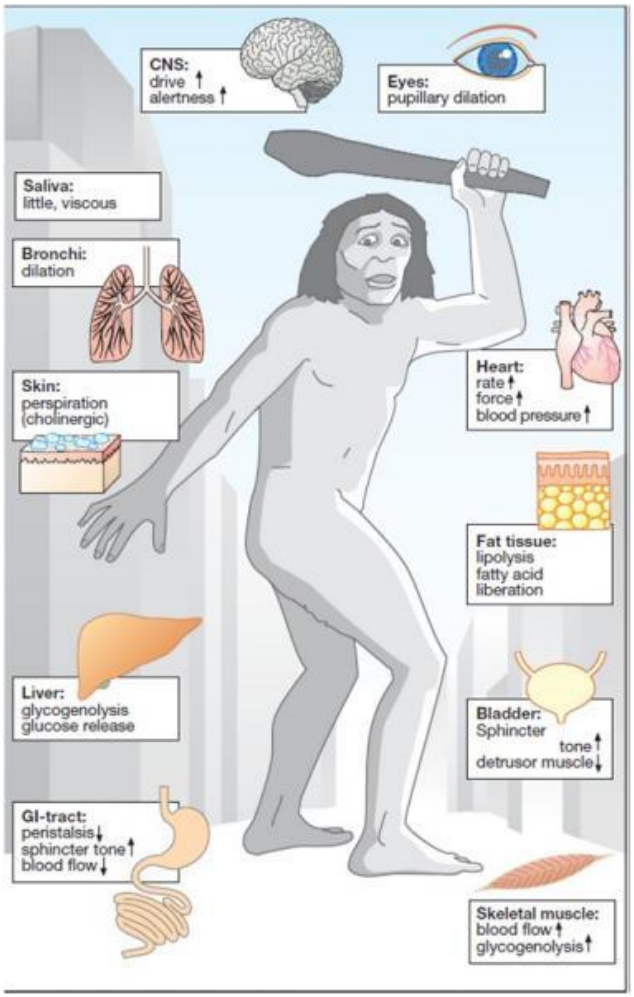
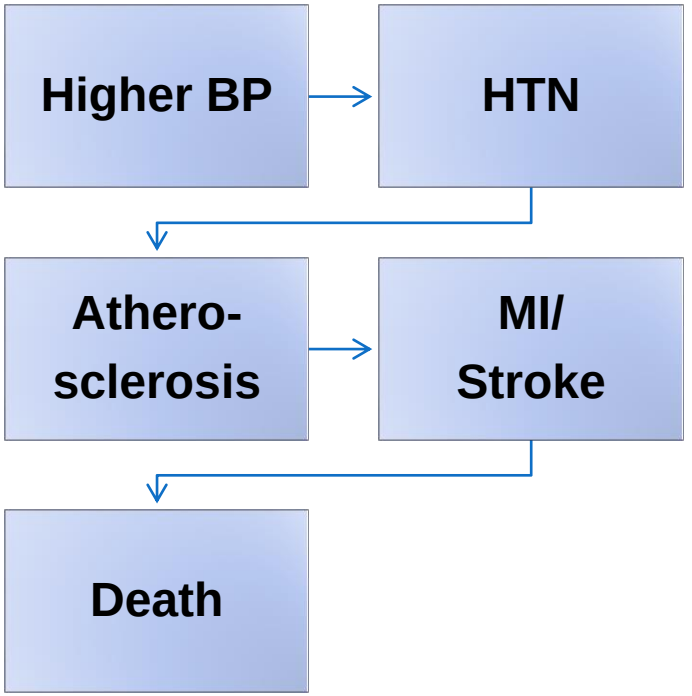


Stress: A Health Trade-off



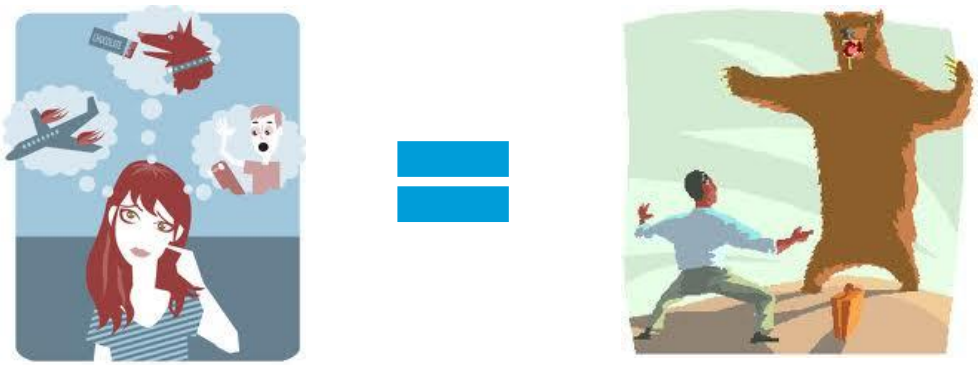
http://www.hakeem-sy.com/main/node/39518

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



Physical Stress → Psychological Stress

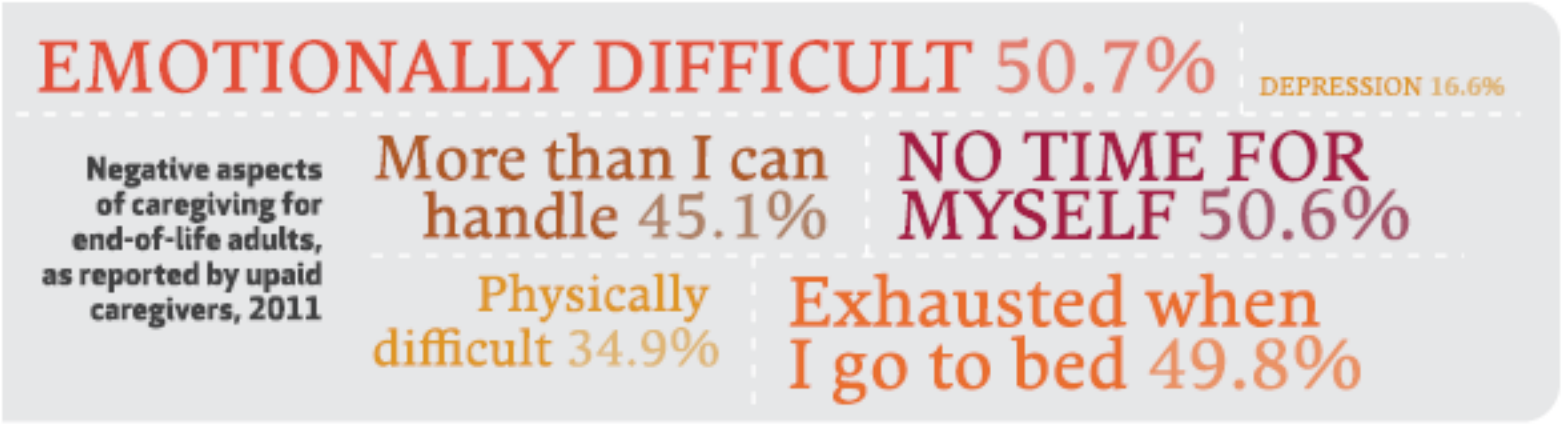
- Psychological stress also activates sympathetic system



- 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



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

See Ornstein et al. on pages 1188 and 1190

Caregiving Impacts Health

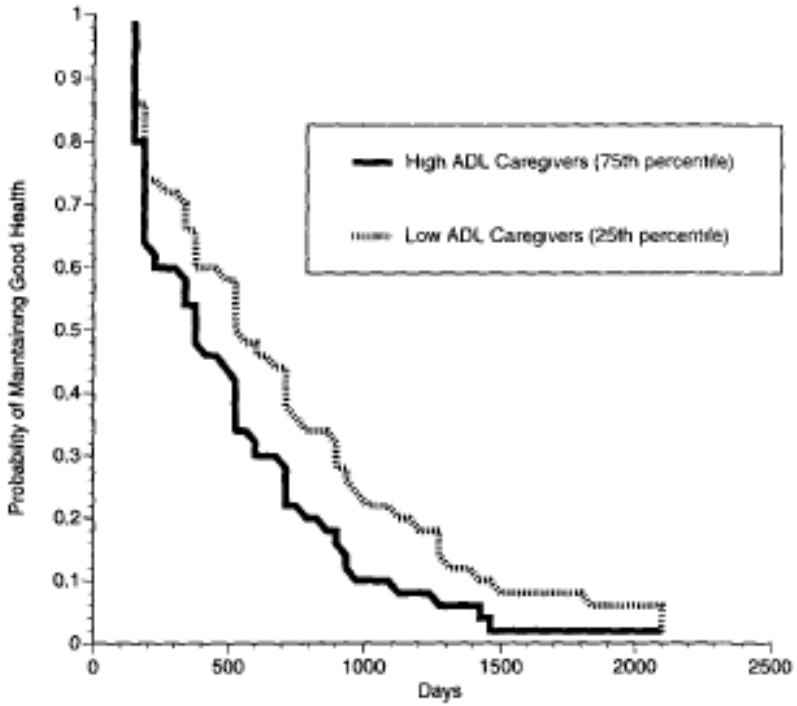


FIGURE 1: Influence of ADL Assistance on the Probability of Maintaining Good Health[a] among Caregivers

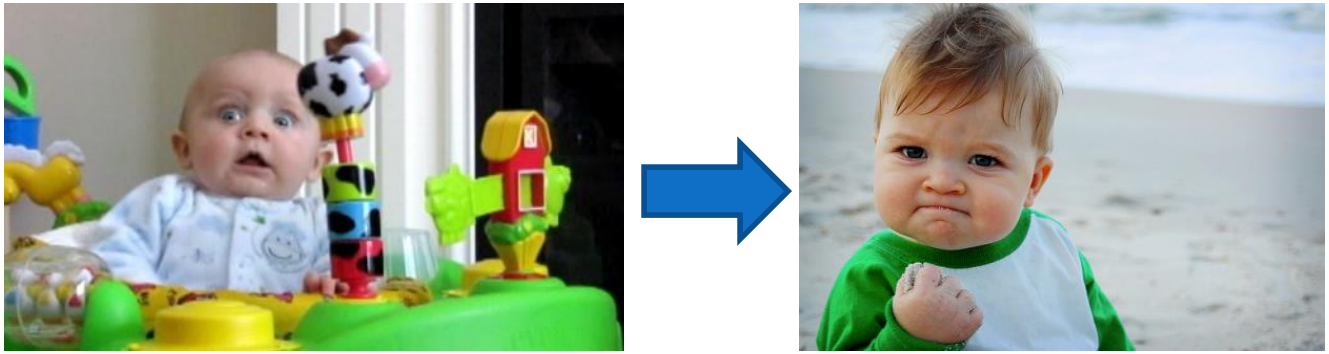
[a]Good health operationalized as (1) absence of inpatient hospitalization, (2) no serious illness lasting more than 30 days, and (3) not requiring medical attention as determined by a nurse rating.

- High caregiver burden/stress is related to worse caregiver health and worse patient outcomes
- (Bevans & Sternberg, 2012; Pinquart & Sorensen, 2003; Adelman et al, 2014)

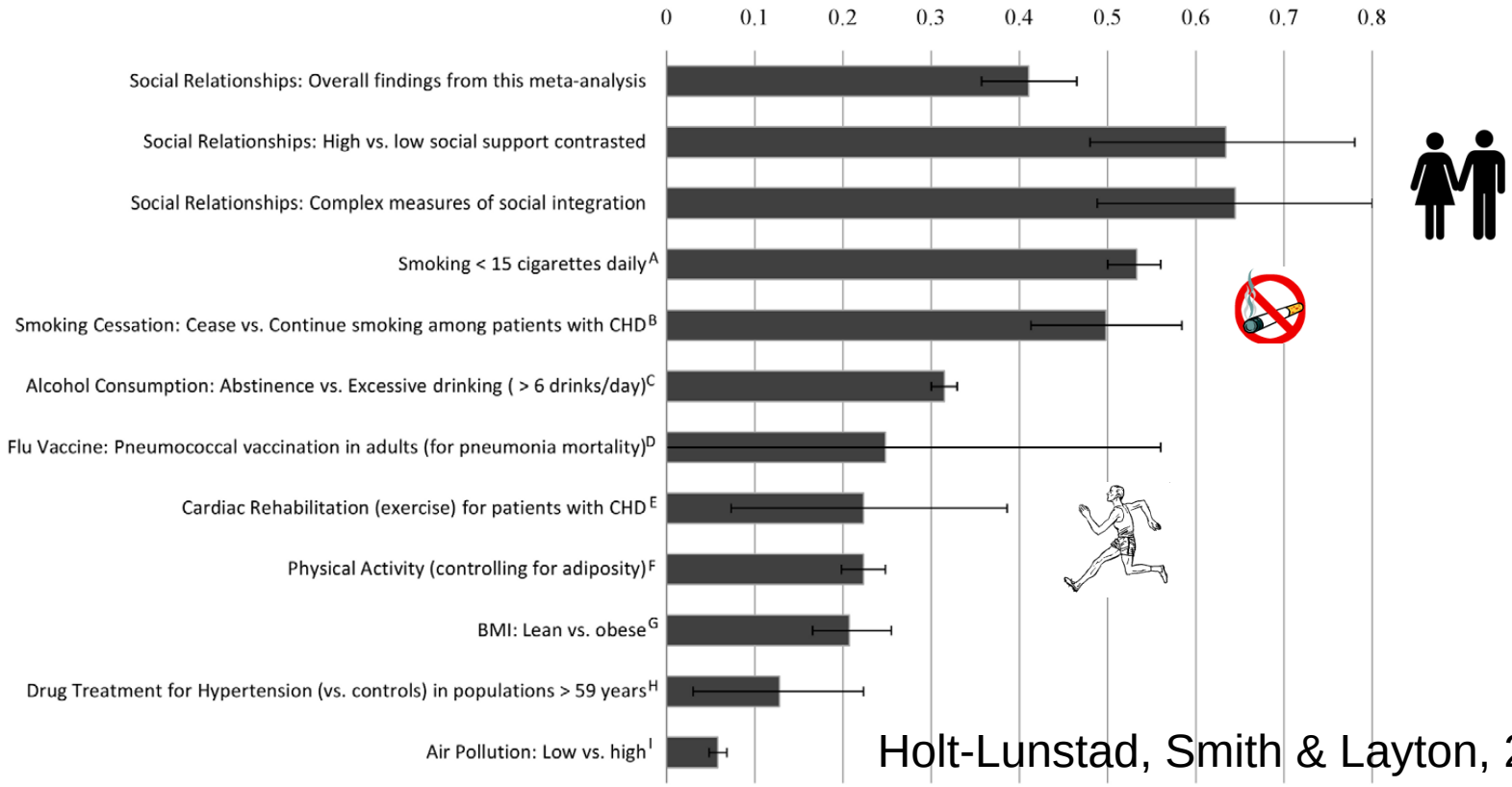
Social Support Can Help

- 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



Better Social Relationships → Lower Mortality

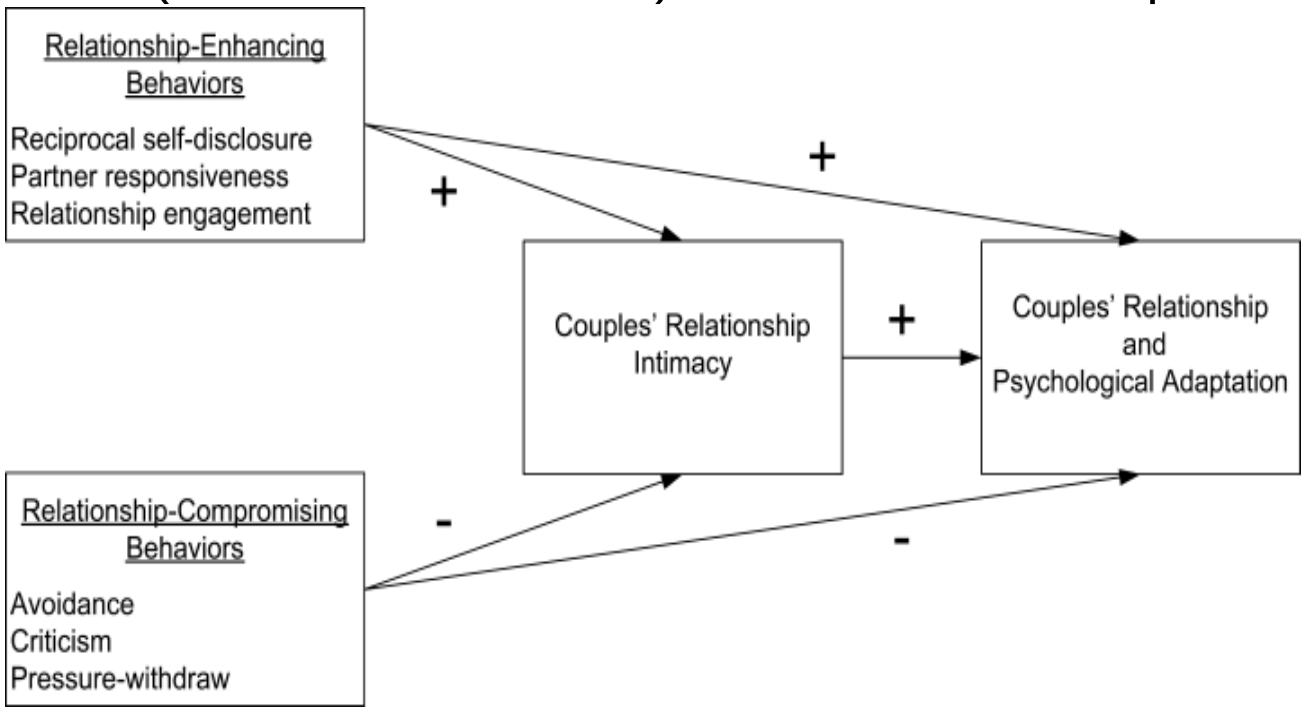


Holt-Lunstad, Smith & Layton, 2010

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**

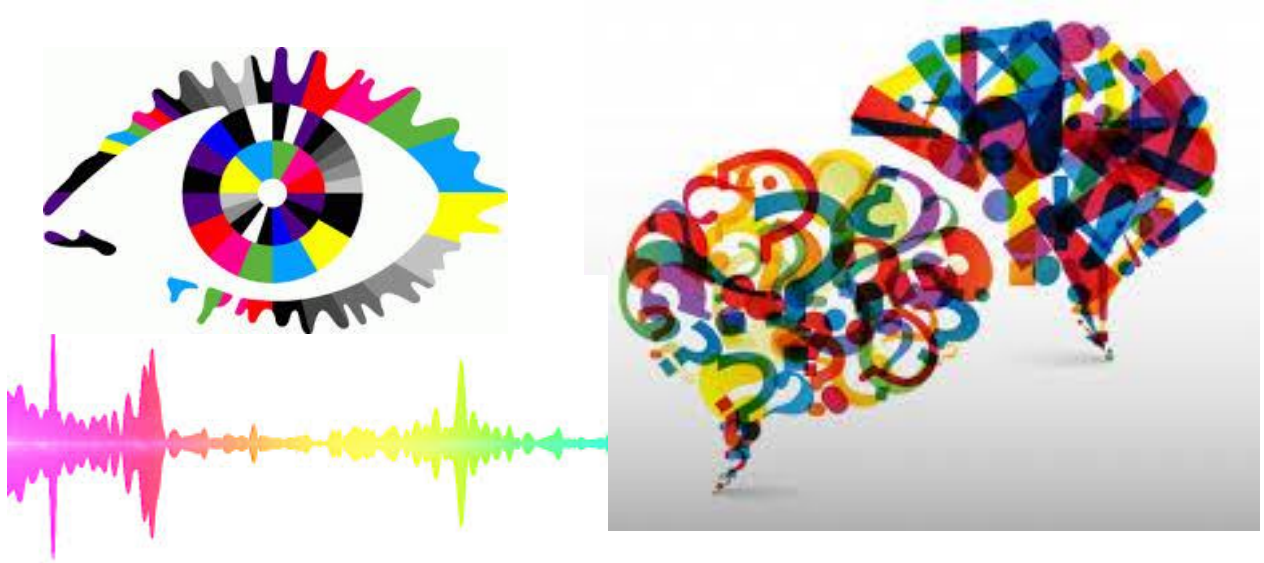


Beyond Caregiver-Patient

- 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
  - 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

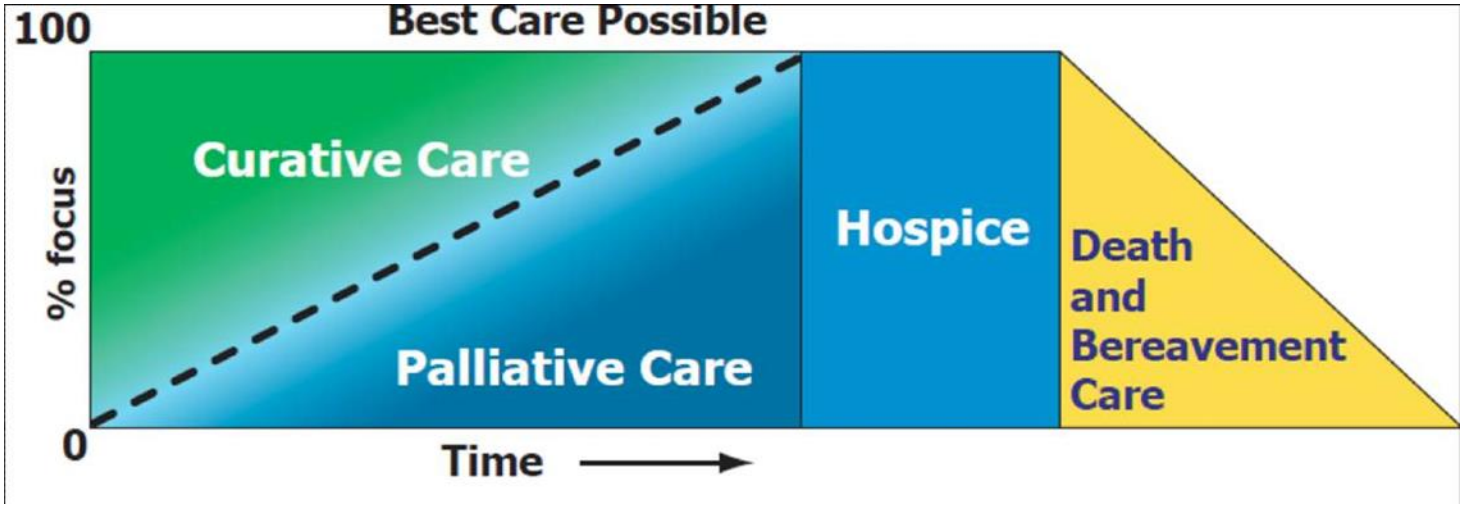
Research Question: Observation

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

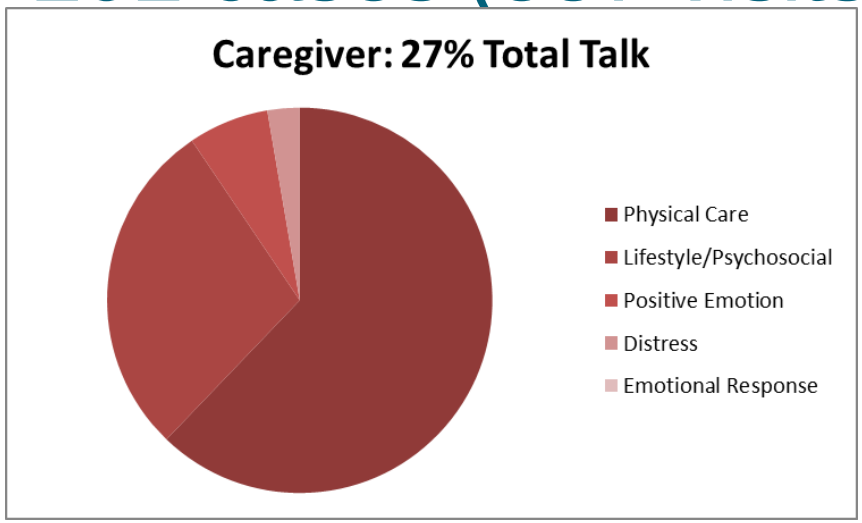
Sample Characteristics

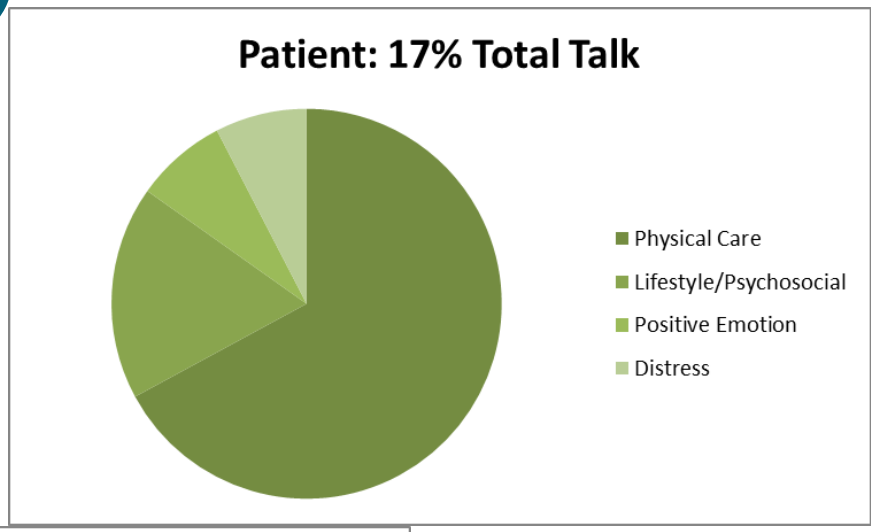
- Caregiver Patient Dyads
  - Mean age = 66 (SD=10.2) (PT mean age =68)
  - 60% female caregivers
  - Most analyses: Spouses--35 years in relationship on average
- Nurse
  - Mean age = 42 (SD=14.6)
  - 92% female
  - 4.5 years as a hospice nurse; 14 years as RN on average
  - 68% had an Associates Degree 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+)

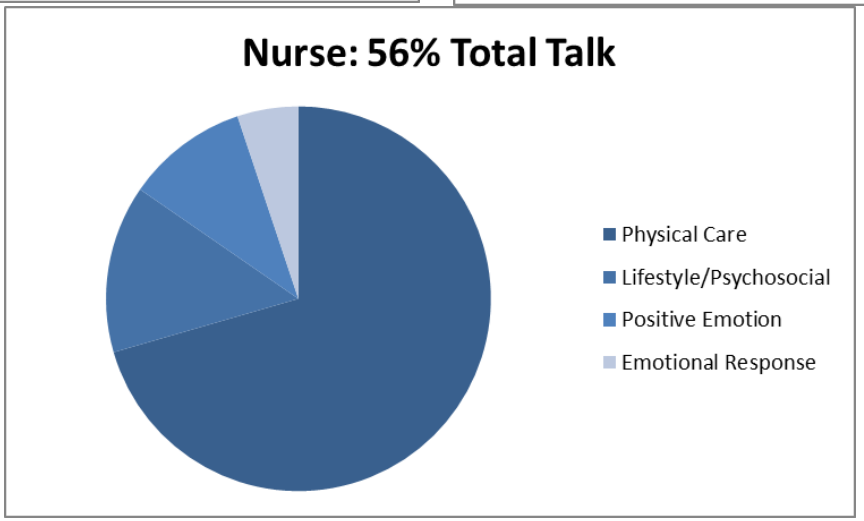
Roter Interaction Analysis System:

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

Mean Proportions of Total Visit Talk
101 cases (537 visits)



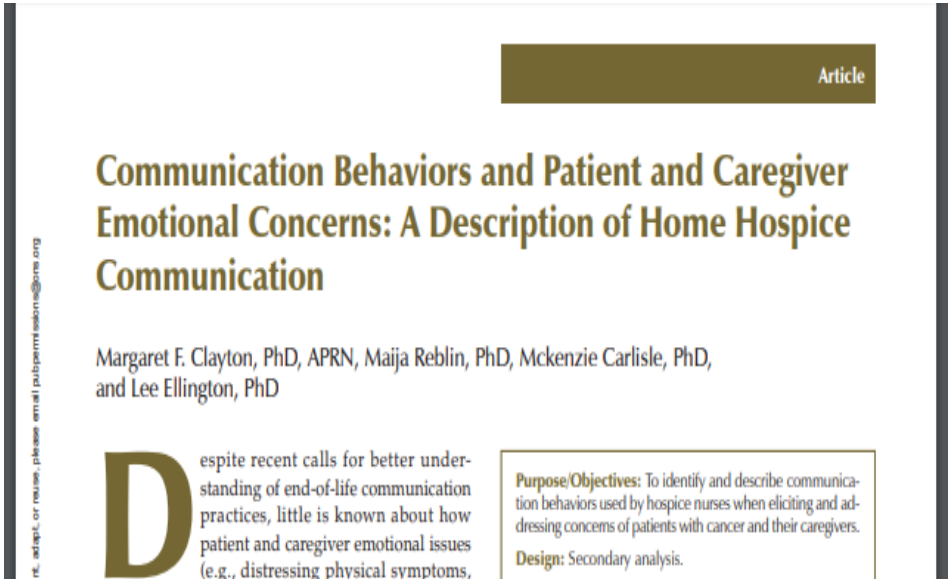




Ellington et al, PEC 2018

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?



Article

Communication Behaviors and Patient and Caregiver Emotional Concerns: A Description of Home Hospice Communication

Margaret F. Clayton, PhD, APRN, Maija Reblin, PhD, Mckenzie Carlisle, PhD, and Lee Ellington, PhD

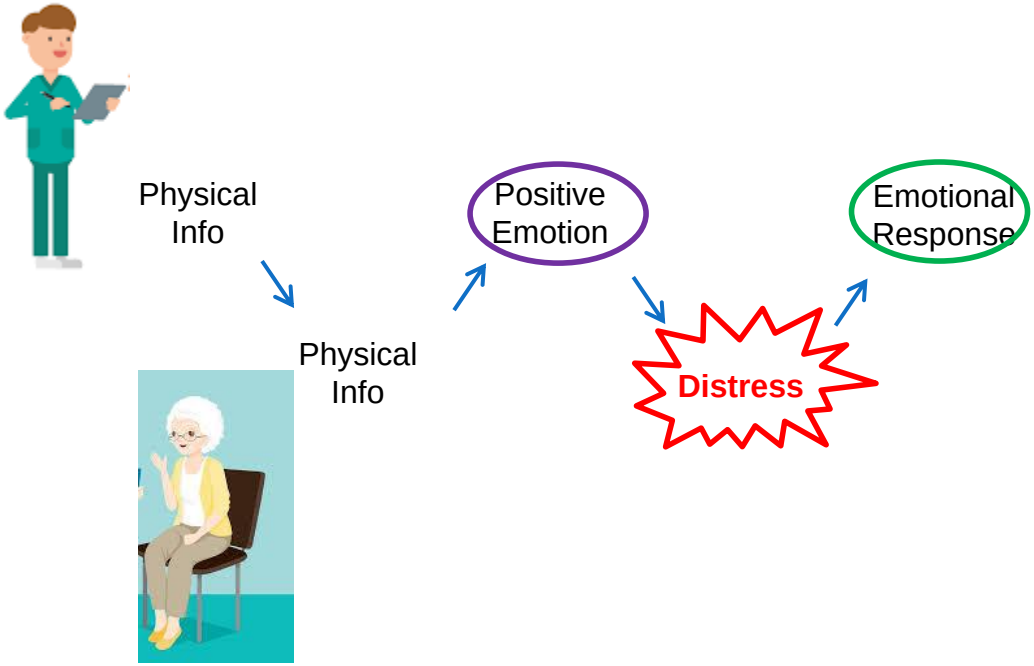
Despite recent calls for better understanding of end-of-life communication practices, little is known about how patient and caregiver emotional issues (e.g., distressing physical symptoms,

Purpose/Objectives: To identify and describe communication behaviors used by hospice nurses when eliciting and addressing concerns of patients with cancer and their caregivers.

Design: Secondary analysis.

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

Table 2. Communication Content of Patient and Caregiver Concerns Coded by Domain of Care (N = 268)

Domain	n	%
Psychological aspects of care	120	45
Physical aspects of care	107	40
Social aspects of care	17	6
Spiritual aspects of care	10	4
Care of the imminently dying patient	9	3
Structure and process of care	5	2

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

	Preconcern Nurse Speech				Postconcern Nurse Speech				Total Nurse Speech			
	Frequency				Frequency				Frequency			
Code	$\bar{X}$	SD	RP	SD	$\bar{X}$	SD	RP	SD	$\bar{X}$	SD	RP	SD
Emotional response	1.03	1.22	0.13*	0.21	1.45	2.08	0.13*	0.2	11.3	14.65	0.02	0.01
Partnering	1.9	2.15	0.2	0.17	1.81	2.12	0.146	0.15	99.61	76.88	0.16	0.06
Physical information	1.93	2.02	0.2	0.23	1.87	2.01	0.22	0.23	125.64	129.75	0.187	0.11
Physical questions	0.68	1.22	0.09	0.18	0.71	0.97	0.12*	0.21	19.3	15.48	0.04	0.04
Positive emotion	1.68	2.27	0.13*	0.14	1.83	2.31	0.13	0.2	39.03	25.2	0.069	0.06
Psychosocial or lifestyle information	2.26	2.99	0.22	0.26	2.42	3.24	0.2	0.2	100	90.48	0.152	0.08
Psychosocial or lifestyle questions	0.61	1.2	0.04	0.04	0.61	1.23	0.05	0.1	16.21	15.99	0.031	0.03
Total hospice nurse utterances	9.68	8.91	–	–	10.33	9.28	–	–	411.75	368.81	–	–

* $p \geq 0.1$

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

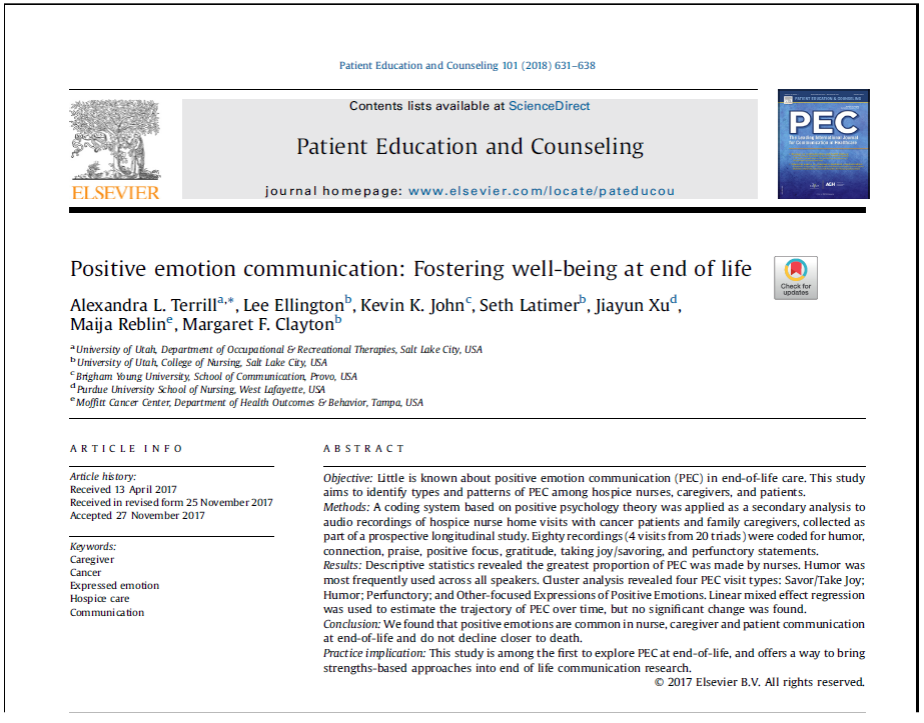
- Patients and caregivers most frequently communicate distress to nurses about psychological or physical domains of care
  - Nurses may acknowledge psychological through emotional response and follow up physical by asking questions to address the concern
- Emotion begets emotion: nurse positive emotion 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)



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Positive emotion communication: Fostering well-being at end of life

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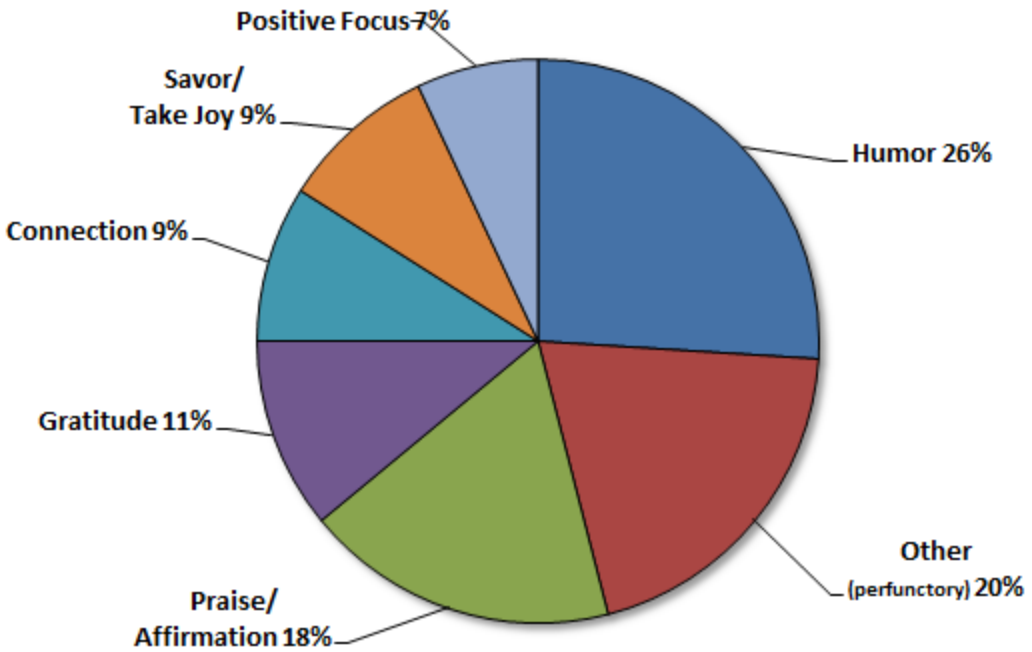
ABSTRACT

Objective: Little is known about positive emotion communication (PEC) in end-of-life care. This study aims to identify types and patterns of PEC among hospice nurses, caregivers, and patients.
Methods: A coding system based on positive psychology theory was applied as a secondary analysis to audio recordings of hospice nurse home visits with cancer patients and family caregivers, collected as part of a prospective longitudinal study. Eighty recordings (4 visits from 20 triads) were coded for humor, connection, praise, positive focus, gratitude, taking joy/savoring, and perfunctory statements.
Results: Descriptive statistics revealed the greatest proportion of PEC was made by nurses. Humor was most frequently used across all speakers. Cluster analysis revealed four PEC visit types: Savor/Take Joy; Humor; Perfunctory; and Other-focused Expressions of Positive Emotions. Linear mixed effect regression was used to estimate the trajectory of PEC over time, but no significant change was found.
Conclusion: We found that positive emotions are common in nurse, caregiver and patient communication at end-of-life and do not decline closer to death.
Practice implication: This study is among the first to explore PEC at end-of-life, and offers a way to bring strengths-based approaches into end of life communication research.

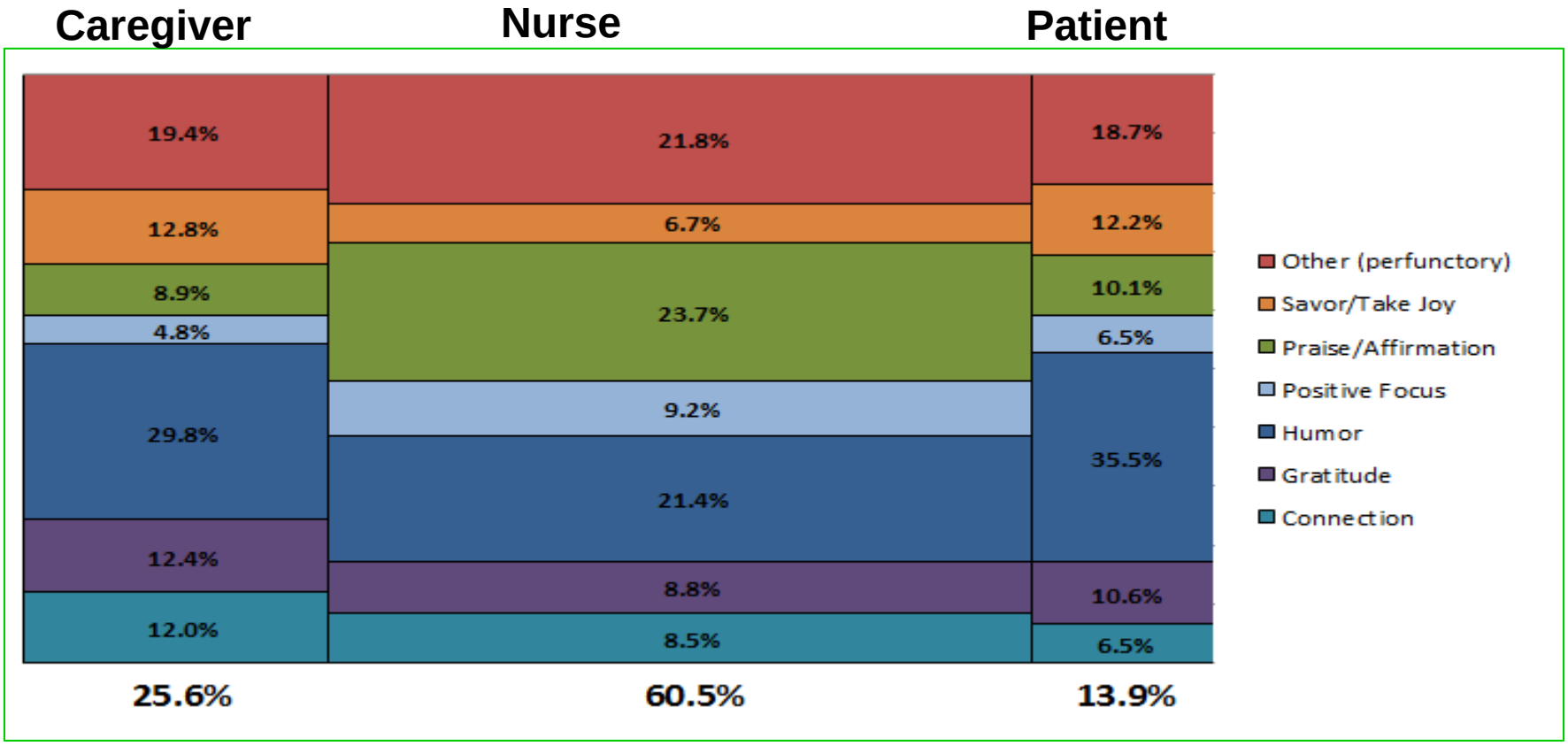
Constructs of Positive Emotion

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

Communication Results for Expression of Positive Emotions



Proportion of Positive Emotion Talk by Speaker



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

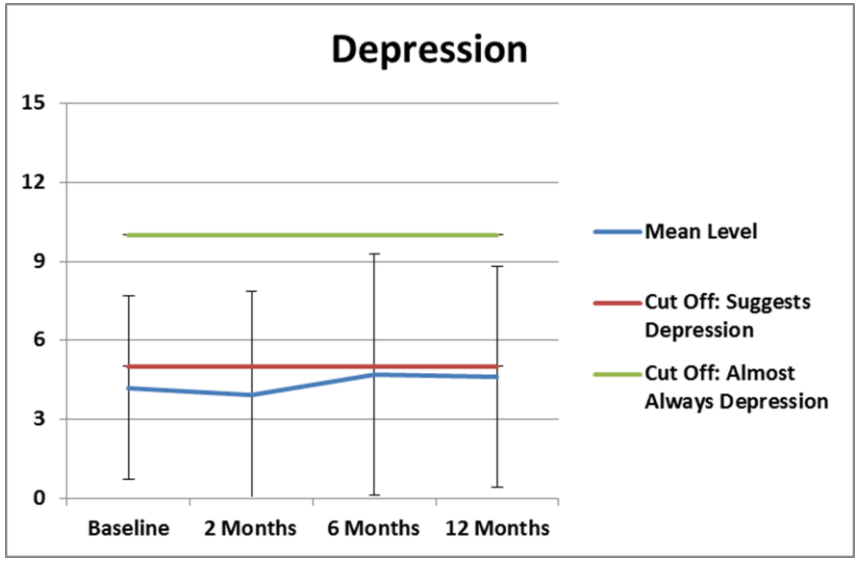
Reblin et al, under review

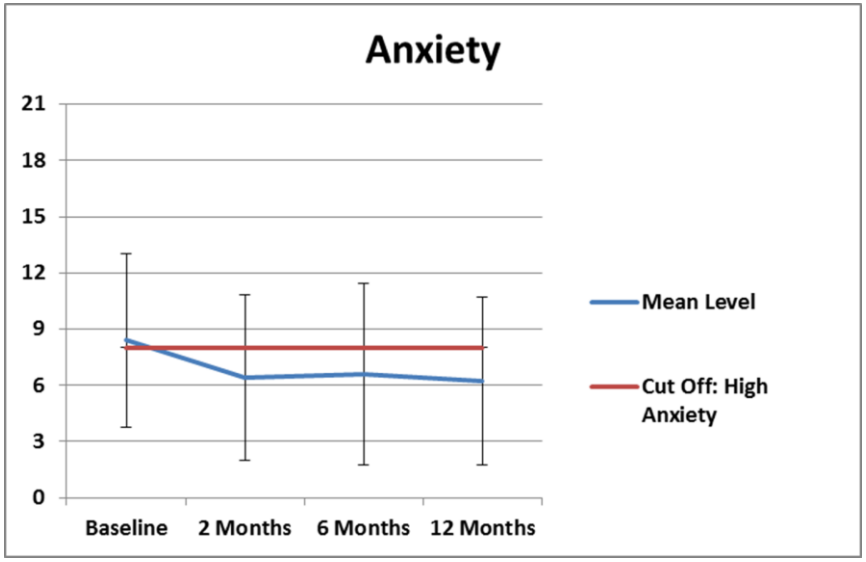
Methods

- 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

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

TABLE 3 Visit communication patterns

	Patient N = 109; 20% (Cluster 5)	Caregiver N = 124; 23% (Cluster 1)	Dyad N = 59; 11% (Cluster 6)
Low distress			
	Patient	Patient	Patient
	Lifestyle/psychosocial information Lifestyle/psychosocial questions Physical care information Physical care questions Positive emotion	Low talk	Lifestyle/psychosocial information Lifestyle/psychosocial questions Positive emotion Emotional response
	Caregiver	Caregiver	Caregiver
	Low talk	Physical care information Positive emotion	Lifestyle/psychosocial information Lifestyle/psychosocial questions Positive emotion Emotional response
	Nurse	Nurse	Nurse
	Physical care questions Positive emotion	Physical care questions Positive emotion	Lifestyle/psychosocial information Lifestyle/psychosocial questions Positive emotion
	Patient N = 64; 12% (cluster 4)	**Caregiver N = 149; 28%) (cluster 2)**	**Dyad N = 32; 6% (cluster 3)**
High distress			
	Patient	Patient	Patient
	DistressEmotional response Physical care information Physical care questions	Low talk	Distress
	Caregiver	Caregiver	Caregiver
	Low talk	Physical care information Distress Positive emotion	Distress Emotional response Physical care information Physical care questions Positive emotion
	Nurse	Nurse	Nurse
	Physical care information Physical care questions Partnering Emotional response	Physical care information	Partnering

Communication at Home

- How do couples cope with cancer in real life?

http://www.nytimes.com/2013/10/20/nyregion/in-sickness-and-in-health-a-wedding-in-the-shadow-of-cancer.html?_r=0

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

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

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

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

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

	Patient	Caregiver
Anxiety (HADS; max=14)**	M=5 (SD=3.5)	M=8 (SD=4.5)
Depression (HADS; max=14)	M=5 (SD=3.0)	M=5 (SD=3.5)
Relationship Satisfaction (CSI; max=24)	M=20 (SD=9.0)	M=20 (SD=16)
Objective burden (max=30/"high"=23)	--	M=22 (SD=4.0)
Stress burden (max=20/"high"=13.5)**	--	M=14 (SD=2.5)
Demand burden (max=20/"high"=15)	--	M=12 (SD=3.0)

Top cancer concerns (Self-report)

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

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

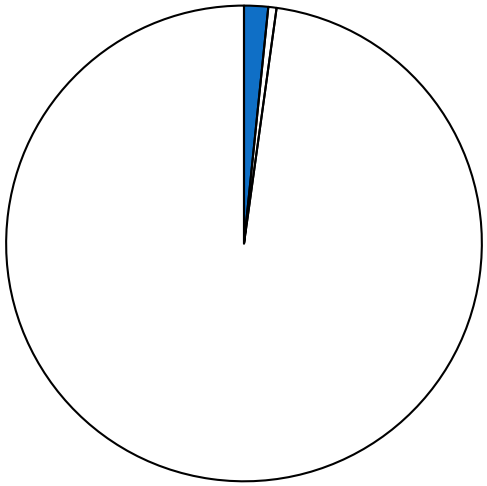
Martinez, et al, under review

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)

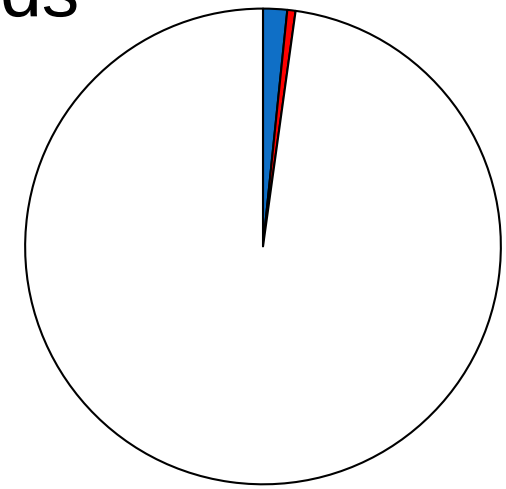
Results

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



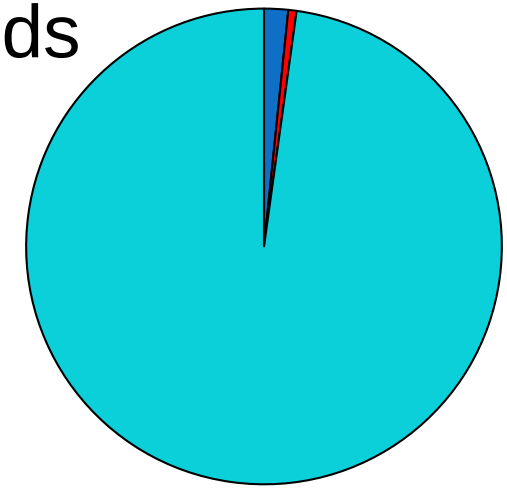
Results

- Cancer talk: median 1.46 minutes
  - 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



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)

Reblin, Sutton, Vadaparampil, Heyman, Ellington; Journal of Psychosocial Oncology. Special Issue: in press

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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Questions?