Identifying and Addressing Distress in the Older Adult

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City of Hope

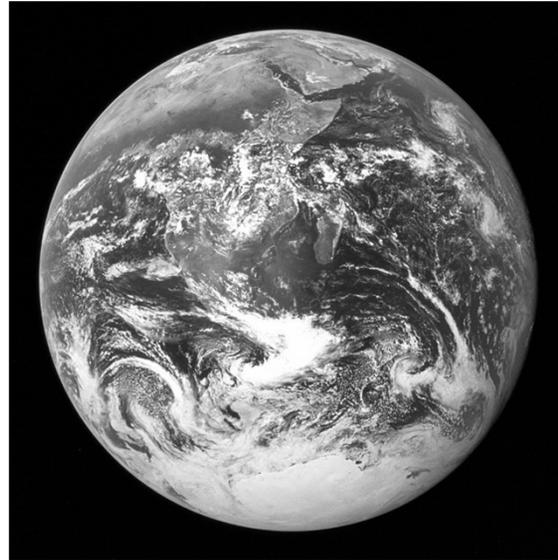CARG
CANCER & AGING RESEARCH GROUP

Disclosures
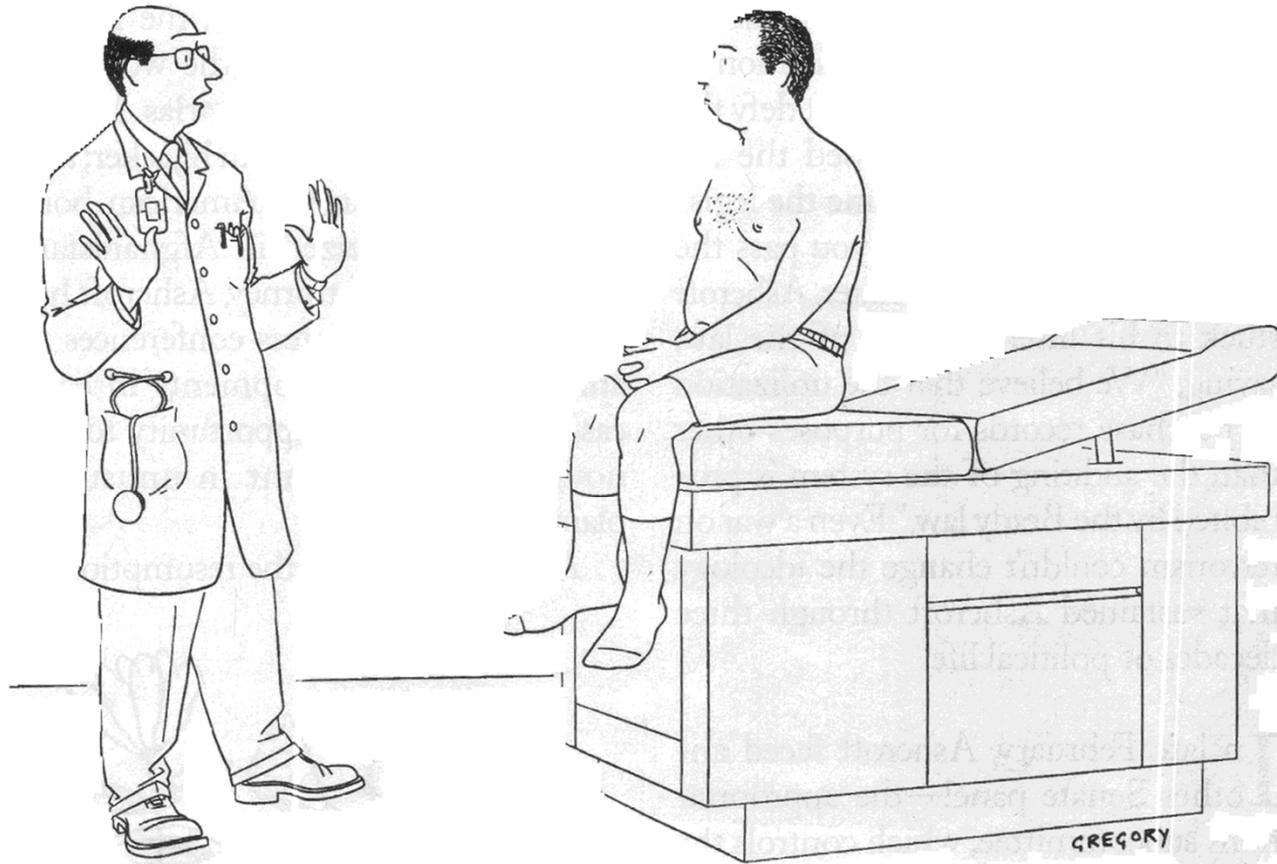
- NCI funding
- SupportScreen royalties

"Either this is the wrong chart or—let's just hope this is the wrong chart."

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Cancer is a Disruption of the Perceived Natural Order of Things

- Physical vulnerability

- Control

- Predictability

- Connection

- Meaning

"Whoa—_way_ too much information."

Communication Matters

- 89% American adults not proficient in health literacy
- 60% immediately forget medical information
- Low satisfaction=higher suing malpractice
- Online sharing Facebook, Twitter, ZocDoc, etc
  - dramatically increased
  - highly personal reviews about experience where drama stands out
  - major implications for how health care providers and institutions are perceived
  - encouragement for lawsuits
- Benefits of most effective communication
  - decreased 30-day re-admit rates, increased adherence to treatment, lower mortality, decreased utilization of services, lower annual charges

One out of four people in this country is mentally unbalanced. Think of your three closest friends; if they seem okay, then you're the one.

Barriers to Comprehensive Biopsychosocial Screening

- Lack of time
- Overwhelming workloads
- Lack of staff to process information
- Avoidance of messy emotional concerns
- Skills to manage psychosocial concerns
- Little to no space
- Ill conceived "Jerry-rigged" readily available extraordinarily expensive technologies
- Perceived lack of access to services and resources
- Fear of disrupting clinic processes
- Concerns about litigation
- Financial reimbursements

It is still the right thing to do!

"Secrets and Surprises" from Screening

- Convenient ignorance of barriers to maximizing benefits of medical care

- Reality of number & complexity of background social problems especially poverty

- Poor coordination and communication within and across settings

- Discomfort with assigned accountabilities

- Large number of patients/families who do not want our help

- Hidden team conflicts affecting medical care

- Lack of respect for colleagues may surface around triage planning and turf

Screening is Effective When…..

- Orients to cancer experience

- Teaches what to expect

- Education relevant to patient and family

- Patient in active teaching role of what matters most to them now

- Motivates to action

- Regulates emotions via focused meaningful actions

- Linkages to tailored resources

- Triage to professionals as appropriate

A Few Benefits of Biopsychosocial Distress Screening

- Orients to context
- Informs
- Educates
- Motivates
- Advocates
- Triages
- Coordinates care

- Communicates across settings
- Documents
- Enhances clinical care and new knowledge
- Essential to person centered care
- Meets standards

Limits as Opportunities

- Communication and Coordination of care as major complaints of patients, families, professionals, payers

- Technology, teams and reimbursements are not aligned (yet) to support person-centered care

- Complexity leads to confusion, high *stress—but great opportunity* for teams of clear and focused minds who share values

- Values, Benefits and Outcomes need to be clarified

| Identify Shared Values	Perceived Benefits	Relevant Outcomes
Patient First	Focus on Medical Care	Higher Patient/Personal Satisfaction
Competence	Best Care Possible	Scholarly Output
Compassion	Identify Patient Priorities	More Quality Time Spent with Patient
Integrity	Efficient/Effective	Quality of Life
Proud of Self	Professional/Personal Recognition	Live Longer
	Institutional Recognition	See More New Patients
	Protect My Time	Increased Revenue

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Alchemizing the ACOS Standards

- <u>Bio</u>psychosocial Distress Screening, Patient Navigation & Survivorship is the connective tissue that has the potential to integrate the cancer experience in form, content and the absolute need to integrate resources across the health care continuum and especially across settings—from day one!

- Nurses are the frontline of screening

City of Hope Experience and Way Beyond: Essential Lessons Learned

- Patient and families are extremely open to programs that are time sensitive, relevant and integrated with overall care

- Institutions large and small have cultures that are risk-aversive, hierarchical, avoidant of the psychosocial aspects of the human experience and too frequently hampered by turf struggles

- Never, ever, before has there been such an opportunity for collaborations that can make a difference, starting today! (Subtle Call to Action)

Using Technology to Bring People Closer Together
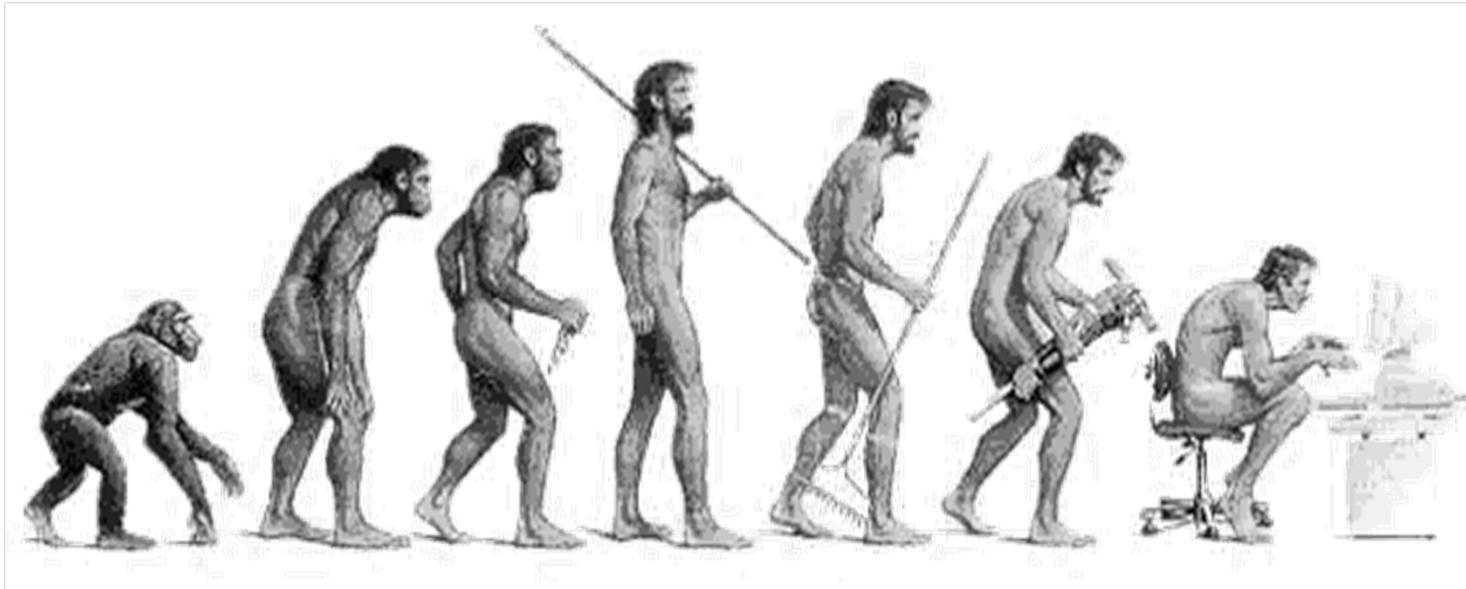
Geriatric Feasibility Data

	Age 65 and Older (n=361)	Age 64 and Younger (n=918)
Prior Use of Computers		
Beginner	40.60%	20.80%
Intermediate	38.90%	37.80%
Advanced	9.70%	28.40%
Expert	1.40%	8.40%
Prefer not to answer/Do not know	9.40%	4.60%
Ease of use of this touch screen computer		
Very easy	65.10%	73.50%
Easy	29.00%	23.10%
Difficult	4.20%	2.80%
Very Difficult	1.60%	0.60%
Average time (in minutes) to complete	7.25	5.95

Big Picture of Screening at City of Hope

- Touch screen implemented in June 2009

- 42,623 screenings

- 24,413 patients

- 70+ physicians

- <1% refusal rate

- Distress screening and questionnaires tailored to specific populations

Population-Specific and Tailored Screening Programs

- Outpatient
- Medical Oncology
- Hematology/HCT
- Breast Cancer Surgery
- Couples Clinic
- Head and Neck
- Plastics
- Gynecology
- Urology
- Pediatrics
- Psychiatry

Additional Sites
- ICU (caregivers)
- Pre-Anesthesia

…and expanding

Where is *SupportScreen* being Used?	How being Used ?
ICU	Family/Caregiver/Patient entered data: preferences and values, Advance Directives, ICU orientation and education, request a family goals of care meeting, biopsychosocial distress.
Outpatient clinics (Med Onc, HEM/Onc, Surgery)	Patients entered data: Biopsychosocial distress screening, Advance Directives, Clinical Trials, New Patient Orientation
Couples clinics (Women's Cancers Program and GI)	Patients and partners entered data: Biopsychosocial distress screening, Metastatic specific questions, prognosis, relationship, role-specific satisfaction
Psychiatry	Patients entered: anxiety and depression screening
Pediatrics	Patients and parents entered: Biopsychosocial distress tailored by age: 8-12 and 13-20 (patients under 8 parent entered only)
Inpatient-Nursing Led Pilot	Patients entered: intake questionnaire and biopsychosocial distress
South Pasadena	Patients entered: biopsychosocial distress
Cancer and Aging Research Program	Patients and Caregiver entered: geriatric assessment – quality of life
Survivorship (Breast, GYN in progress)	Patients entered: biopsychosocial distress and symptom screening to populate survivorship care plan
Pre-Anesthesia Testing Clinic	Patients entered: Post-operative nausea, Advance Directives, tobacco use, distress screening

Screening Real-Time Outputs
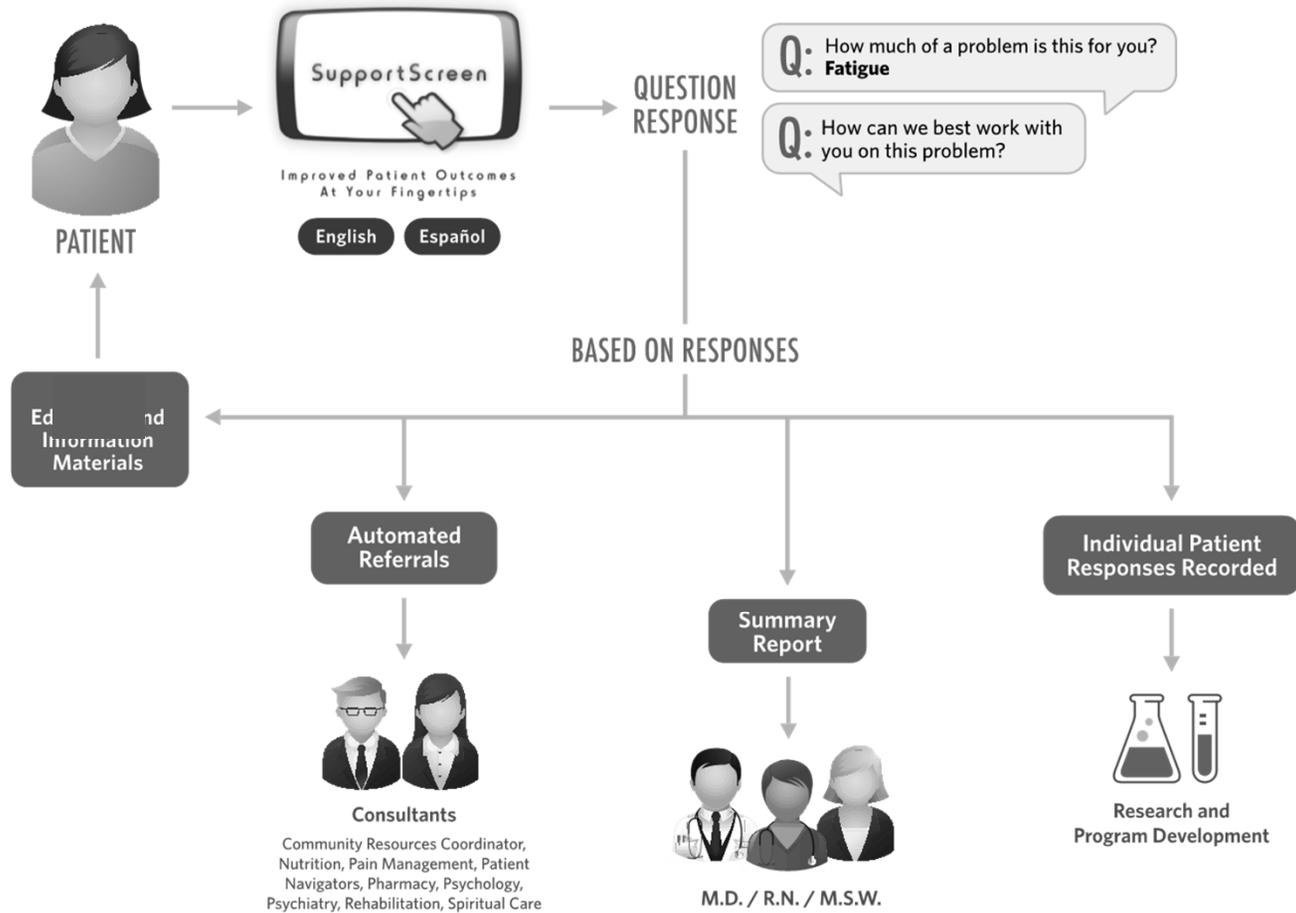
All of the content and outputs can be modified to fit the individual setting.

City of Hope

Introduction

Dear Test,

Welcome to City of Hope, where we partner with you and your family to get the most out of your medical care. Our goal is to provide you and your family with comprehensive and compassionate care.

To get started, please complete the *You, Your Family and City of Hope are a Team* touch-screen program.

Your answers to these questions will be shared with the team and will enable us to begin working together as a team to address any concerns or problems related to your care at City of Hope.

To respond to the questions, simply use your finger to touch the button that best represents your situation.

To move backwards touch the back button. You do not need to use the next button. The screen will automatically move to the next page after the two questions on each page are completed.

Sincerely,

Please *touch the button* below to begin

Touch here to begin

Item Format

How Much Of A Problem Is This For You? **Health Insurance** | Severity Rating 1-5 |

| Not a Problem | Mild Problem | Moderate Problem | Severe Problem | Very Severe Problem |

| Prefer not to answer | Do not know |

How Can We Best Work With You On This Problem? | Level of Assistance |

| Provide Written Information | Talk with a Member of the Team | Written Information & Talk with Team Member | Nothing Needed at this Time |

E-Mail Summary Report Example

Attention Dr. Bertram Yuh,

Your patient, XXXXXXXX [MRN: XXXXXX], seen on 6/27/2015 1:07:33 PM, is requesting help from you or a member of your team.

MD:

- Preferred spoken language - SPANISH
- Racial/ethnic background - LATINO/HISPANIC
- Patient is experiencing pain at this time
- Requested information on clinical trials
- Advance Directive - Yes, but COH does not have a copy
- Have you had a discussion with your loved ones about who you would want to speak for you (your decision maker) and what your wishes are - Yes, I have discussed with my immediate family

PE/RN:

- Sleeping - MODERATE PROBLEM (EDU materials provided)
- Controlling my urine or stool - MODERATE PROBLEM (EDU materials provided)
- Pain - SEVERE PROBLEM (EDU materials provided)

MSW:

- Transportation - MODERATE (MSW info provided)
- Being unable to take care of myself - MODERATE (MSW info provided)

Other:

- Would you like to receive information about upcoming courses and events at City of Hope? Please type your e-mail address below. (This information will not be shared with another entity): XXXXXXXX@GMAIL.COM

Survey Title: ACOS SupportScreen - English

Survey Language: English

If you have any questions or concerns about this screening process please contact Matthew Loscalzo at mloscalzo@coh.org

Tell us how we're doing ?
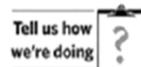
Example of Information Provided in Real-Time

Reducing Barriers to Pain and Fatigue Management

Strategies to Help with Promoting Sleep

Sleep Hygiene Strategies:

- Avoid coffee, tea, chocolate, soft drinks before going to bed
- Avoid exercising 2-4 hours before bedtime
- Sleep in a dark, cool, quiet, and relaxing room
- Develop a bedtime ritual (i.e. warm milk before bedtime)
- Use your bed only for sleeping and intimacy
- If possible, go to bed at the same time each night

Sleep Restrictions Strategies:

- Add one additional of hour of sleep if you feel ill or feel unable to get up at the scheduled time in the morning
- Limit naps to no more than two everyday, each lasting less than an hour

Relaxation Strategies:

- Take a warm shower or bath before going to bed
- Listen to soothing music
- Use meditation, massage, progressive relaxation, or other strategies to decrease stress

Funded by NCI

Role of Biopsychosocial Screening in Cancer Care

Matthew Loscalzo, LCSW,* Karen Clark, MS,* Sumanta Pal, MD,† and William F. Pirl, MD‡

TABLE 1. Percentage of Cancer Outpatients Reporting High Distress and Requests for Assistance (n = 4819)

Concern	High Distress	Requested Assistance*
Finances	39.9%	33.6%
Sleeping	38.3%	35.6%
Worry about the future	37.1%	35.6%
Fatigue	36.7%	32.3%
Adverse effects of treatments	34.5%	33.9%
Pain	32.7%	29.5%
Feeling anxious or fearful.	27.8%	28.7%
Feeling like there are still important things that I need to take care of in my life	26.4%	13%
Feeling down or depressed	25.8%	29.4%
Walking, climbing stairs	25.4%	15.1%

*Requested assistance is defined as tailored educational/resource information and/or talk with a member of the team.

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Top 10 Biopsychosocial Problems Rated
High Distress (N=18,682)

Biopsychosocial Distress Items	% High Distress (Moderate to Very Severe)
Sleeping	36.6%
Fatigue	34.0%
Side effects of treatments	32.6%
Talking with doctor	31.6%
Finances	30.9%
Worry about the future	30.7%
Pain	30.6%
Feeling anxious or fearful	26.5%
Walking, climbing stairs	22.4%
Losing control	21.8%

Biopsychosocial problem-related distress in cancer: examining the role of sex and age

Karen Clark[1]*, Cristiane Decat Bergerot[2], Errol J. Philip[3], Sorin Buga[1], Richard Obenchain[1] and Matthew J. Loscalzo[1]

[1]*Sheri & Les Biller Patient and Family Resource Center, Department of Supportive Medicine, City of Hope, Duarte, CA, USA*
[2]*Universidade Federal de São Paulo (UNIFESP), São Paulo, Brazil*
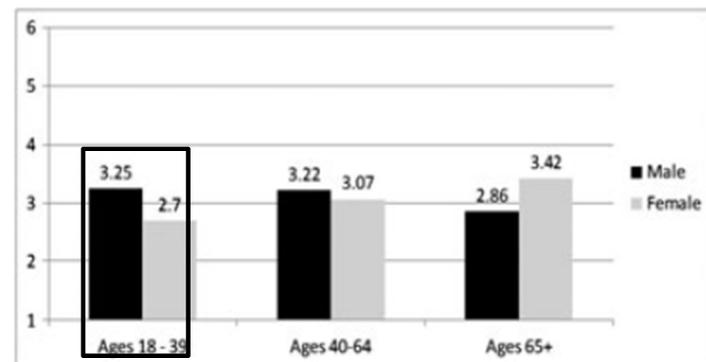[3]*The Notre Dame Laboratory for Psycho-Oncology Research, Notre Dame, Notre Dame, IN, USA*

Men ages 18-39 reported: higher distress and requested to talk with a member of the team
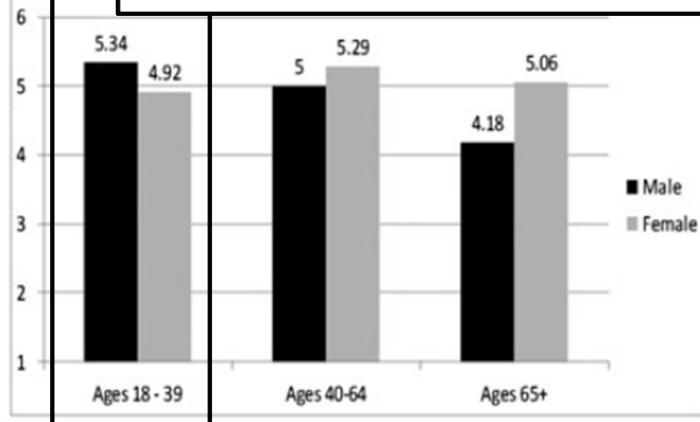
Significant interaction of gender and age and level of distress, p=.016

Figure 1. High distress (moderate to very severe) (average no. of problems) by sex and age (N = 6462)

Significant interaction of sex and age and requesting to talk with a member of the team, p=.005

Figure 2. Patients request to talk with a member of the team (average no. of problems) by sex and age (N = 6462)

Most common biopsychosocial problems reported as highly distressing by geriatric patients (65+) vs. younger patients (<65)

Geriatric patients (65+)
(N=3,582)

Fatigue	34%
Sleeping	34%
Side effects of treatments	31%
Pain	29%
Walking, climbing stairs	29%
Bowel movement constipation	23%
Joint Limitations	20%
Transportation	20%
Solving problems	19%
Questions/fear about end of life	18%

Younger patients (<65)
(N=6,141)

Finances	39%
Sleeping	38%
Side effects of treatment	33%
Fatigue	35%
Pain	31%
Feeling anxious or fearful	29%
Managing work, school and home life	24%
Fear of Medical Procedures	23%
Managing my emotions	23%
How my family will cope	22%

City of Hope, Unpublished Data-2017

Biopsychosocial screening data consistently demonstrates…

- Problems with sleep, fatigue and pain are common in older adults

% High Distress
(moderate to very severe) patients 65 and older
by sex (N=2,746)

	Females (n=1,384)		Males (1,362)
Fatigue	38.1	Fatigue	32.6
Sleeping	36.4	Sleeping	32.4
Pain	32.8	Side-effects of treatments	31.4
Side-effects of treatments	32.0	Pain	27.8
Finances	27.7	Walking, climbing stairs	23.9
Feeling anxious or fearful	26.8	Sexual function	23.4
Bowel Movement/Constipation	24.8	Finances	21.6
Walking, climbing stairs	24.4	Bowel Movement/Constipation	18.1
Fear of Medical Procedures	23.9	Recent weight change	17.6
Transportation	23.8	How my family will cope	17.5

Sleepless From the Get Go: Sleep Problems Prior to Initiating Cancer Treatment (N=5,702)

- 12.5% high sleep problems (*severe to very severe*)

- Across diagnoses, 4.3-13.8%
  - prostate cancer patients *least* likely
  - gastrointestinal cancer patients *most* likely

- *Lower* likelihood: o*lder age, having a partner, higher education/household income*

- *Increased:* f*emale, Black, Hispanic*, and reporting *anxiety* or *depression*

CrossMark

Sleepless from the Get Go: Sleep Problems Prior to Initiating Cancer Treatment

Eric S. Zhou [1,2] · Karen Clark [3] · Christopher J. Recklitis [1,2] · Richard Obenchain [3] · Matthew Loscalzo [3]

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Abstract

Purpose Cancer patients are likely to experience sleep problems. Understanding their perception of sleep problems is important as subjective symptom experience is associated with treatment-seeking behavior. We explored the prevalence of sleep problems and its correlates in a large sample of cancer patients at an important but understudied stage of their cancer journey: prior to initiating treatment.

Methods Cancer patients (5702) (67.5% female; 76.9% White; 23.0% Hispanic), following diagnosis and prior to initiating cancer treatment, completed an electronic screening instrument. Patients across eight different cancer diagnoses (breast, gastro-intestinal, gynecological, head and neck, hematological, lung, prostate, urinary) rated their sleep problems on a five-point scale, with those reporting "severe" or "very severe" sleep problems classified as having high sleep problems.

Results Overall, 12.5% of patients reported high sleep problems. Across diagnoses, the proportion of patients reporting high sleep problems ranged from 4.3 to 13.8%, with prostate cancer patients least likely and gastrointestinal cancer patients most likely to report high sleep problems. Older age, having a partner, higher education, and higher household income were associated with a lower likelihood of experiencing sleep problems. Being female, Black, Hispanic, and reporting anxiety or depression was associated with an increased likelihood of sleep problems.

Conclusions A sizeable proportion of cancer patients experience significant problems with their sleep before any treatment has occurred. This clinical issue cannot be ignored as treatment is likely to worsen existing sleep problems. Oncology providers should routinely screen for sleep-related problems. Identifying and treating patients for sleep problems during a vulnerable period early in their cancer trajectory should be an essential component of clinical care.

Keywords Sleep problems · Sleep dysfunction · Sleep disturbances · Cancer patient · Oncology

Elevated Distress, Race, Age, Education, Income and Type of Cancer: It's Complicated. A Study in a Population of <u>3,407 Men</u> With Cancer

- *Low income significantly predicts high problem-related distress in key domains:*

  – *Physical*

  – *Practical*

  – *Functional*

  – *Emotional*

  – *Overall*

Elevated distress, race/ethnicity age, education, income, and type of cancer: It is complicated

Sebastien Montel | Karen Clark | Matthew Loscalzo

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Clinical Correspondence

Partners' clinic: an innovative gender strengths-based intervention for breast cancer patients and their partners immediately prior to initiating care with their treating physician

Courtney Bitz[1]*, Karen Clark[1], Courtney Vito[2], Laura Kruper[2], Philip H. G. Ituarte[3] and Matthew Loscalzo[1]
[1]*Department of Supportive Care Medicine, City of Hope, Duarte, CA, USA*
[2]*Division of Surgical Oncology, City of Hope, Duarte, CA, USA*
[3]*Department of Surgery, Division of Surgical Oncology, City of Hope, Duarte, CA,*

Table I. Problem-related distress described by patients and their partners

Problem-related distress item	Patient (N = 86)	Partner (N = 82)	p-value
	(% High distress)		
Feeling anxious or fearful	51.2	31.2	0.014*
Managing my emotions	39.8	8.8	0.003*
Finances	33.3	26.2	0.355
Sleeping	33.3	25.6	0.280
Being unable to take care of myself	31.5	5.0	0.000*
Fatigue	26.6	21.3	0.431
Feeling down or depressed	25.0	24.4	0.962
Finding community resources near where I live	20.6	15.6	0.460
Pain	19.2	10.4	0.122
Transportation	14.0	8.5	0.268
Substance use by you or in your environment	7.7	1.3	0.049*
Feeling unsupported by my partner	5.0	4.3	0.851
Tobacco use	3.8	8.8	0.198

*statistically significant.

<u>Patients Significantly Higher Distress than Partner:</u>

- Feeling anxious or fearful
- Managing my emotions
- Being unable to take care of myself
- Substance use

"Which statement is closest to your understanding of your or your partner's present medical situation?"

Question	Patient (127)	Partner (117)
Cure is very likely and is in the range of 76% to 100% for me/my partner	18.9%	23.1%
Cure is likely and is in the range of 51% to 75% for me/my partner	9.4%	15.4%
Cure is possible but not likely and is in the range of 26%-50% for me/my partner		
Cure is not at all likely and ... treatment is to control the ...	46.5%	40.2%
Cure is not at all likely and is in the range of 0-25% for me. The goal of treatment is to focus on comfort, time with family and quality of life.	3.9%	3.4%

Alignment with Medical Situation: All patients are metastatic and by definition not curable
- 49.6% of patients believed they were curable
- 56.4% of partners believed they were curable

Did you find any of the questions or topics upsetting? (N=821)

- 93% patients/partners responded No

- 7% positive responses (free text)
  - Chemotherapy (12)
  - End of Life (10)
  - Treatment/Side Effects (7)
  - Miscellaneous
    - Finances, Insurance, Spouse, Emotions
  - Help this group!

Patient

Partner

Communication, Compassion, Courage, Coordination=Connection