

Providing Palliative Care Services to Individuals with Serious Mental Illness



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Objectives

- Review the relationship between SMI and physical illness
- Describe disparities in morbidity and mortality, as well as health care access, utilization, and quality of care among individuals with co-morbid SMI and advanced serious illness
- Identify innovative integrative care models for treating this population
- Highlight challenges in managing individuals with specific mental disorders and related comorbidities and promising interventions

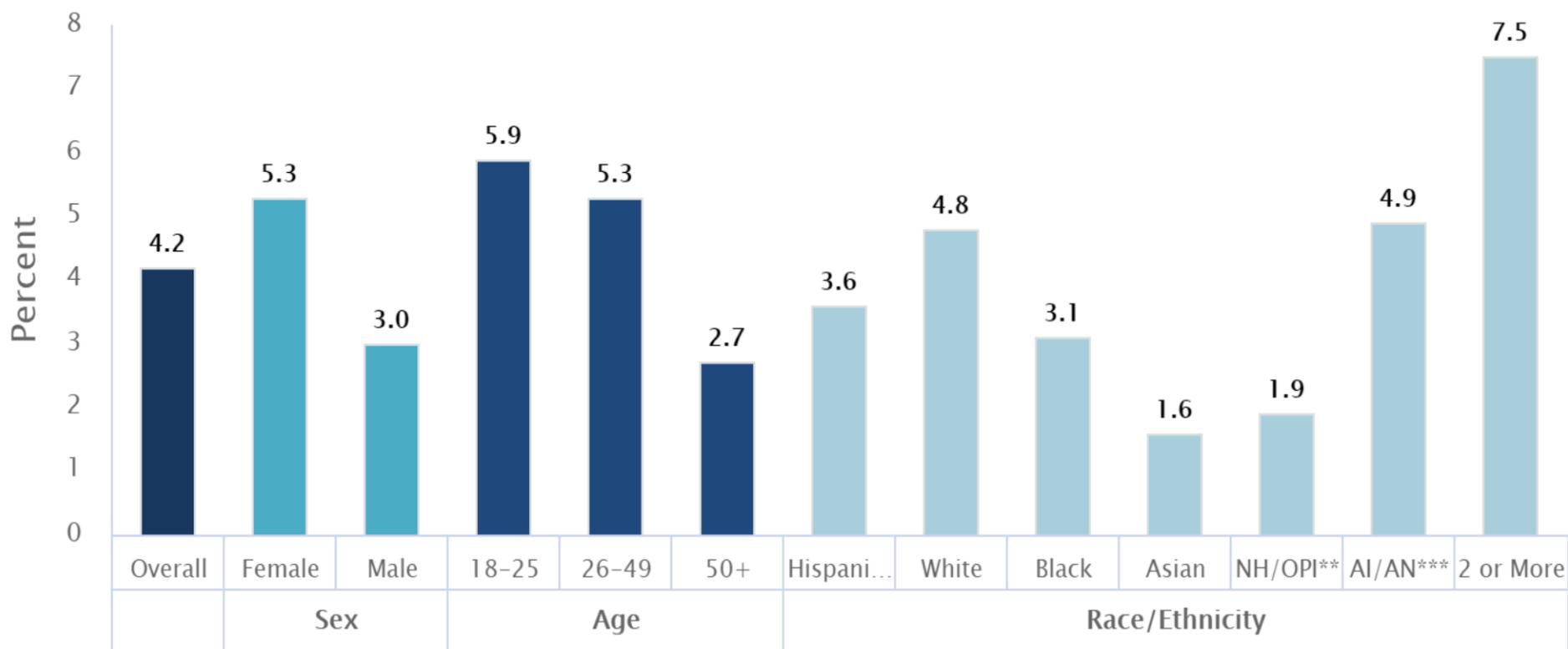
Severe/Serious Mental Illness Defined

- **SMI:** a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities

Prevalence of SMI

Past Year Prevalence of Serious Mental Illness Among U.S. Adults (2016)

Data Courtesy of SAMHSA



The Experience of SMI

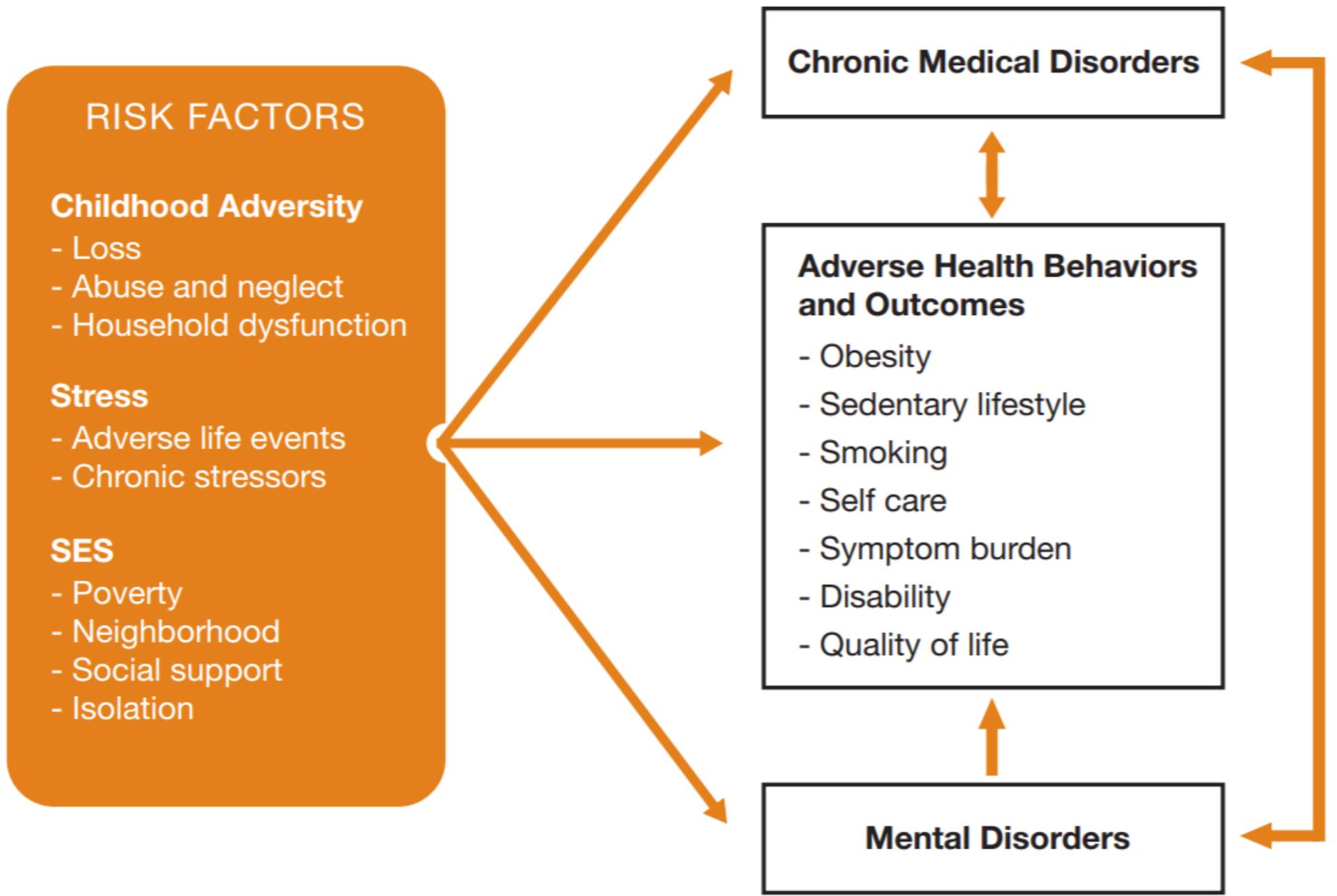
LIVING WITH A MENTAL ILLNESS



<https://www.youtube.com/watch?v=yYJV0hBulws>

Medical Comorbidity

- < 68% of adults with a mental disorder, at least one medical condition
- Comorbidity is associated with
 - elevated symptom burden
 - functional impairment
 - decreased length and quality of life
 - increased costs
- Pathways complex, bidirectional
 - medical disorders may lead to mental disorders
 - mental conditions may increase risk for medical disorders
 - mental, medical disorders may share common risk factors



Source: Modified from Katon (Reference 5)

SMI & Medical Comorbidity

- People with SMI have a 13-30 year shorter life expectancy (Chang, Hayes, Perera, et al., 2011; Viron & Stern, 2010) though mortality risk varies with age, gender, ethnicity (Chang, Hayes, Broadbent, et al., 2010)
- They are at increased risk for medical illness, higher morbidity and more severe functional impairments (Weissman, Pratt, & Parker, Dickey et al., 2002; Hahm & Segal, 2005; Mitchell & Malone, 2008.)
- Increased risk is due to a variety of behavioral factors as well as disparities in health care access, utilization, quality of care

Medical Management Complicated

- Behavioral factors
 - Smoking, poor diet and exercise
 - Substance abuse
 - Unsafe sexual behaviors
 - Medication
 - Non-adherence
 - Deleterious effects of atypical antipsychotics, mood stabilizers, antidepressants—increased risk obesity, Type 2 diabetes, cerebrovascular disease, metabolic disorders
- Practical constraints affecting access / utilization
 - Incarceration
 - Transportation difficulties
 - Limited financial resources
 - Little-to-no medical insurance
 - Limited support systems

Medical Management Complicated

- Pt factors affecting access / utilization & quality
 - Limited insight due to cognitive problems and perceptual distortions
 - Emotional dysregulation
 - Difficulty describing problems
 - Poor tolerance of interventions, adherence to treatment as prescribed
 - Mistrust, fear of psychiatric hospitalization
 - Skill and knowledge deficit (e.g. how to use health care system, navigating relationships) (Goldenberg et al., 2000; Emsley et al., 2008)

Medical Management Complicated

- Provider factors affecting access / utilization & quality
 - Lack of clarity re who should be responsible for medical preventive care, disease management for those with SMI (Lawrence & Kisely, 2010)
 - Receive fewer routine cancer screens, lower rates of surgery, fewer chemotherapy sessions (Kisely et al., 2013)
 - Lower likelihood of specialized interventions for CAD or circulatory meds (De Hert et al., 2011)
 - Stigma, discomfort caring for people with SMI (Steinstra & Chochinov, 2006; Tarzian et al., 2005; Zolnierek & Clingerman, 2012)
 - Hospice nurses expressed lack of knowledge, anxiety, fears for own safety, dislike, belief that it is “not our role” (McCausland, 2007)
 - “no right place to die” (Morgan, 2016)

SMI and Palliative Care

- Little known about rates of SMI in PC populations or how often individuals with SMI seek out or receive PC (Chochinov et al., 2012; Lloyd-Williams et al., 2014)
- One New Zealand study found that individuals with SMI are 3.5 times less likely to receive palliative care than those without SMI (Butler & O'Brien, 2017)
- Another study across six VAs found DNR status at time of death did not vary as a fx of mental health dx (Bailey et al., 2012)
- Ganzini and colleagues (2010) found that veterans with schizophrenia dying from cancer, though less likely to receive home hospice d/t lack of a caregiver, had otherwise comparable if not better EOL care than non-mentally ill counterparts
 - Of note, individuals were *not* transient and/or nonadherent to their treatment and were well integrated into VA

Prevalence of Serious Mental Illness in Hospice?

Based on 1,381,182 million Medicare beneficiaries who received hospice services in 2015 (2017): 58,000 would have serious mental illness

Location of Death	Percentage	Principal Diagnosis	Percentage
Home	44.4 %	Cancer	27.7 %
Nursing Facility*	32.3 %	Cardiac and Circulatory	19.3 %
Hospice Inpatient Facility	15.0 %	Dementia	16.5 %
Acute Care Hospital	7.6 %	Respiratory	10.9 %
Other	0.6 %	Stroke	8.8 %
		Other	16.7 %

* Includes skilled nursing facilities, nursing facilities, assisted living facilities, and RHC days in a hospice inpatient facility.



Innovative Care Models

Integrated PC & SMI models (pilots)

IMhPaCT (Australia)

- Sought to increase mental health knowledge of PC providers & PC knowledge of mental health providers through workshops, observation of assessment processes, & access to educ. programs
- Aimed to improve PC to individuals living with SMI through development & evaluation of a triage tool, along with use of validated case conferencing (Taylor et al., 2012)

Mehac Foundation (India)

- Created partnerships between community mental health & PC programs in an attempt to strengthen psychosocial component of PC delivery (<http://www.mehacfoundation.org>)



Other Promising Programs

- Chronic Disease Self-Management programs
 - Incorporate self-management tasks
 - Action-planning, feedback
 - Modeling, problem-solving
 - Reinterpretation of symptoms
 - Training in specific disease management techniques
 - Resulted in improvements in patient activation, greater likelihood of using primary care services
- Peer-Patient Navigator programs
 - Assist with making sense of health care system, enhance treatment engagement
 - Need to consider how cognitive, emotional, interpersonal aspects of SMI affect

A note on Goals of Care

- Individuals with SMI receptive to goals of care conversations, advance care planning
- Yet, often assumed to be unable to participate, lack capacity
- Treatment decision making:
 - Recognize that capacity may fluctuate
 - Conduct frequent assessment of mental status
 - Explore & document preferences during stable & competent periods
 - Obtain info for medical & psychiatric preferences,

(Foti, et al., 2005¹; Foti, et al., 2005²; Candilis, et al., 2004)

values, beliefs

When I Die

Sometimes life is troubling, sometimes I cry
Who will be there when I die,
In and out of hospitals, more and more pills
Who will protect me, I am mentally ill,
I am afraid, it is driving me insane
I want to be comfortable, feel no pain,
My family is the staff, I am so confused
Who will stop them if life sustaining treatment is used?
I can't be a burden or live by a machine
A tube down my throat is not so keen,
No one seems to listen, their smiles are fake
I pretend to be sleeping when I am awake
Why should I wait, the fear I can not bare
Back in the hospital, acute care,
I don't want to die alone with two hour checks
I want to remain home with dignity and respect

The Experience of Comorbidity

It could be worse... you could have cancer...

“In the weeks since Natalie’s death, the outpouring of sympathy and grief from legions of people who have fought demons have made me keenly aware that the pain I feel from her loss is but a drop in the ocean of pain created by untreated mental illness. Wrote one woman, “I have bipolar disorder and can’t even begin to tell you how many people over the years have said to me, ‘Be glad that is all you have.’ ‘It could be worse, you could have cancer or some other terminal illness. . . .’ It saddens me that so many people do not realize that mental illness, while treatable, is not a curable disease, and can lead to death.”

“My daughter lived more than six years with an incurable disease that filled her head with devils that literally hounded her to death, and she did it while laughing, painting, writing poetry, advocating and bringing joy to the people around her. She was the bravest person I have ever known, and her suicide doesn’t change that.”

Dors Fuller, Washington Post, April 20, 2015

Hope, Natalie Fuller, December 2013

• Hope

There is a little piece of glitter following me around
I see it on the carpet and I see it on the ground
that’s been following me for quite some time
guess I never noticed it before
But I know what it means, that little glitter on the floor
It’s hope.

It’s not coincidence, nope, it’s hope.
And I know that I’ve failed you
yeah I know I’ve been untrue
but that glitter on the floor
tells me it doesn’t matter any more
Cuz’ no matter how many times I fail
I’ve got hope.

This time, I’m gonna be better
and I know there’s stormy weather
Please believe in me
I will solve this mystery
and I will show you
to have hope.

It’s not coincidence, nope, it’s hope.
Someday that glitter will shine
Gonna write my rhyme until the time.
My heart’s beatin’ outta my chest
I wanna rest but that don’t impress
I gotta fight this urge
gotta get the electricity surge
I know I can do it

Beat my demons



"Inner Demons" Dadu Shin

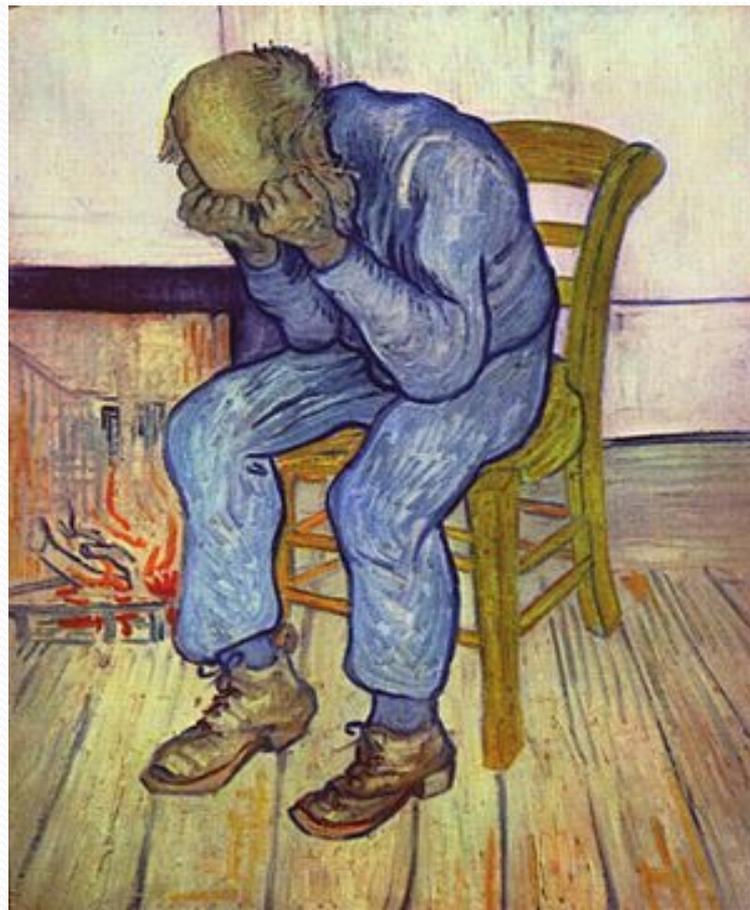
Schizophrenia & Medical Illness

- Higher rates of smoking, obesity, substance abuse, cardiovascular disease, COPD, diabetes (Copeland et al., 2008; Hendrie et al., 2014)
- More postoperative complications; greater delays between dx of cancer & initiation of rx (Irwin et al., 2014; Hendrie et al., 2014)
- Lower utilization of hospital-based or community-based palliative care (Chochinov et al., 2012)
- Increased likelihood of dying in nursing homes (Chochinov et al., 2012)
- Psychotic symptoms can impact relationships with health care
 - Withdrawn or bizarre affect, disordered thought processes, communication and perceptual disturbances may make it difficult to obtain information, engage in treatment

Schizophrenia & Medical Illness

- Medical management
 - Less likely to receive pain medication, potential reasons:
 - Pain insensitivity / fewer pain complaints (Dworkin, 1994; Talbott & Linn, 1978; Karasu et al, 1980)
 - Less able to communicate sx's or verbalize pain; rather may appear quieter, display affect flattening, more negative sx's
 - Pain may be incorporated into delusions, thereby distorting experience or reporting of pain (Webber, 2012)
 - Odds of receiving antipsychotics decreases with increasing medical complexity (Chawastisk et al., 2006)
 - Argues for good continuity / care coordination between mental health and medical care providers (McNamara, Same, Rosenwax, Kelly, 2018)

Van Gogh "At
Eternity's Gate"



Depressive Disorders & Advanced Illness

- MDD 5%-50% in advanced serious illness; prevalence varies by setting & disease (Akizuki et al., 2016; Mitchell et al., 2011; Walker, Hansen, Martin, et al., 2014; Walker, Hansen, Martin, et al., 2013)
- Risk factors
 - Complications of disease & treatment, impact of illness
 - Poor performance status, loss of control / autonomy
 - Loss of purpose, meaning in life
 - Pain
 - Previous history of depression
 - Perception of oneself as a burden
 - Poor support
 - Concurrent stressors (e.g. financial strain, younger age)
(Gibson & Breitbart, 2003; Goy & Ganzinni, 2003; King, et al, 2005; Lie et al., 2015; Wilson et al., 2009;)
- Independent predictor of poor survival in advanced cancer, of rehospitalization & death in heart failure (Freedland et al, 2016)

Elevated Risk for SI in Persons with Cancer

- Most vulnerable after learning of prognosis and experiencing distress (Misono, Weiss, Fann, Redman, Yueh, 2008)
- Additional risk factors
 - Poor prognosis
 - Lack of social / familial support
 - Hopelessness
 - Helplessness
 - Diminished control
 - Poor communication with healthcare providers
 - Difficulties with making treatment decisions & with everyday living
 - Substance use
 - Family history of suicide

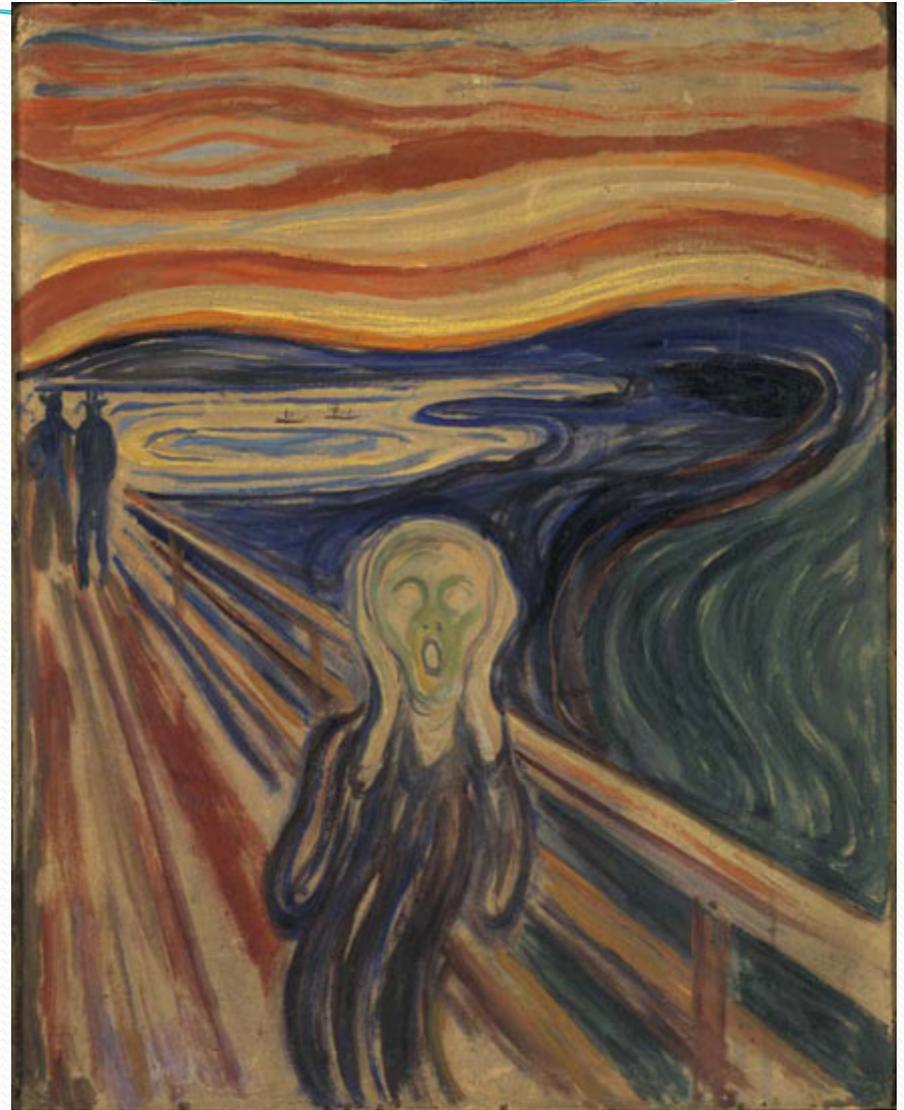
Interventions for Depression

- Collaborative care model (advanced cancer)
 - Antidepressants
 - Problem Solving therapy
 - Behavioral Activation
 - Care coordination between primary care, oncology, psychiatry
- Managing Cancer and Living Meaningfully (CALM) (advanced cancer)
 - Sx management
 - Communication
 - Changes in relationships / self
 - Existential approaches: meaning, purpose, concerns related to future)
- Dignity therapy, Meaning-Centered Psychotherapy (advanced illness)
- Promise for Acceptance and Commitment Therapy (ACT), CBT

(Lo, et al., 2014; Nissim et al., 2012; Sharpe, et al., 2014; Walker et al., 2014)



"Anxiety" by Edvard Munch (1894)



"The Scream" by Edvard Munch (1910?)

Anxiety Disorders & Advanced Illness

- Prevalence
 - 2% -30% (average 10%) in individuals living with advanced serious illness (Roth & Massie, 2007; Kadan-Lottick et al., 2005; Miovic & Block, 2007; Spencer, Nilsson, Wright, Pirl, & Prigerson, 2010)
 - Higher rates of GAD, Panic among COPD vs. general pop.
- Risk factors (Holland et al.,1999; Bambauer,et al., 2006; Gibson, et al, 2006; Goy & Ganzinni, 2003; Sheikh, 2003; Hofmann, et al, 2017)
 - Underlying disease (pneumonia, pulmonary embolism, lung cancer, pleural effusion, COPD); symptom burden (partic. pain, nausea, dyspnea, loss of appetite, tiredness)
 - Meds (adverse / paradoxical reactions to corticosteroids, stimulants)
 - Substance use
 - Conditioned response to treatments (radiation, chemotherapy)
 - Uncertainties / fears of living with life-limiting illness
 - Time constraints for attending to unresolved issues
 - History of diagnosable disorder (GAD, OCD, Panic)
 - Anxiety disorder in caregiver

Interventions for Anxiety

- Modified CBT
 - psychoeducation
 - goal setting
 - relaxation training
 - coping strategies for cancer related fears
 - activity planning & pacing
- Relaxation / imagery with breathing retraining
- Mindfulness-based cognitive therapy
- Mindfulness-based stress reduction

(Chambers, Foley, Galt, Ferguson, & Clutton, 2012; Greer et al., 2011; Shennan, Payne, & Fenlon, 2011)



Girija Kaimal et al. BMJ Open 2018;8:e021448



Girija Kaimal et al. BMJ Open 2018;8:e021448

PTSD & Advanced Illness

- Increased risk for CAD, poor health behaviors (Ahmadi, Hajsadeghi, Mirshkarlo, Budoff, Yehuda, & Ebrahimi, 2011; Zen, Zhao, Whooley, & Cohen, 2012)
- Cancer can be interpreted as life-threatening experience &, in combination with tx, may increase risk for PTSD or lead to persistence of PTSD (Gold et al., 2012; Cordova, Riba & Spiegel, 2017)
 - Prevalence of PTSD from cancer = 3%-45% (4%-6% median) (French-Rosas et al., 2011; Gold et al., 2012; Kangas et al., 2005)
 - Elevated dissociative reactions, acute emotional distress within initial mos following dx predicts development of PTSD 3 mo post-tx (Kangas et al., 2005);
 - Up to one third of pts who were initially dx with PTSD had persistent or worsening sx 4 years later (Chan et al., 2018)
- Stressors of illness may trigger / worsen PTSD symptoms
 - Fear of death
 - Intrusive treatments, medical care
 - Lack of privacy in hospital room
 - EOL reminiscence, magnification of perceived moral injury

Pain and PTSD

- Pain interference associated with PTSD symptoms
 - Pain interference = disruption of activity or functioning because of pain, fear of pain
 - Daily awareness of pain interference may act as reminder of cancer-related trauma
- Pain anxiety & pain catastrophizing mediate relationship between pain interference & PTSD SXS (Roth, St. Cyr, Harle, & Katz, 2013)
 - Pain anxiety = cognitive anxiety, escape/avoidance behaviors, fear of pain, physiological sxs of anxiety
 - Pain catastrophizing = exaggerated negative mental set during actual or anticipated pain experience characterized by rumination magnification helplessness

Interventions for PTSD

- CPT, PE may require careful considerations
 - Does the person wish to or is able to process trauma
 - Time constraints
 - Grounding strategies, mindfulness exercises
 - General coping skills
 - Modified Acceptance and Commitment therapy (ACT), Cognitive and Behavioral therapy (CBT)
- Stepwise Psychosocial Palliative Care model
(Feldman, Sorocco, & Bratkovich, 2014)

(Glick, Cooks, Moye, & Kaisr, 2018)

Stepwise Palliative Care Model

- Three stages; progress to next stage only if the previous stage did not effectively diminish symptoms
 - Stage I --rapport-building through active listening, problem-solving strategies for practical issues, social/ environmental modifications to prevent trauma triggers, and facilitation of communication between family, individual with PTSD, and providers
 - Stage II --psychoeducation about PTSD and introduction of basic coping skills (relaxation and breathing retraining, thought-stopping, mindfulness-based interventions, and communication skills). In this stage, the provider also trains family members to help the individual with PTSD practice these skills

Stepwise Palliative Care Model

- Three stages (cont.)
 - Stage III --exposure-based interventions with emphasis on cognitive processing and meaning making. Tailored to the individual's ability and used only when prior stages do not sufficiently reduce symptoms
 - Providers are encouraged to use their clinical judgment when using this final stage, given the emotional, psychological, and existential distress this may evoke
 - Limited research exists on this proposed model of intervention, with hopes for more outcome data on its efficacy

Substance Abuse & Palliative Care

- Among individ. living with cancer, including those admitted to PC units / seen through outpatient PC services, substance use disorders ranges from 20%-38% (Barclay et al., 2014; Braiteh et al., 2007; Carmichael et al., 2016; Dev et al., 2011; Parsons et al., 2008)
- Substance use disorders can exacerbate suffering, decrease QOL, complicate management of symptoms & distress family care partners (Krashin et al., 2012; Passik & Theobald, 2000)
- Individuals actively using can be difficult to engage in treatment, less compliant with treatment (Morasco et al., 2011)
- Individuals with addiction histories may be at increased risk of relapse when prescribed pain meds; risk or fear thereof should be acknowledged and non-pharm interventions offered (Krashin et al., 2012)
- Context of substance use disorders or fear of opioid misuse can complicate pain management
- High risk individuals should be monitored and opioid risk management approaches utilized (Kwon, et al., 2015; Pergolizzi et al., 2016)

Summary

- Palliative and end-of-life care should focus the unique needs and challenges of those individuals living with SMI
- Innovative care models may be needed, particularly those that include cross-training in palliative care and mental health
- Best practices should integrate people with SMI, families, mental health care, palliative care, family medicine, and social services