

# Mental Health and Serious Illness Care

## **AUTHORS:**

Harold Alan Pincus, MD  
*Columbia University/ New York State Psychiatric Institute*

Daniel Shalev, MD  
*Columbia University/ New York State Psychiatric Institute*

Brigitta Spaeth-Rublee, MA  
*New York State Psychiatric Institute*

Stephanie Cheung, MD  
*Columbia University*

Mingjie Li, MS  
*New York State Psychiatric Institute*

Jon Levenson, MD  
*Columbia University*

*Prepared for the Gordon and Betty Moore Foundation  
August 2018*



**CONTACT INFORMATION:**

Harold Alan Pincus, MD  
1051 Riverside Drive, Unit 09  
New York, NY 10032

Phone: 646.774.5400

Fax: 646.774.8443

Email: [Harold.Pincus@nyspi.columbia.edu](mailto:Harold.Pincus@nyspi.columbia.edu)

## Executive Summary

Behavioral health problems are highly prevalent among people with serious medical illnesses including cancer, stroke, heart disease, chronic obstructive pulmonary disease, end stage renal disease, chronic neurologic/neurodegenerative disease, and dementia. Individuals with comorbid behavioral health problems often experience inadequate and fractured (“siloed”) care that not only fails to address their specific clinical and social needs, but often goes against the patient’s wishes as well as those of their caregivers. Gaps in behavioral health care in this population, including care for serious mental illnesses and substance use care, can impact clinical outcomes and patient satisfaction, caregiving, decision-making, and overall cost of care. At the same time, the ability to effectively address the needs of seriously ill patients with comorbid behavioral health issues is impeded by an acute shortage of adequate workforce in the field, which will be further compounded by demographic changes.

Within the past decade, multiple innovative programs and demonstration projects have illustrated new approaches to integrated behavioral health and medical care to address the mental, physical, and social needs. However, most of these emerging models are not easily applicable to the serious illness care setting to address the specific needs of patients at this interface, many of whom are elderly, disabled, and/or frail.

Against this background, the objectives of this white paper are to:

- Describe the scope of behavioral health needs among people with serious illnesses;
- Provide a conceptual model detailing key components of behavioral health provision in serious illness care;
- Recognize current gaps in behavioral health services provision for people with serious illness;
- Identify clinical, organizational, and policy opportunities for improvement of behavioral health care in serious illness care settings.

The proposed behavioral health – serious illness care model (BH-SIC Model) provides a conceptual framework of ‘building blocks’ to support behavioral health integration into serious illness care across the serious illness care continuum. Its design can conform to variations in existing serious illness care programs, including severity of medical/behavioral health diagnosis in patient population, care setting (e.g., hospitals, outpatient settings, post-acute facilities, community-based or home-based care settings, and nursing homes, etc.), as well as existing program design, internal capabilities, and funding sources/payment arrangements.

However, the implementation of these building blocks and the successful shift toward more integrated, person-centered care for these individuals across the care continuum requires the realignment of existing regulatory, organizational and funding structures, adequate training and retention of clinical workforce, and overall cultural change through leadership buy-in from stakeholders and disciplines throughout the entire healthcare system.

## I. Introduction

This work was conducted as part of a wider initiative by the Gordon and Betty Moore Foundation to improve community-based care for persons with serious medical illnesses such as diabetes, heart disease, chronic lung disease, cancer, and dementia. The foundation prioritized five primary strategies to advance this agenda: surveillance systems, public education, payment and accountability, workforce development, and model programs (exemplars of high-quality care). This work is built upon the recognition that serious illness care involves individuals who require holistic care in a number of dimensions spanning both physical and behavioral health. Establishing the behavioral health component of serious illness care as a core part of all five primary strategies is an important step forward in building an understanding of the role of behavioral health in serious illness care.

There are various definitions of serious illness (1). For the purpose of this report, we define “serious illness” as a health condition that carries a high risk of mortality and either negatively impacts a person’s daily function or quality of life, or excessively strains their caregivers (2). Individuals with serious medical illness have high rates of behavioral health comorbidity. Behavioral health issues commonly emerge in the serious illness care setting, either as a manifestation of systemic disease processes, and/or as a result of the psychosocial stressors of illness and disability. Additionally, persons with pre-existing behavioral health needs who develop serious medical illnesses are at high risk of exacerbation of their behavioral health problems as their needs and access to pre-existing behavioral health services change.

Despite the behavioral health burden in the serious illness population, our health system operates in separate systems of care for addressing medical/surgical conditions and mental health conditions. These “silos” have evolved over centuries creating conceptual, cultural, policy, and practical barriers to effective integration of care. Individuals with comorbid behavioral health problems and serious medical illness often experience fractured care that fails to address the extent of their needs. Gaps in behavioral health care in this population can impact every aspect of their care including clinical outcomes, caregiving, decision-making, and cost.

This project focuses on persons with high medical needs, as defined by a 2014 Institute of Medicine report *Dying in America*, at the interface of care for serious illness and behavioral health care (3). To explore behavioral health care in the context of serious illness care, we identified current models, surveyed and interviewed experts, and reviewed the literature in the field to better understand the scope of behavioral health needs in the serious illness population, data on effective interventions, and key gaps and barriers to improvement.

The objectives of this white paper are to:

- Review the scope of behavioral health needs among people with serious illnesses.
- Provide a conceptual model detailing key components of behavioral health provision in serious illness care.
- Recognize current gaps in behavioral health services provision for people with serious illness.

- Identify clinical, organizational, and policy opportunities for improvement of behavioral health care in the serious illness care setting.

## II. Methodology

We applied a pyramid of four approaches in broadly gathering and synthesizing information for the project:

### 1) Systematic literature review

We conducted a systematic literature review to better understand the key issues, particularly focusing on a) the prevalence of behavioral health conditions (i.e., mental and substance use disorders) in individuals with serious illnesses – cancer, stroke, heart disease, chronic obstructive pulmonary disease, end-stage renal disease, and dementia – which were selected based on Centers for Disease Control and Prevention’s mortality statistics (4); b) available screening tools, treatment interventions, and care programs targeting behavioral health conditions in the context of serious illnesses; c) evidence-based interventions to address behavioral health issues for individuals with serious illnesses and their family caregivers, and d) policy issues affecting those patient populations. We conducted an extensive review of the literature that was published from 2007 to 2017 using PubMed; this included screening of the cited references, conducting an additional search of “grey literature”, and reviewing literature recommended by experts. Through this comprehensive review, we provide an in-depth description and analysis of the scope and contours of the problem, identify critical gaps in knowledge and key barriers to reform, and describe promising opportunities for impact at the clinical, organizational, and policy levels.

### 2) Expert survey

A survey was sent to 113 experts who are either well-known leaders in this field or who are currently actively involved in serious illness care and behavioral health care services. We received 55 responses from those experts and their colleagues. Experts were asked the following questions: a) how can behavioral health care be improved for people living with serious illnesses; b) what are the major challenges to implementing those improvements; and c) what are the strategies to successfully integrate behavioral health care into serious illness care. In addition, we asked them to recommend specific clinical programs or systems that may inform best practices.

### 3) Targeted key informant interviews

We conducted interviews with two groups of key informants: a) national experts and stakeholders with backgrounds related to research, clinical care, and experience in serious illness care and behavioral health; and b) serious illness care program leaders. We identified program leader interviewees through a review of the grey literature and recommendations from expert surveys. In total, we interviewed 11 experts and 12 program leaders.

#### 4) Expert advisory group

With input from the foundation, we convened a national multidisciplinary Advisory Group with 11 members, whose expertise encompassed aging, palliative care, behavioral health, health policy, patient advocacy, and serious illness care models. Meetings were conducted remotely with each advisory group member to elicit feedback about proposed Behavioral Health and Serious Illness Care Model (BH-SIC Model), and to obtain input on the design and structure of this white paper.

### III. Nature and Extent of the Issue

#### 1) Prevalence per subpopulation

To date, the epidemiology of behavioral health problems in people living with serious medical illness has been organized around medical diagnoses and care settings. Discrete, robust bodies of data exist about the epidemiology of various behavioral health diagnoses among those with specific serious medical illnesses. Such data, when considered holistically, demonstrate that behavioral health problems are common among people with serious medical illnesses. The nature of behavioral health needs evolves over the trajectory of medical illness; while anxiety and mood disorders are most commonly recognized and studied in the early and intermediate phases of illness, agitation and delirium supersede these among those at the end-of-life. Behavioral health needs differ by setting; patients in outpatient clinics may have high burdens of depression and anxiety, while those on in-patient hospice units may have a much higher prevalence of delirium. Additionally, though data remain limited, there are likely epidemiologically significant differences in behavioral health needs among persons of different genders, socioeconomic backgrounds, ethnicities, and other demographic factors (5). Below is a brief review on the epidemiology of behavioral health problems in selected common serious medical illnesses.

Of note, relatively little epidemiologic data exist on substance use disorders (SUD) and serious mental illness (SMI) in the seriously medically ill. However, the burden of SUD and SMI in serious illness care is significant. Rather than address this in our epidemiology section, we address it more robustly later in the white paper, predominantly in our sections on implementation and policy challenges. Please refer to this section for further information.

##### a) Cancer

There is relatively abundant data on the epidemiology of behavioral health problems among people with cancer. Approximately 50% of people with cancer experience a psychiatric disorder; this may increase in advanced cancer (6). While a cancer diagnosis is a risk factor for exacerbation of pre-existing mental illness, many individuals with cancer develop de novo psychiatric illnesses in the setting of their diagnosis and treatment (7).

The most studied behavioral health problems among persons with cancer are depression and anxiety. Of note, data is mixed between symptoms, subsyndromal presentations, and full

syndromal presentations of anxiety disorders and major depression creating wide variation in estimated incidence and prevalence. Prevalence of depression among individuals with cancer range across data sets from 7% to 60% (6,8–14)(15). The wide range in prevalence is reflective of differences in cohorts studied including cancer type, stage, and care setting, as well as in screening methods. Among studies using structured clinical interviews to formally diagnose depression, rates of major depressive disorder are significantly lower at 11% (16). Rates of suicide among persons with cancer are elevated, particularly in persons with recent diagnoses of advanced cancers, and specific types of cancer including pancreatic, lung, and head/neck cancer (12–14). Although a causal relationship has not been fully established, the magnitude of risk of suicide conferred by a diagnosis of cancer is variable and ranges from a mortality ratio of 1 to 11, likely depending on demographic and disease-specific factors (20). The prevalence of anxiety also varies widely, ranging from 3.2-5.2% to 70% among individuals with advanced disease and/or patients in the intensive care unit (ICU) setting (6,9,10,21). Such discrepancies reflect differences in screening and lack of differentiation between anxiety as a symptom and anxiety disorders. The relationship between depression, anxiety, and cancer distress (a separate entity used to measure emotional distress in psychooncology settings) remains unclear and may obfuscate epidemiologic data (22).

Although less robustly studied, other behavioral health problems among persons with cancer include posttraumatic stress disorder (PTSD) (prevalence of 2.4%, though with up to 50% of them having sub-syndromal symptoms), and sleep disturbance (54-60.8%) (6,11,23,24). As patients move from diagnosis to disease-oriented treatment to either survivorship or purely palliative care, the nature of behavioral health problems change. For instance, up to half of advanced cancer patients in the inpatient setting may experience delirium and/or agitation, particularly in the intensive care or post-procedural setting (21,25–28).

Recent data among veterans with cancer showed a comorbid substance use disorder rate of 6.64%. Veterans with comorbid substance use and cancer were more likely to have other medical and mental disorders, were more likely to be homeless, and were higher utilizers of medical and psychiatric services (29). Earlier studies show high rates of alcohol use disorder among patients with end-stage cancer pain (30).

## **b) Stroke**

Individuals with stroke are at high risk of psychiatric morbidity because of psychosocial stressors caused by cognitive and physical deficits following stroke and inherent neuropsychiatric effect of the stroke. Individuals with stroke have high prevalence of depression that may persist long after the initial event; prevalence of depression among persons with recent stroke (within one year) ranges from 17% to 56%; some data suggest that the variation may partially be due to the degree of deficits caused by the stroke (9,31–35). In addition, approximately 15% of persons with acute stroke experience suicidal thoughts, and of this cohort, 22% have an explicit plan (36). Prevalence of anxiety is also high among individuals with stroke; 25-29% of them had screening scores suggestive of an anxiety disorder following stroke and 18% of them had anxiety disorders by clinical interview over six months following a stroke (37). Prevalence

and incidence of anxiety disorders remains elevated for years following cerebrovascular accident; among persons with aneurysmal subarachnoid hemorrhage, 59% had clinically significant anxiety by screen in the two years following the event (38). Psychosis is a rare complication of stroke most commonly found among persons with significant cognitive deficits (39). Among individuals with aneurysmal subarachnoid hemorrhage, 26% had positive PTSD screens three years following the event suggesting a possibly under-recognized burden of PTSD in these patients with cerebrovascular disease (40).

### **c) Heart disease**

Persons with both myocardial infarction (MI) and congestive heart failure (CHF) are at high risk of psychiatric comorbidity. Prevalence of depression among individuals with CHF ranges from 10-60% depending on assessment method and the severity of the heart disease (41–43). Among initially non-depressed individuals, hospitalization for CHF is a significant risk factor for development of depression; 22% of non-depressed individuals develop depressive symptoms within a year of hospitalization for CHF (44). Similarly, persons with myocardial infarction have rates of depression ranging from 15-50% in the acute phase with an increase to 60-70% in the months following the infarction (9). A significant proportion of individuals (30%) remain clinically depressed years after myocardial infarction (45). Persons with MI are also vulnerable to suicidality. Myocardial infarction is associated with an odds ratio of 3.25 for suicide among individuals without prior psychiatric diagnosis compared to those without MI. Among people with both MI and prior psychiatric diagnosis the odds ratio is 64.05 compared to people with neither conditions (46).

PTSD and anxiety disorders are also significant comorbidities among individuals with cardiac disease. Four percent of inpatients hospitalized for MI meet criteria for PTSD and 12% have some symptoms of PTSD without meeting full diagnostic criteria (47). People with MI also have an approximately five-fold increase in risk for development of an anxiety disorder compared to healthy controls (48). Following MI, approximately a third of individuals experience clinically significant anxiety and half of them continue to experience significant anxiety at one year (49). Additionally, 10-50% of individuals with MI meet criteria for panic disorder (9). Likewise, people with CHF have anxiety disorder rates of 11-45% and this may be higher in those requiring implantable cardiac defibrillators (42,43).

Following myocardial infarction, approximately 5.7% of individuals become delirious (50). However among patients with acute heart failure, the incidence of delirium during hospitalization is 23% (51). Additionally, 24.5% of patients undergoing cardiac surgery have subsequent post-operative delirium and 15% of elective cardiac surgery patients screened positive for depression in the PHQ-9 (52).

### **d) Chronic obstructive pulmonary disease**

Chronic lung disease is particularly associated with high rates of anxiety secondary to dyspnea and other pulmonary symptoms, though rates of depression are also significantly



elevated in people with chronic obstructive pulmonary disease (COPD). Prevalence of depression in people with COPD varies widely from 8-80%, though studies using structured clinical assessment trend towards higher prevalence and the vast majority of data suggests significantly increased odds ratio of depression in persons with COPD (43,53–59). For a variety of reasons, including the overlap of the somatic symptoms of depression and medical symptoms, individuals with COPD may be undertreated for depression, which may also be true for other populations (56,60). Additionally, COPD is associated with increased risk for suicide attempts which scales with severity of disease. Individuals with severe COPD have an odds ratio of 2.83 for making a suicide attempt, and hospitalization for COPD is associated with an odds ratio of 2.6 for completed suicide (61,62).

Prevalence of anxiety disorders among individuals with COPD ranges from 10-74%, likely with similar rates among outpatients and inpatients (43,58,59,63,64). Prevalence of panic disorder may be as high as 41% (64). There is also evidence of prevalent disordered sleep among individuals with COPD; 35% report difficulty with sleep on symptom assessment (63). Little data exist on the relationship between PTSD and COPD (65).

#### **e) End-stage renal disease**

Depression and anxiety are common among people with end-stage-renal-disease (ESRD) owing to psychosocial stressors associated with fatigue, need for ongoing dialysis, and potentially the wait for renal transplantation, as well as metabolic derangements inherent to severe kidney disease. Among individuals with end-stage kidney disease, 23.7% meet criteria for depression, and depressed persons have greater cognitive deficits than non-depressed controls (66). Forty-two percent of individuals with ESRD meet criteria for clinically significant anxiety (67). Additionally, among people awaiting renal transplantation, rates of depression and anxiety rise over time (67).

#### **f) Chronic neurologic/neurodegenerative disease (excluding dementia)**

People with chronic neurologic disease, such as amyotrophic lateral sclerosis (ALS) and Parkinson's disease, experience high psychiatric symptom burden. Both ALS and Parkinson's disease may have inherent neuropsychiatric symptomatology from the disease itself, and a subset of people with both conditions develop dementing syndromes with the full spectrum of neuropsychiatric symptoms associated with dementia. Among individuals with ALS, rates of depression are significantly higher than the general population; within the first year of diagnosis, the odds ratio of a depression diagnosis is 7.9 that of matched controls, and a sizable minority of depressed individuals with ALS experience severe depression (68,69).

Among outpatients with Parkinson's disease, 27-38.7% screen positive for clinically significant anxiety, while 18-36% screen positive for depression (70,71). However, some evidence suggests that full major depressive disorder may be significantly less common than depressive symptoms (72). Obsessive-compulsive disorder-type symptoms are also prevalent, affecting up to 52.8% of individuals with Parkinson's disease (71).

## g) Dementia

Dementing illnesses differ somewhat from other serious medical illnesses in that psychiatric symptoms comprise part of the inherent symptom cluster of the illness, rather than comorbidities. Behavioral and psychiatric symptoms of dementia include a range of symptoms ranging from psychosis to affective and anxiety symptoms, to apathy, agitation, and aggression (73).

Neuropsychiatric symptoms among people with dementia are extremely common. Among individuals with dementia being admitted in the acute care setting, some 75% have behavioral and psychiatric symptoms during their hospitalization (73). In the inpatient setting, aggression and activity disturbances are the most commonly occurring behavioral symptoms (73).

Among patients with dementia in the primary care setting, behavioral and psychiatric symptom burden differs. Approximately 43.8% of patients with dementia exhibit behavioral health symptoms in the primary care setting, however, apathy (35% of persons with behavioral symptoms), anxiety (23% of persons with behavioral symptoms), and delusions (22% of persons with behavioral symptoms) were more common in this setting (74). Similarly, among patients with mild cognitive impairment, a possible precursor to dementia, affective/anxiety symptoms such as depression, irritability, and anxiety were most common (75). Among patients in long-term care facilities over several years, almost all (97%) have neuropsychiatric symptoms (76). Depression is particularly common among individuals with mild to moderate dementia with a prevalence of up to 42% (77). Among patients in the outpatient setting, anxiety is also quite prevalent with 19.5% having clinically significant anxiety and 22.5% subclinical anxiety. As is intimated by the above data, it is likely that as dementing illness progresses, the burden of neuropsychiatric symptoms changes from affective and anxiety symptoms to psychosis and ultimately to agitation, apathy, and aberrant behavior (76,78). This progression has been demonstrated in a number of longitudinal studies, particularly in the nursing home setting.

## 2) Impact of behavioral health conditions on course of medical illness and serious illness care

It is estimated that nearly half of Americans will meet criteria for a Diagnostic and Statistical Manual (DSM) disorder in their lifetimes (79); subsequently, a considerable proportion of people entering serious illness care will be affected by a behavioral health condition. Most prevalent are anxiety and depressive disorders, but substance use disorders and trauma-related conditions are also significant and may be complex.

Treating serious mental illness is particularly challenging in a serious illness context as mental health conditions are complicated by multiple comorbid medical conditions and potential cognitive deficits in the seriously ill elderly population; for example, psychotropic prescribing practices can be heavily impacted by medical comorbidities. However, despite increased medical morbidity among this patient population, they face challenges receiving appropriate medical care. Even if medical treatment is available, SMI patients may refuse treatment or lack capacity to make medical decisions (or have no designated surrogate) which can complicate the course of treatment and negatively impact patient outcomes.

Substance use disorders in the serious illness care setting may lead to either laxity or over-restriction in controlled substance prescribing and/or symptom management. Clinicians, particularly in the oncology and palliative care setting, may feel that it is not a priority to treat substance use disorders in the serious illness care setting and, consequently, may inadvertently worsen the morbidity imposed by the substance use (80). Conversely, individuals with underlying substance use may have inadequate symptom management owing to underprescribing (81).

Pre-existing conditions may complicate serious illness care; medical illness, treatments, and even milieu can exacerbate behavioral health conditions. Cognitive impairment such as dementia is common in the elderly, and in other cases may be the result of congenital disorders or traumatic brain injury. The medication regimen of a longstanding anxiety disorder in a person with a head or neck cancer may be disrupted in times when the oral route is unavailable. Steroid treatments for inflammatory lung diseases could exacerbate a chronic mood or psychotic disorder. People with dementia are far more vulnerable to delirium from infections and organ insufficiency, and they may have dubious capacity to consent to or refuse treatments. A history of trauma can interfere with engagement in care. Personality disorders are played out in a setting of heightened distress and stakes. Interpersonal conflict and socioeconomic difficulties may leave someone with poor social support and significant obstacles to follow up.

Just as medical illness, medical treatments, and treatment milieu can complicate pre-existing behavioral health conditions, so too can they produce new ones. For example, delirium is common among serious illnesses, especially in people with baseline cognitive impairment and is linked with poorer outcomes (82)(83)(84). New, and perhaps temporary, cognitive impairment could result from environmental change (like transfer to an ICU), chemotherapy, radiation, and treatments such as topiramate for pain secondary to disease etc. Pain itself could contribute to delirium as can misuse of opioids. Steroids, used frequently in malignancy, infection, and autoimmune disorders, can cause new onset manic episodes, anxiety, and insomnia. Neurological drug treatments such as ketamine and levetiracetam can affect serious psychiatric symptoms such as psychosis. The strain of a serious illness, concerns about the future, worries about family members, symptom burden, and change of roles from being an independent person to being the sick person can induce depressive and anxious feelings, existential distress, and interpersonal strain. Further, people may be deprived of basic pleasures such as food and sexual relations, reducing quality of life.

### **3) Impact of behavioral health conditions on clinical outcomes and cost of care**

#### **a) Clinical outcomes**

While this study seeks to explore the role of behavioral health in serious illness care and how to better address the needs of these individuals, it is important to note that patients with chronic mental illness (schizophrenia, bipolar disorder, schizoaffective disorder and major depressive disorder) have a two to three-fold higher mortality rate and poorer health outcomes than the general population (85).

Depression and anxiety are widely recognized as being associated with poor clinical outcomes and reduced quality of life across a wide range of medical illnesses and diagnoses. For example, depression is a risk factor of excessive morbidity and mortality in heart failure (86); similarly, depression is independently associated with a 1.6-fold increased risk for 7-year mortality in patients treated with percutaneous coronary interventions and anxiety is associated with increased risk of mortality in people with coronary artery disease (87)(88). Depression and anxiety also adversely affect the prognosis in COPD, conferring an increased risk of exacerbation and possibly death (89). Likewise, depressive symptoms are common in the acute phase after stroke and are associated with persistent depression and increased mortality after 12 months (90). Older adult patients with schizophrenia have an overall significantly higher mortality risk (HR: 1.25, CI: 1.07–1.47) than patients without schizophrenia; more specifically, they are more likely to die of heart disease/vascular disease and pulmonary disease than patients without schizophrenia (91).

A 16-month follow-up study of baseline rates of depression and anxiety diagnoses in ESRD patients having hemodialysis showed significantly lower quality of life and self-reported health status for people who are persistently depressed (compared with non-depressed or intermittently depressed cohorts) (92). This is consistent with earlier findings that consistently high levels of depression are a significant predictor of mortality in ESRD patients treated with hemodialysis (93).

Depression diagnosis and higher levels of depressive symptoms are also associated with higher mortality in people with new and existing cancer diagnoses, independent of disease stage and cancer site (e.g., leukemia/ lymphoma, breast, lung, and brain as well as others such as colon and pancreas) (94). Patients with serious mental illness, particularly schizophrenia, experience elevated cancer-specific mortality and die more than twice as from many common cancers (breast, prostate, lung, colorectal) (95).

Not only are psychological variables such as depression and anxiety linked to increased mortality; individuals with a depression diagnosis are three times more likely to have adherence issues with medical treatment than non-depressed individuals. Various studies which analyze the relationship between depression and medication adherence in different patient groups confirm these findings (96)(97)(98).

## **b) Utilization of health care services**

Various studies also show a link between mental illness, medication non-adherence, and emergency department visits. Among individuals with cancer, the presence of depression is associated with greater healthcare utilization including significantly more annual non-mental health provider healthcare visits, emergency department visits, overnight hospitalizations, and 30-day hospital readmissions compared to non-depressed individuals with cancer.

Paradoxically, despite increased health care utilization, access to appropriate medical care

maybe lower among people with serious illness and behavioral health issues. For example, individuals with heart failure and depressive symptoms have a significantly longer delay between clinical deterioration and hospital admission (99). Similarly, people with acute MI and a history of depression are more likely to receive a low-priority emergency department triage score than those with MI and other comorbidities, and have worse associated performance on quality indicators in acute myocardial infarction care (100). Individuals with SMI are less likely to receive routine cancer screening (101)(102). They are more likely to present with metastases at time of diagnosis and less likely to receive specialized interventions including surgery, radiotherapy, or chemotherapy (103).

At the clinical level, effective screening for and management of depression may help reduce overall healthcare utilization and cost while improving care quality. More broadly, there is growing recognition of disparities in access to and receipt of quality care for individuals with behavioral health conditions and calls for assessing healthcare quality separately for persons with behavioral health conditions by creating a new 'disparity category' to better understand and address these issues at the research and policy level (104).

### c) Cost

U.S. health care spending reached \$3.3 trillion or \$10,348 per person in 2016 (105). Medicare and Medicaid most often serve people with advanced serious illness and expenditures for both programs are expected to rise in the future. There is also a high prevalence of mental health conditions among fee-for-service Medicare-Medicaid dually enrolled beneficiaries with 41% having one or more mental health diagnoses (106). Research suggests that costs are highly concentrated among a relatively small proportion of the population. About 60% of Medicaid's highest-cost beneficiaries with disabilities were found to have co-occurring physical and behavioral health conditions and the presence of behavioral health disorders is associated with substantially higher per capita costs and hospitalization rates (107)(108).

The cost of behavioral health conditions such as major depressive disorders to health insurance systems and society as a whole are well documented. For example, depressed individuals have significantly higher costs than non-depressed individuals across 11 chronic comorbid diseases including congestive heart failure, coronary artery disease, and hypertension (even when controlling for number of chronic comorbid diseases) (109). Depression is also associated with significantly higher healthcare costs in fee-for-service Medicare recipients with diabetes mellitus and congestive heart failure (110). An assessment of three Medicaid programs revealed differences in Medicaid cost of treating cancer associated with specific chronic conditions such as cardiac disease, respiratory disease, diabetes, and behavioral health disorders: the cost of treating cancer alongside a variable chronic disease range from \$4,385 for cardiac disease to \$11,009 for behavioral health disorders (111). The mean costs for Medicare and Medicaid were significantly higher for patients with schizophrenia than for patients without (Medicare: \$63,335 and \$49,829, respectively; Medicaid: \$130,954 and \$19,996, respectively)(91).

#### 4) Impact of behavioral health conditions on family caregivers

'Family caregivers', with family defined broadly, refers to family members, friends, partners, companions, and others who are involved in assisting patients with daily living as part of the care team. Caring for individuals with serious illness increases the risk of behavioral comorbidity in family caregivers. About 13% of caregivers of stroke patients experienced considerable emotional strain (112). Clinically significant symptoms of depression are actually twice as common in the spouses of patients with advanced cancer as in the patients themselves (113). The stress of caregiving affects psychological functioning, sleep, physical health, immune function, and financial status (114). Older caregiving spouses who experience mental strain have higher risk of dying than those who are not caregivers (115). More than half of the family caregivers of individuals with advanced-stage cancer had one or more behavioral health conditions including depression, anxiety, posttraumatic stress disorder, and alcohol use disorder (116). More than half of family caregivers of people with Alzheimer's suffer from worsened health, fatigue, and insomnia; approximately 34% of those caregivers have depression, 44% have anxiety, and 27% use psychotropic medication (114) (117).

Caregiving creates a psychological burden for family caregivers who often receive little training in how to perform tasks safely and often lack support services (118). Researchers have been studying family caregivers' needs and the types of supportive interventions to address those needs. Around 20% of family caregivers of individuals with cancer want formal psychological support, particularly distressed caregivers (119). In general, there has not been sufficient research on family caregiver needs, particularly non-spouses. However, current studies provide implications for the importance of screening family caregiver in order to identify service gaps. One model of systematic assessment of caregiving within a family systems framework is developed by Qualls and Williams (120). Caregiver needs assessment should be embedded in long-term care and services as well as other serious illness care settings (121).

#### IV. Behavioral Health and Serious Illness Care Model (BH-SIC Model)

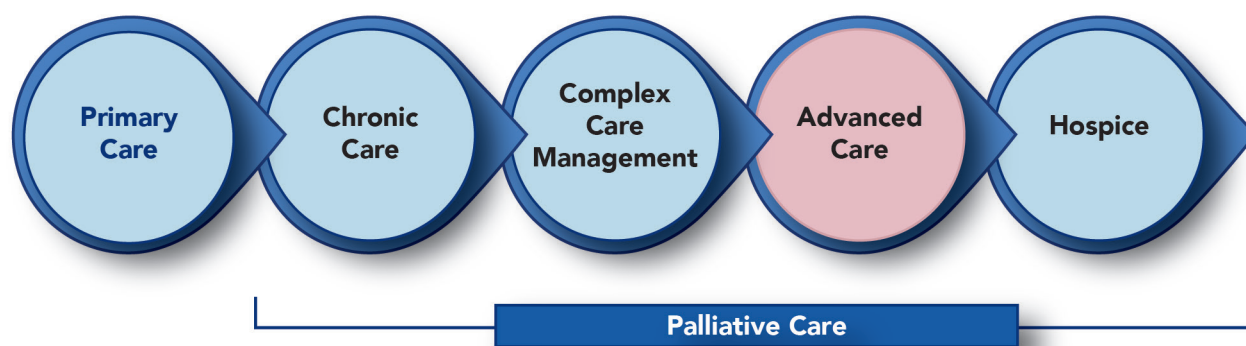
The primary focus of this paper is to describe a model for integrating behavioral health care into serious illness care. Within the past decade, various integrated behavioral health and general medical care models have been developed, tested, and applied to increase access and improve health care quality for the growing population with behavioral health conditions and comorbid chronic diseases. These include the Collaborative Care Model (122), the Improving Mood Promoting Access to Collaborative Treatment (IMPACT) model (122), the Primary Care Access Referral and Evaluation (PCARE) model (123), Partners in Care (124), and the Prevention of Suicide in Primary Care Elderly Collaborative Trial (PROSPECT) model (125), among others. In addition, large-scale public and private programs such as The Primary and Behavioral Health Care Integration (PBHCI) grant program, the Medicaid Health Home model, and the Patient Centered Medical Home (PCMH) have evolved to support the implementation of integrated care.

Although specific approaches and services vary across those programs, they share common

essential structural components such as multidisciplinary teams, coordination of care with specialists, and linkages to community and social services. While significant progress has been made in developing models to integrate behavioral health into general medical care, these efforts have generally not extended to serious illness care settings.

The BH-SIC model especially builds on two distinct models that exemplify the development of integrating behavioral health into general medical care and serious illness care– the United Hospital Fund Continuum-Based Framework for Advancing Integration of Behavioral Health into Primary Care (126), and the Coalition to Transform Advanced Care (C-TAC) Serious Illness Program Design & Implementation Framework (127). Also, the work from American Academy of Hospice and Palliative Medicine (AAHPM) has informed components of the BH-SIC model (128)(129).

**Figure 1: Care Continuum**



Source: Coalition to Transform Advanced Care (C-TAC), The Advanced Care Project (130)

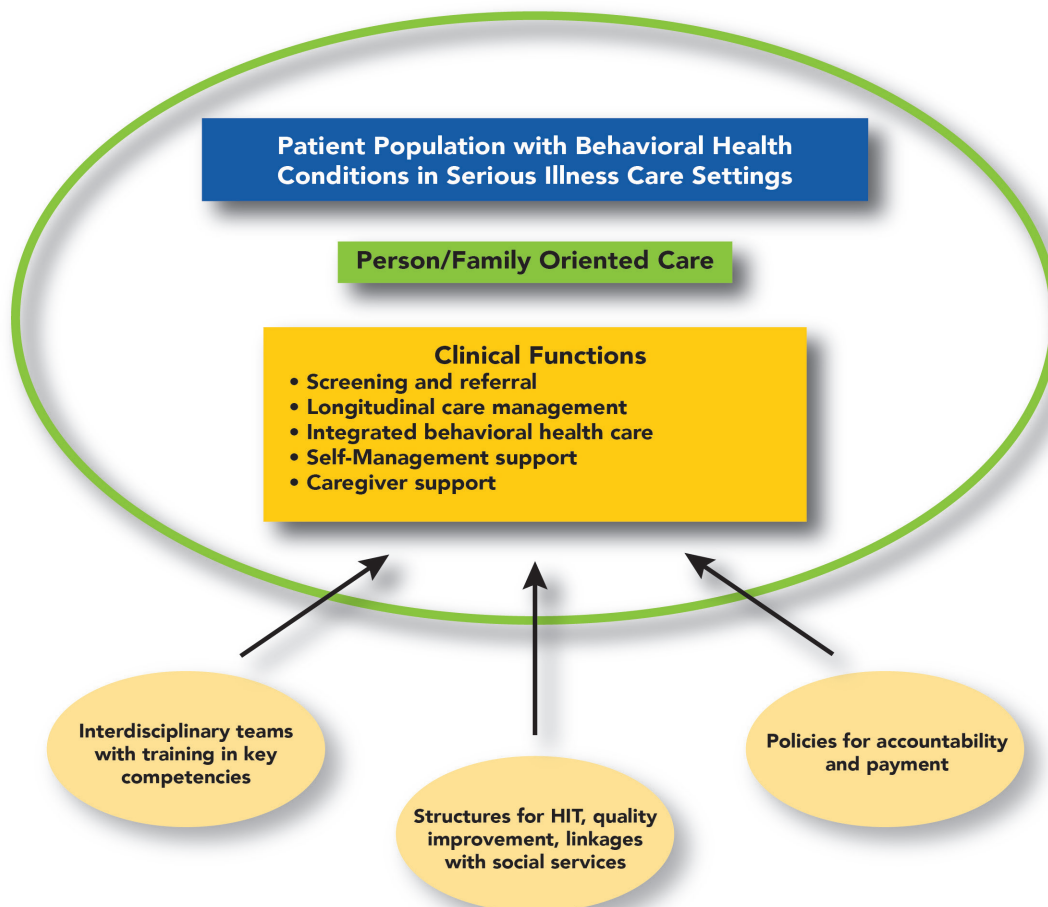
The proposed BH-SIC Model described below incorporates essential program elements with the goal of maximizing flexibility for application and implementation.

The model provides a conceptual outline of key components that serve as ‘building blocks’ to support behavioral health integration into serious illness care. These key components can be applied and adapted to the various stages of the advanced care continuum as defined by C-TAC which span from *Primary Care* at the low-intensity end of the care spectrum to the various stages of palliative care including *Chronic Care*, *Complex Care Management*, *Advanced Care* and *Hospice* at the high-intensity end of the care spectrum (130). Furthermore, the BH-SIC Model’s design recognizes local variations in existing serious illness care programs and related factors including severity of medical/behavioral health diagnosis, care setting (e.g., hospitals, outpatient settings, post-acute facilities, community-based or home-based care settings, and nursing homes, etc.), as well as existing program design, internal capabilities, and payment arrangements.

The proposed BH-SIC model takes these varying modalities into consideration by providing a set of key components and sub-components that can be adjusted and applied to different settings and stages across the care continuum. For example, over the course of the disease trajectory, individuals at the interface of serious illness and behavioral health care may receive care in a number of settings including outpatient clinics, inpatient acute care settings, long-term care facilities, and at home. Additionally, the modalities and care teams may shift (for example, patients interacting primarily with oncologic teams for potentially curative cancer treatment may, at some point, transition to receiving the majority of their care from a hospice program). With care transitions from one provider or setting to another, resources available for behavioral health services during one portion of a patient’s disease trajectory may suddenly become unavailable. Additionally, maintaining a behavioral health team with whom a patient or family unit form a therapeutic alliance may be contingent on a particular setting or phase of their illness.

The model is guided by four principles adapted from the principles identified by C-TAC (130): 1) person/family-centered care reflecting individual goals, values, preferences and concerns, 2) interdisciplinary team-based care, 3) coordinated and integrated care, and 4) value-based and accountable care.

**Figure 2: BH-SIC Model - Concepts**





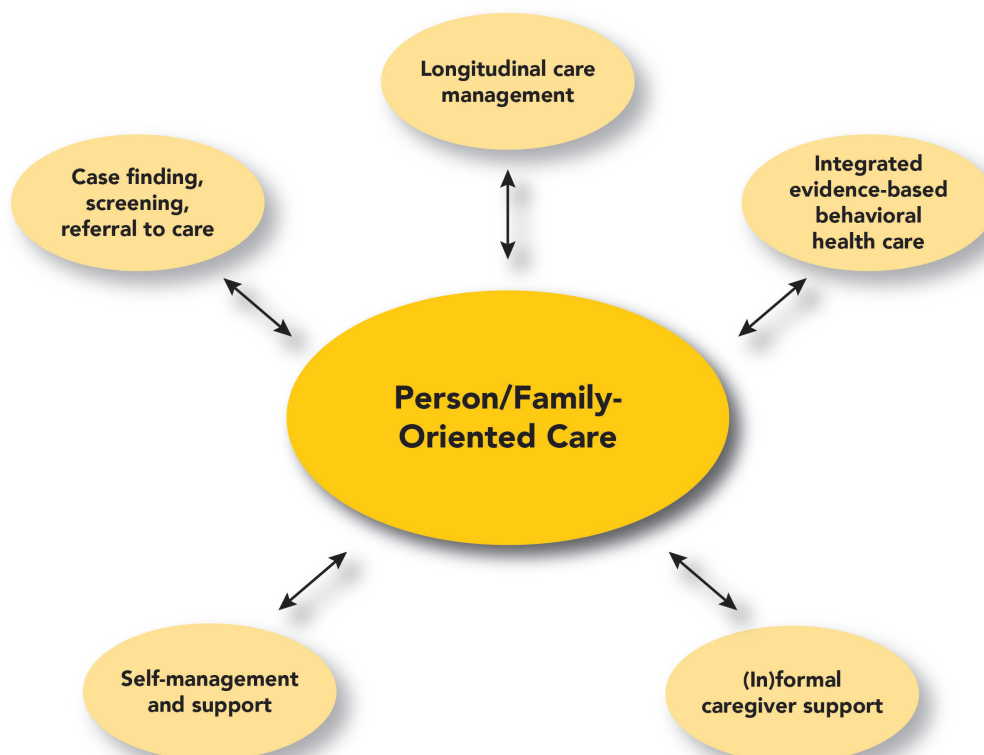
## 1) Person/Family-centered care process

### a) Provider and patient communication

Serious illness care spans evolving stages of a disease and different care settings. Shared decision-making regarding all aspects of care, including behavioral health care, is paramount to achieving the goal of incorporating what really matters to the person into care process. Effective communication lays the foundation for ensuring that an individual's wishes are revealed in terms of their personal values and goals. The model also includes family caregivers' perspectives and needs due to the vital role in providing care, and the impact that behavioral health issues of individuals with serious illness can have on them (particularly for their own health and lifestyle). An accurate understanding of an individual's motivations and up-to date care plans can help guide discussions about realistic goals and expectations, treatments options, and needs for other support services. Individuals and family caregivers should be engaged throughout the care process to ensure shared decision-making and continuous treatment alignment that will result in care that is responsive to a person's evolving goals, wishes and values. In the context of serious illness care, effective communication to honor the individual's wishes can and should be supported by systematic advance care planning. However, the lack of advance care planning earlier among individuals with comorbid behavioral health illness often means that care decision-making is made by proxies if an individual lacks the capacity to participate in these discussions due to cognitive impairment, effects of medications or other treatments, and potential psychosis or delirium.

## 2) Clinical functions

Figure 3: BH-SIC Model - Key Clinical Functions



## a) Case finding, screening, and referral to care

Early detection and referral aim to address behavioral health issues before they can exacerbate morbidity and interfere with engagement in treatment for serious medical illness. Obtaining a past history of behavioral health conditions and treatments should be routine. Standardized screening protocols should be in place and do not necessarily require behavioral health specialists for effective execution. In outpatient settings, screening by pharmacists helped introduce patients to treatment earlier (131) and screening and assessments by staff of various disciplines (pharmacist, social worker, occupational therapist, registered dietitian) in an outpatient palliative radiation setting were associated with improvement in symptoms of anxiety and depression (132). The model includes screening tools, trained personnel, and a protocol of referrals to a network of behavioral health specialists.

### *Screening tools*

Screening tools should be standardized and easy-to-use instruments that most or all members of the team can administer. Screening with these tools would supplement taking the medical history and physical examination, which would also glean risk factors and symptoms that require attention.

The ideal behavioral health screening tools would be valid in a medically ill population. For example, such a tool would not rely heavily on physical symptoms to indicate anxiety or depression. It would also be tolerable in the setting of serious medical illness. A seriously medically ill person should not be expected to engage attentively in a lengthy interview. Given the relative dearth of behavioral health specialists such as psychologists and psychiatrists, these tools should not require extensive training for accurate use.

The tools that most frequently appeared in literature do not require extensive training for use: these are the Hospital Anxiety and Depression Scale (HADS), the Edmonton Symptom Assessment Scale (ESAS), the Patient Health Questionnaire (PHQ), the Generalized Anxiety Disorder 7-item (GAD-7), and the Beck Depression Inventory (BDI). Most of these may require too lengthy a recall period for very ill or cognitively impaired patients. The BDI (133) and HADS request the person to recall symptoms within the past week, and the PHQ (133) and GAD-7 require that the person recall symptoms going back two weeks. The ESAS asks for an assessment in the moment.

In general, there are no assertive data supporting the use of specific depression or anxiety screening tools over others among the reviews and meta-analyses. The relevant articles covered the use of screening tools for depression, anxiety, and delirium in patients with cancer, acute stroke, acute myocardial infarction, and Parkinson's. Screening for depression in cancer was covered most robustly with mixed reviews of the HADS (133–135), poor reviews for the ESAS (136,137), and advice to use the 2- or 9- question version of the PHQ (138) or BDI. For anxiety screening in the setting of cancer, use of the GAD-7 was advised (138), there were mixed

reviews for HADS (134,135), and again the ESAS was not recommended (136,137). Regarding screening for depression after acute myocardial infarction, the BDI and HADS were found to be the most commonly used, but studies of their use were not of sufficient quality to draw conclusions about the validity or usefulness of these tools in such a population; again, the PHQ-2 or PHQ-9 were suggested (139). For screening for depression in Parkinson's disease, an array of tools was considered valid, including the above mentioned BDI and HADS (140).

Substance use disorder is a significant category of behavioral health issues not covered in the screening tools mentioned above. Tools for detecting substance use have been applied in the serious illness care with some effectiveness. Use of the Kreek-McHugh-Schluger-Kellogg (KMSK) scale (141) in a group of patients with viral hepatitis uncovered more cocaine, alcohol, and heroin use than did the medical record alone (142). Recommended scales are brief and easily administered tests for patients with cancer include the CAGE (for alcohol use), the CAGE-AID (includes other substances), and the urine drug screen (143).

Identifying cognitive deficits and dementia is important for treatment planning and management. A tool such as Cumming's Neuropsychiatric Interview (NPI) – a 20-minute structured interview – may be too long and involved to qualify as a brief and easily administered screening. The Mini-Mental Status Exam (MMSE), which takes about five minutes to perform, was not found to be useful in asymptomatic populations (144) but can be helpful for assessing the degree of impairment in those already with mild cognitive impairment (145). The Montreal Cognitive Assessment (MoCA), which also takes only a few minutes to perform, was a more reliable tool than the MMSE for detecting cognitive impairment in those who have already experienced cerebrovascular events (stroke or transient ischemic attack) (146) or who have Parkinson's (147).

### *Initial assessment and follow-up*

In typical outpatient medical practice, patients are referred to a behavioral health provider for evaluation and management. Alternatively, if patients cannot find a behavioral health provider or are reluctant to see one, an involved physician/nurse practitioner/physician assistant may take over prescribing psychotropics, and/or a professional with some behavioral health training may provide psychotherapy. Though not ideal, this is a practical approach given limited access to behavioral health-specific providers.

Access to specialist behavioral health providers is often especially problematic in the home/hospice setting. Multidisciplinary hospice teams seldom include a psychiatrist or a psychologist; however, other members of the team can fill some of the gaps. For example, nurses and non-psychiatric physicians can make medical adjustments such as improving shortness of breath to relieve anxiety; social workers and chaplains can help with social stressors, support needs, and existential crises; practitioners of complementary therapies can offer extra care and support. They can apply their disciplines to behavioral health manifestations that fall within their domains with some success. For example, anxiety and depression of cancer patients improved in the setting of collaboration of oncological and palliative providers (148). Patients may even find it more acceptable to receive behavioral health in a non-behavioral health setting. One cohort

of breast cancer patients found it preferable to receive antidepressants from their oncologists rather than from a behavioral health provider (149).

However, more serious or nuanced issues including severe persistent mental illness, dementia with behavioral problems, personality disorders, anxiety that cannot be attributed to worsening physical discomfort, and substance use disorders are best managed by a psychiatrist or other highly trained behavioral health specialist.

Easy access to highly trained behavioral health specialists or multidisciplinary behavioral health teams would enable timely initial assessments and follow up. The bar to access could be lowered by having such clinicians and team members on-site with or integrated into the medical teams. Collaboration between the medical team and the behavioral health specialist should not only facilitate assessment, referral, follow up, but also appropriate observance of shared protocols, and coordination in addressing the patient's needs.

## **b) Longitudinal care management**

Longitudinal care management comprises two sub-categories: 1) coordination of care over the arc of an illness over time and across settings, and 2) facilitation of acute clinical crisis management.

People with comorbid serious medical illness and behavioral health problems are at high risk of adverse outcomes stemming from the complexity of their needs. The care of such patients is composed of contributions from multiple professionals including physicians, physician assistants, nurse practitioners, nurses, case managers, social workers, behavioral health staff, pharmacists, and physical or occupational therapists. Without appropriate coordination, care may be fractured across providers, increasing risk of care gaps or of iatrogenic harm. Additionally, as the behavioral health and serious illnesses develop, changes in needs, involvement of family caregivers, and changes in settings increase the complexity of care.

Care management is a "team-based, person-centered" approach to facilitating a coherent care plan reflecting a person's goals and wishes across the span of an illness, including longitudinally adjusting to changes in individuals' needs and to transitions across and between healthcare settings. Care management involves population-level identification of modifiable risk factors for high utilization and poor outcomes, and then aligning services and training personnel to address these risk factors. Evidence from studies of care management interventions suggests that high complexity individuals, such as those with comorbid serious illness and behavioral health issues, benefit most from care management in terms of utilization reduction and improvement in behavioral health symptoms (150). Most important is the need to ensure "relentless" follow-up to avoid having them "fall through the cracks." Having a designated care manager or navigator assigned to an individual to coordinate care across multispecialty care teams, services, and settings, could strengthen those efforts.

Care management teams may have to manage a crisis which requires immediate intervention.

Behavioral health crises may include violence, aggression, suicidality, and acute mental status changes. Among individuals with comorbid behavioral health issues and serious medical illness, medical and behavioral crises may be intimately related. Medical crises such as uncontrolled pain or dyspnea may contribute to behavioral health crises; conversely, individuals in behavioral health crises, for example, may be too impaired to adhere to their regimen, thereby precipitating medical crises. For this reason, crisis management in this population requires the same interdisciplinary approach required for long-term care management. Such an approach integrates both medical and behavioral health providers in shared, person/family-centered problem solving regardless of care setting. Flexibility is required for high quality crisis management. Care teams, patients, and family caregivers should collaborate on medical and behavioral crisis prevention and management plans.

### **c) Integrated evidence-based and measurement-based care**

Integrated evidence-based and measurement-based behavioral health care is an essential component of clinical functions of the BH-SIC model, which contains two sub-components: supporting measurement-based stepped care and providing access to evidence-based psychopharmacological and psychosocial interventions. Implementation of care pathways or protocols which relate to a series of evidence-informed steps and can involve multidisciplinary teams at various care levels (i.e. primary, secondary, etc.) are important to support decision-making of integrated evidence-based and measurement-based behavioral health care for patients with complex diagnoses.

#### ***Evidence-based psychopharmacological and psychosocial interventions***

Pharmacologic interventions can be used in treating depression, anxiety, delirium, and agitation in people with serious illnesses. In people with dementia, antidepressants can be effective in the treatment of depression, though few studies identify specific agents (151). Similarly, the effectiveness of antidepressant has also been validated in people with cancer (152). As for treatment of psychotic symptoms, short-term, low-dose use of antipsychotics for controlling the symptoms of delirium in cancer patients has been supported by evidence. Health care providers should closely monitor for possible adverse effects, especially in older persons with multiple medical comorbidities (153). Similarly, various antipsychotics show benefit in managing psychotic symptoms in older persons with dementia. However, attention should be paid to the potential side effects and risks, which include increased mortality and cardiovascular and cerebrovascular events (154).

Psychosocial interventions are effective in improving mental health among individuals with serious illnesses. However, the evidence differs in terms of the types of psychosocial intervention that are effective in a particular patient population. A variety of psychotherapies, such as cognitive-behavioral therapy, educational interventions, and meaning-centered group psychotherapy, are effective in improving psychological well-being in individuals with advanced cancer (155) (156) (157) (158) (159). Collaborative care for comorbid major depression in people with cancer is also effective (160). However, there is not enough evidence to prove

that psychosocial interventions are effective in improving mood in people with head and neck cancer (161). For persons with dementia, enriched group cognitive stimulation is recommended for mood improvement (162). Psychological interventions are effective to improve self-reported depressive symptoms, anxiety, and stress in people with coronary heart disease (163). Cognitive behavioral interventions have small effect in anxiety but not depression in individuals with COPD (164). There is lack of evidence to show the benefit of psychotherapy for treating depression after stroke (165).

Even though ample evidence supports the efficacy of psychosocial interventions for individuals with serious illnesses, overall, the quality of evidence is low and the heterogeneity of psychological outcomes is high. Although some types of psychosocial treatment, such as psychoeducational therapy, consistently found to be efficacious, the magnitude of the effect varies, and, in most cases, the effects are transient.

Complementary care may also improve behavioral health symptoms, as well as alleviate pain. Music interventions are effective in reducing anxiety, depression, pain, and fatigue among people with cancer, and also lead to fewer depressive symptoms among older people with dementia (166)(167). Other therapies, including massage, acupuncture, yoga, and physical exercises, may be effective in decreasing pain, fatigue, anxiety, depression, and psychological stress in people with cancer (168)(169)(170)(171)(172). Aside from psychosocial and complementary interventions, spiritual interventions may improve spiritual well-being, anxiety and depression (173). Recent studies have demonstrated that psilocybin (a substance derived from hallucinogenic mushrooms used recreationally) improves cancer-related mood and anxiety symptoms (174). A limited but growing body of evidence on complementary care suggests it may be of use in treating behavioral health problems among patients with serious illnesses, particularly cancer.

People with serious mental illness (SMI), such as chronic psychotic disorders and bipolar disorder, may require ongoing psychiatric care throughout their medical illness. Importantly, they are also at risk for not receiving needed specialty medical care, emphasizing the importance of linkage and integration. Medical illness may put individuals with chronic psychotic disorders and severe mood disorders at higher risk of acute exacerbations. In addition, patients with SMI are at risk of receiving suboptimal medical care (175). Changes in renal and hepatic function, as well as increasingly complex medication regimens increase the risk for adverse effects, necessitating adjustments of long-standing psychopharmacologic regimens. In addition, among individuals with certain serious illnesses, oral medication regimens may not be feasible because of alterations in gastrointestinal structure and function, and swallowing issues. Strategies exist to mitigate these challenges including orally dissolvable medication formulations, short and injectable antipsychotics or mood stabilizers such as valproic acid. While dose alteration and cross-titration between medications may be necessary for persons with comorbid SMI and serious illnesses, most of them can be maintained on an efficacious and safe psychopharmacologic regimen throughout their medical illness.

Though substance use disorders (SUD) are poorly studied in the seriously medically ill, they

likely occur at similar rates as in the general population (176). Individuals with substance use pose significant ethical and clinical challenges to clinicians in the serious illness care setting. Appropriate serious illness care for individuals with comorbid substance use disorders entails both active treatment of the substance use disorder, but also active symptom management, including with directed use of controlled substances.

The therapeutic alliance between a medical team and an individual with both SMI and SUD may be more challenging than among other patients. Some medical teams will not initiate symptom management until the SUD is managed, and the medical teams themselves are unlikely to offer such management. Medically, ongoing SUD may exacerbate an already complicated illness either by direct effects or interactions with medical treatment. Practically, ongoing SUD (and its sequelae) may interfere with a person's ability to follow up with appointments, reliably adhere to treatment, and pay insurance premiums and copays.

One particularly fraught part of treating people with both SMI and any history of SUD is the management of pain. SUD may leave them with altered pain thresholds and medication tolerance, making it more likely that they will be inadequately treated. Concerns by the medical teams are that they are contributing to an addiction, colluding with diversion activities, or in danger of causing an overdose may lead to poorly treated pain. Inadequate pain treatment may trigger relapse or exacerbate an existing addiction along with straining a therapeutic alliance (177). An interdisciplinary team approach with both palliative medicine and behavioral health and SUD expertise should follow the principles of prescribing controlled substances for individuals with SUD history. Important elements include: a clear care plan that explains the roles of care team, expectations of treatment, expectations for follow up, and consequences of aberrant drug-taking; involving the person's family caregivers in the care; and using nonopioid analgesics and adjuvants, of which there are many options (178).

### *Measurement-based, stepped care*

Measurement-based care refers to the use of systematic data collection of symptom rating scales (e.g., depression, anxiety) to monitor care progress and directly inform care decisions. Measurement-based care provides insight into treatment progress, highlights ongoing treatment goals, and improves health outcomes (179). Key steps of developing measurement-based care in serious illness care settings include establishing and implementing standardized evidence-based treatment interventions (with access to informal "curbside" consultation with behavioral health specialists), and integrating the behavioral health symptom monitoring data system into electronic health records. (180).

### **d) Self-management support**

Self-management support is a crucial part of the person/family-centered care process, which aims at increasing autonomy and improving quality of life. Self-management support for individuals with serious illnesses and their families consists of two components- promoting patient activation and developing self-management skills. Patient activation- building the skills

and confidence that equip individuals to actively engage in their health care- has shown to produce improved health outcomes and care experiences (181). Self-management for individuals with serious illnesses and their family caregivers contains multiple facets of management, such as managing the medical aspects of the illness, the changes in roles brought on by the illness, and the psychological consequences of the illness. Informed individual decision-making is essential for persons to play an active role in their care, and thus it is important for health care professionals to educate patients about serious illness as well as behavioral health issues to improve health literacy.

### e) Family caregiver support

Family caregiver support is an integral component of serious illness care model. Family caregivers play a key role in the care process and may require support from health care professionals.

New models of home and community health care delivery and emerging communication technologies make the choice of receiving care at home increasingly possible for individuals with serious illnesses. However, support for their family caregivers is often lacking. Family caregivers of patients linked to palliative care often feel unprepared to care for individuals with serious illnesses, even though they receive some systematic support. But family caregivers of patients not receiving palliative care may lack any systematic caregiver support (182). One source of stress for family caregivers is the complex care tasks and the challenges of training and preparation to manage these medical/nursing tasks. To meet the needs of individuals with serious illnesses, it is important to conduct a caregiver risk assessment at the time of diagnosis, and their family caregivers must receive expanded access to supportive services. Care team should provide health coaching for family caregivers to recognize and respond to behavioral health symptoms in patients and themselves (183). Other members of the care team, such as home health aides, should be skilled in de-escalating minor agitation and provided with access to more advanced resources. Assistance with conflict resolution within the family regarding the goals of care and demands of the caregiving situation can alleviate stress. Appropriate toolkits can also be applied to facilitate the discussion between patient/family and the care team.

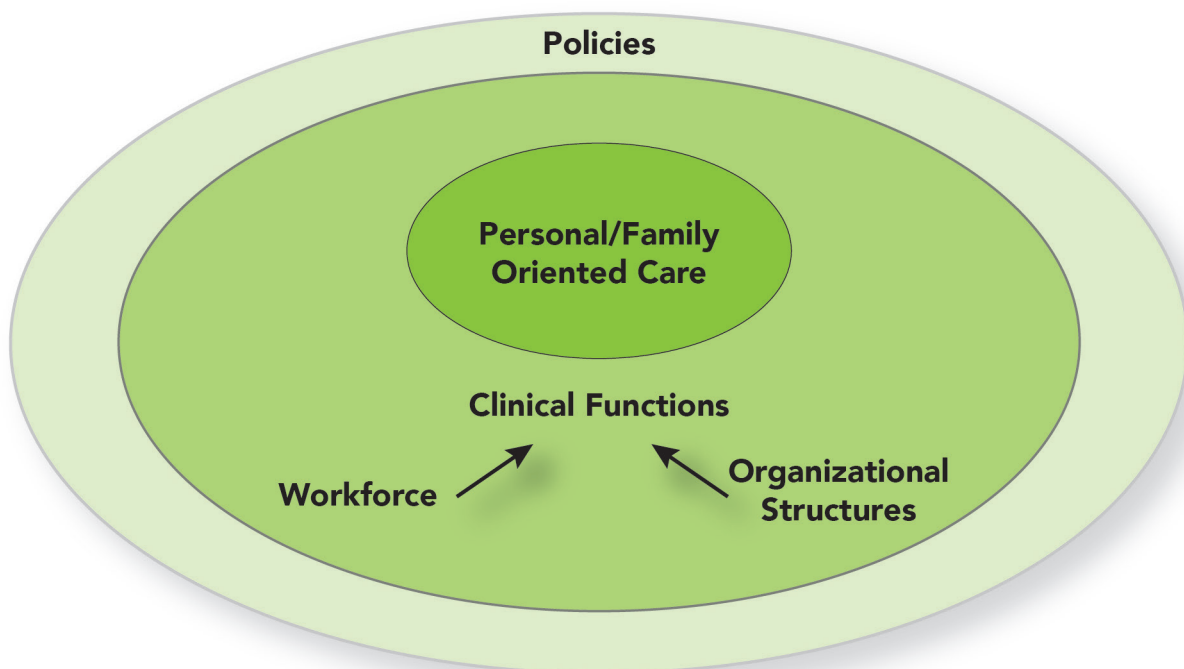
Family caregivers themselves need informal emotional support or treatment interventions to address their own behavioral health issues that likely develop from intensive caregiving. Research supports the moderate effect of psychosocial interventions on caregiver psychological well-being. Among psychosocial interventions, psycho-educational interventions have shown to yield positive results in alleviating depression, anxiety and care burden among caregivers of individuals with heart failure (184). Some of the interventions for caregivers show varied effects by chronic illness condition or disease stage. For example, coping skills training intervention has been shown to be more beneficial to caregivers of people with Stage II or Stage III cancer, while the education and support intervention is more effective to caregivers of individuals with Stage I cancer (185). Psychosocial support for caregivers should also be disease specific. In addition to psychosocial interventions that directly aim at mitigating caregiver distress, other types of supports also hold promise in improving caregiver psychological wellbeing. For example, the technology support (e.g., emergency response systems) can reduce individuals' dependency on



caregivers, respite care may provide relief for caregivers, and online support groups may also alleviate caregiver stress (186).

Bereavement, the experience of losing a loved one to death, has physical, psychological, and social consequences. Common resources for caregivers to deal with bereavement include bereavement support groups and the bereavement support that starts at the beginning of hospice care and continues for up to 13 months following the death of a loved one. Early initiation of hospice care is linked with improved bereavement outcomes (187). As a response to bereavement, grief (e.g., anticipatory grief, prolonged grief disorder), including a variety of psychological and physiological symptoms, evolves overtime. The majority of people recover from grief without clinical support. However, about 7% of bereaved older adults will develop prolonged grief disorder (188). Prolonged grief disorder is characterized by intense grief that lasts longer than expected based on social norms. Psychotherapy has been shown to be efficacious as the first-line treatment for prolonged grief disorder (189). Psychoeducation also shows potential in reducing prolonged grief disorder (190).

**Figure 4: BH-SIC Model - Overview of Key Components**



### 3) Workforce to support clinical functions

Integration of behavioral health into serious illness care models presents significant personnel challenges. Beyond simply requiring the addition of behavioral health experts to teams, behavioral health care integration also requires training of all team members in basic behavioral health skills and knowing how and when to engage team members with more expertise in behavioral health. The ability to address needs of patients at the interface of behavioral health

and serious illness care can be further strengthened by including geriatric and pain management competencies.

### **a) Interdisciplinary team**

The complex multidimensional needs of individuals with comorbid serious medical illness and behavioral health problems cannot be met by individual providers working in silos. Such individuals require an approach that integrates a range of clinical expertise paired with other services. Providing this range of care requires that teams compose of clinicians with varied backgrounds and expertise including, though not limited to, physicians and other licensed independent practitioners across specialties (including psychiatry), nurses, medical and behavioral health aides, social workers, counselors, psychologists, family caregivers, care managers, chaplains, and peers to support families and patients.

'Interdisciplinary' refers to care that is organized in a way that deliberately integrates the expertise and skills of professionals with different training and skills, including many or all of those listed above. Interdisciplinary team approach is fundamentally heterogeneous and operating across a range of models. However, successful interdisciplinary team approaches share characteristics including common vision, delineated objectives, leadership, support, defined roles, communication, respect, adaptability, and self-evaluation (191). Additionally, limited data exist on optimal function of specific aspects of interdisciplinary teams. For instance, data on interdisciplinary team meetings across chronic illness diagnoses show that such meetings are most efficacious in improving patient care when they are treatment-focused, well-documented, clearly planned for implementation, accountable, and when they consider patient comorbidities (192).

For individuals with comorbid serious medical illness and behavioral health problems, interdisciplinary teams must address both their medical illness and their behavioral health needs. Interdisciplinary team members must include clinicians capable of prescribing psychiatric medications (psychiatrists, psychiatrically-trained nurse practitioners and physician assistants, non-psychiatrist physicians with behavioral health training), providing psychosocial treatment of behavioral health conditions (psychiatrists, psychologists, social workers, nurses, and other professionals), and providing medical care (physicians, other independent practitioners, nurses). Supportive and interdisciplinary professionals such as care coordinators and case managers, social workers, spiritual care providers, legal advisors, and others further enrich the capacity of the team to provide adequate holistic, person-centered care services including social support services.

### **b) Workforce competencies**

Workforce education and training in behavioral health care for patients with serious medical illness consists broadly of two approaches: training providers from medical backgrounds (including palliative care, primary care, and specialty medical care such as geriatrics, oncology and cardiology) in behavioral health and training behavioral health providers in serious illness

care. Effective behavioral health care in the serious illness care framework must provide all members with core common-skills as well as allowing for expert involvement when complexity increases. In this vein, cross-disciplinary training for both behavioral health and medical providers is important for several reasons. Training can increase the number of providers that can implement basic, high-yield interventions to address behavioral health and serious illness care needs. It also breaks down disciplinary silos between medical and behavioral health care by creating a shared framework of knowledge and skills. Creating a culture of cross-disciplinary training and education also allows for instituting high yield education on topics germane to both behavioral health and medical providers, such as psychosocial aspects of end-of-life and serious illness care including goals-of-care and end-of-life discussions.

Education for behavioral health providers working in the serious illness care setting should focus on extending knowledge and skills regarding diagnosis and management of behavioral health issues common to the serious illness setting. Such training should include diagnosis and management of behavioral health manifestations of serious medical illnesses including delirium, anxiety, mood disorder, and psychopathology secondary to medical conditions (193). Additionally, education should focus on the interactions between comorbid behavioral health disorders and serious medical illness. Individuals with comorbid behavioral health and medical illness may have a difficult time accessing and engaging with care, and thus behavioral health experts should be educated in assisting them and their care teams with such challenges. Education on serious illness care for behavioral health providers should vary in intensity depending on the level of training and degree of involvement. According to the Accreditation Council for Graduate Medical Education (ACGME) and scholarship in the field, all psychiatric trainees should have core competencies in palliative care psychiatry and opportunities for further advanced training through fellowships and continuing medical education (193,194). Such mandates reflect that psychiatry trainees are interested in further training on end-of-life care and generally feel underprepared to provide psychiatric care to persons with serious medical illness (194,195).

Given the dearth of behavioral health providers nationally, particularly in serious medical illness setting, it is imperative that non-behavioral health providers be trained in basic core behavioral health skills. Such training should include basic information on screening and assessment of behavioral health morbidities in the serious illness care population and basic training in psychopharmacology and psychosocial interventions (193,196). The focus should be on common behavioral health issues (such as mood and anxiety disorders), high-yield, teachable interventions (such as basics of prescribing antidepressants and anxiolytics in the seriously medically ill population), and brief, operationalized psychosocial interventions (such as motivational interviewing).

Education on common skills at the interface of behavioral health and serious illness care are key for both behavioral health and medical providers. All providers should be trained in general psychosocial care of seriously ill or dying patients, such as goals-of-care discussions and advance care planning (196). Additionally, regardless of degree of training, all members

of the team should be trained in risk management, de-escalation techniques, and recognition of serious behavioral health pathology (193). Such training may differ depending on the scope of practice of individual team members but should include basics of assessment of suicidality, dangerousness towards others, psychosis, and delirium. Effective communication and care coordination between providers are paramount when caring for individuals with comorbid behavioral health problems and serious illnesses. Therefore, all providers should also be trained in effective methods to facilitate communication across medical silos between general medical and behavioral health providers.

#### 4) Structures to support clinical functions

##### a) Health information technologies and other technology support

Health information technologies (HITs) and other technology supports are important structural components to maintain systematic tracking and sharing clinical information among members of the care team across different care settings. To capture diagnoses and treatment options for patients at the interface of serious illness and behavioral health care, behavioral health concepts and terms need to be built into HIT systems. Ideally, electronic health records (EHRs) would capture data based on standardized behavioral health screening and assessment tools related to individuals' function, cognition, frailty, symptom distress, socio-economic determinants, disease types, as well as their family caregivers' capacity and burden. Using a standardized approach, EHRs should capture individuals (and family caregivers') highest priorities for future care in the context of a serious and often progressive illness, as well as the patient's health care proxy appointee. In addition, EHRs should possess registry functionality to support longitudinal care management for behavioral health issues and to enable easily understandable data dashboards to display treatment progress (or lack thereof) over time. EHRs should be interoperable to allow care team members to work in multiple settings across the care continuum. In this way, the individual's care needs can be addressed in a comprehensive and efficient manner. Interoperability may extend to granting access to co-located psychosocial information in EHRs to round out fully integrated care approaches to include social services. Ideally, data sharing platforms would include secure mobile devices to connect all care team members. Additional technologies enabling passive collection of data and patient reported outcomes and potential technology-mediated behavioral health interventions (e.g., mental health apps such as *Anxiety Reliever*, *CPT Coach*, *iCBT* etc.) should be integrated into the care team "toolbox" as they are developed.

##### b) Linkages with communities/ social services

Identifying and establishing partnerships with local community and social services that can initiate and maintain formal arrangements with housing, entitlement, and other social support services tailored to an individual's needs is another important component of our BH-SIC model. Individuals with SMI and serious illnesses are not only at high risk of disruptions to their psychosocial treatments, but loss of long-standing community care providers and supportive housing programs. Due to the unique combination of serious illness and behavioral health

issues, this patient population is also at high risk of various forms of abuse as well as neglect, financial exploitation and abandonment. Screening for social determinants of health with tools such as Health Leads and others could potentially help alleviate some of these risks (197) (198).

For individuals at the interface of behavioral health and serious illness, loss of housing/homelessness, self-neglect, food insecurity, etc. can be serious issues related to certain behavioral health diagnoses including schizophrenia. Patients can be supported by ensuring basic needs like food and housing services, maintaining stability in the treatment team, and inviting long-standing care providers (such as community psychiatrists and case managers) to continue the relationship with their patients across the care continuum and care setting. Individuals facing impaired function and frailty may benefit from home safety and access modifications and the availability of home maker services that would allow them to live and receive treatment and care in the residence of their choice (“Aging in Place”) rather than an institutional setting such as a nursing home. This gap is particularly pertinent for people with SMI – e.g., Medicaid beneficiaries with schizophrenia between the age of 40-64 are four times more likely to be admitted to a nursing home compared to those without a mental illness (199).

However, formalized arrangements and funding for these kinds of community-based support services and partnerships is often lacking. For example, many services such as transportation, personal care, family caregiver support etc. are either not currently covered (Medicare) or reimbursed at much lower rates than needed (Medicaid). The dearth of these support services can lead to “revolving door” nursing home stays, hospitalizations, and emergency room visits. Not only are these transitions extremely costly for the public and private health care systems, but more importantly, they result in poor quality of life and overall patient outcomes. Researchers and advocates increasingly focus on rebalancing mechanisms to shift services and resources to community settings (200)(201). Beginning in 2019, CMS will allow Medicare Advantage plans to cover certain home- and community-based services including assistance with activities of daily living (eating, bathing, dressing) and instrumental activities of daily living (meal preparation, housekeeping), which could be the beginning of expanding these services for Medicare in general (202).

### **c) Systematic quality improvement**

Application of relevant quality metrics along with improvement strategies targeted specifically at the care for individuals with behavioral health issues are important structural components to support clinical functions in serious illness care. The routine uses of validated quality measures (structure, process, and outcomes including quality of life as well as individual and family experience), supported by data from integrated EHRs and other sources (e.g., patient surveys) for tracking, coordination, and evaluation, are essential to guiding systematic quality improvement efforts (“Measure. Analyze. Improve. Repeat.”). However, the quality measurement and improvement infrastructure at this interface lags behind other components of the health care system. This can be partially attributed to a confluence of factors specific to the BH-SIC context which poses many challenges for the delivery of evidence based behavioral health treatment.

Those challenges include the treatment of a very diverse patient population with varying severity of illnesses (both physical and behavioral), frequent changes/adjustments in treatment modalities, and diverse providers of care and other support services involved in care delivery, often having limited training in quality improvement tools and techniques. Furthermore, very few measures with a strong evidence-based link between process performance and patient-(reported) outcomes exist for this specific patient population. Quality improvement efforts at the provider level could be strengthened by having designated quality improvement personnel to assist with the implementation, monitoring, and evaluation of these efforts across multi-specialty care teams and settings.

## 5) Policies

### a) Accountability

Assuring accountability across providers and payers is an essential component of the serious illness care model. Within the fragmented US health care system, it is critical to establish mechanisms of shared accountability across the silos of current organizational, regulatory, and financial structures. This is particularly relevant in the context of serious illness care which is provided in very different types of settings (e.g., general/psychiatric hospitals, outpatient settings, post-acute facilities, nursing homes, hospice, and community and home-based care settings) and funded by multiple sources (Medicare, Medicaid, private health insurance, out-of-pocket etc.). Appropriate accountability mechanisms require a set of multi-faceted components and interventions that include a) adequate ways to measure the quality of both physical and behavioral health care services provided to seriously ill patients and their caregivers; b) systems to support and incentivize quality improvement in both general medical and behavioral health domains of care; and c) application of these mechanisms in a way that supports the shared responsibility of all team members involved to meet quality and performance standards for all aspects of care (including behavioral health care).

Two recent projects, NCQA's Serious Illness Care Measures Project (203) and NQF's Serious Illness Care Initiative (204) are both aiming to reinforce system accountability through strengthening quality measurement efforts of care delivered to seriously ill patients regardless of setting, program or type of clinical provider. However, mental health thus far, has not been a significant focus.

### b) Payment

The way health care services are financed is a key determinant of access, quality, and cost of care. Novel payment models are moving away from existing long-standing volume-based payment arrangements (as exemplified by fee-for-service payments) to payments that are more closely related to outcomes at the individual and population level (value-based payment models). These payment models aim to encourage high quality and efficient care that incorporates adequate resources for needed services by rewarding quality, safety, efficiency, and improved health outcomes.

Novel payment arrangements for serious illness care (such as those by the American Academy of Hospice and Palliative Medicine and C-TAC that were recently recommended to The U.S. Department of Health and Human Services Secretary) will need to incorporate behavioral health related costs which are often carved out in existing payment models. Neither the AAHPM model nor the C-TAC model address behavioral health specifically; however, they do allow for interdisciplinary teams comprised of disciplines relevant to the care of these patients and their families. This could provide a mechanism to have behavioral health as a covered component under these payment models. Yet, none of these models can be separated from changes in care delivery and necessary investments in measurement and reporting infrastructure. In addition, new payment models need to be able to operationalize the definition of value in behavioral health and serious illness care.

## V. Implementation and Policy Challenges

### 1) Stigma and assumptions regarding behavioral health clinical syndromes

Care for individuals with comorbid behavioral health problems and serious illness may be influenced by biases about mental illness. This is particularly true in the case of persons with severe mental illness and substance use disorders. Individuals with SUD and/or SMI are subject to biases by clinicians including assumptions that such conditions are non-improvable and/or preclude engagement with providers around serious illness care decision-making, care planning, and symptom management, and exclusion from clinical trials. Assumptions made about persons with SMI and SUDs affect care in a number of ways including reducing access to specialist palliative care, symptom management, and reducing involvement in advance care planning.

Among individuals with SMI, despite high serious illness morbidity, palliative care provision is lacking (205)(206). People with chronic psychotic disorders have poor access to palliative care, receive less opioid analgesia than non-psychotic individuals and are more likely to die in nursing homes (207). People with SMI are also less likely to engage in advance care planning, despite data showing that they are interested and largely able to participate in advance care planning and selection of health care proxies (208).

Individuals with SMI or SUD may experience significant bias by untrained, non-psychiatric clinicians who often feel inadequately trained in working with people with severe behavioral health conditions (209). Clinicians may avoid caring for persons with SMI and/or SUD, perceive them as dangerous, or incorrectly attribute medical and/or neuropsychiatric symptoms to underlying psychiatric illness; this may be particularly problematic in the setting of complex medical illness in which there may be clinical uncertainty about disease trajectory and symptom burden, and also challenging given the clinical urgency and high risk of declining care (210). Clinicians may assume that people living with SMI lack decision-making capacity, despite data demonstrating that many individuals with SMI retain the capacity to participate in medical decision-making (209). In situations in which individuals lack capacity, clinicians may be uncertain regarding surrogate decision-makers for chronically mentally ill individuals

who may be disenfranchised and lack family support (211). Additionally, clinicians may feel unable to manage chronic suicidality and other possible symptoms of chronic mental illness.

## 2) Gaps in knowledge

### a) Epidemiology

Behavioral health epidemiologic data that is circumscribed to discrete medical diagnoses precludes the formation of a broader serious illness care paradigm. Recognizing behavioral health epidemiology across a variety of medical diagnoses may promote a broader model of behavioral health care in serious illness care. Organizing patient cohorts by care setting, and illness trajectory, rather than by medical diagnosis, may broaden epidemiologic understanding of behavioral health needs in people with diverse serious medical illnesses.

As shown by the results from our literature review (Section III-1), the scientific literature focuses primarily on depression and anxiety-spectrum illnesses. Little epidemiologic data exist on serious mental illness, personality disorders, and trauma. This is an especially significant gap given the disparities in both behavioral and medical care in these populations.

### b) Clinical care (screening and treatment)

Conceptual challenges in defining and circumscribing discrete behavioral health diagnoses (as described above) make it challenging to standardize screening mechanisms for behavioral health issues among people with serious medical illness. This is exacerbated by the fluidity of the serious medical illness category, which spans many diagnoses and care settings and has yet to be given a standardized definition. The available screening tools are, for the most part, not well validated and potentially not well tolerated in the medically ill. More rigorous studies or development of new or modified screening tools could bridge this gap and provide guidance on effective screening for treatable behavioral health disorders. While tools such as HADS empower clinicians to screen medically ill individuals for depression and anxiety (212), few tools exist to screen for other behavioral health diagnoses in the medically ill population.

With a few exceptions (depression in people with heart disease and advanced cancer, for instance), relatively little high-quality, standardized evidence exists about the treatment of behavioral health issues among people with serious medical illness. Generally, individuals who have medical illnesses are excluded from randomized clinical trials of psychiatric interventions, and few trials exist for such individuals (perhaps with the exception of neuropsychiatric symptoms of dementia). Treatment decisions are based on limited data or on populations dissimilar from those being treated in the serious medical illness setting. Therefore, it is critical to design clinical trials to include real-world populations. In addition, as the use of complementary and alternative treatments (including marijuana and its derivatives) among these populations has significantly expanded, more rigorous information is needed on the potential uses and adverse effects (213)(214).



Furthermore, there is tremendous ethnic and racial variation in the receptivity to treatment and the extent to which interventions have been adapted for and tested with various populations has been insufficient. Further research is needed to elucidate relevant ethnic and cultural aspects in serious illness care in general and especially with regard to behavioral health care for this population.

### 3) Availability and preparation of workforce

#### a) Workforce shortages and lack of training

Access to behavioral health care among individuals with serious illness is often limited by behavioral health provider workforce shortage and the lack of behavioral health care competency in general medical providers.

Reasons for this are likely multifactorial. Behavioral health trainees, particularly psychiatrists, have little exposure to palliative and serious illness care (194). For example, while psychiatry trainees are eligible to complete palliative care fellowship training, only 58 psychiatrists were board certified as of 2013 (196) and only 127 psychiatrists and neurologists were board certified as of 2017(215). The lack of interested and appropriately trained providers may be attributed to a dearth of opportunities to work in the serious illness care setting post-training for behavioral health providers. In addition, due to inadequate funding and reimbursement streams, many provider organizations are unable to retain qualified care staff (“revolving door” of staff) nor provide high-level competency training.

Training non-behavioral health providers in basic behavioral health assessment skills and interventions could help address the workforce shortage. Basic training in behavioral health competencies addressing the needs of people with serious illnesses will require buy-in and support from certification and accrediting bodies across multiple disciplines as well as state licensing bodies. Other potential avenues to increase behavioral health workforce capacity and competency among the incumbent workforce may include expanded and updated offering of continuing professional education target topics included in the BH-SIC Model.

In addition, non-medical providers such as chaplains can be trained in various psychosocial interventions to augment those services provided by prescribing clinicians. This is particularly true in a collaborative or integrated model in which one behavioral health expert can provide population-level care by serving as a supervisor and consultant to non-behavioral health trained providers. In order to make such interventions tenable, behavioral health work needs to be integrated into the clinical workflow, training has to be available and incentivized for providers, and reimbursement mechanisms that pay for those services should be incorporated. In addition, medical clinicians (who are often on the front-line of treating behavioral health problems in the medically ill population) would benefit from the rigorous development of up-to-date clinical decision support mechanisms outlining psychosocial and pharmacologic treatment for common behavioral health conditions across a range of common serious medical diagnoses.

#### 4) Development of quality measures specifically adapted to behavioral health care in the context of serious illness

Over the last ten years, increased efforts have been made to identify and develop serious illness care measures – for example, the National Consensus Project for Quality Palliative Care (216), The University of North Carolina’s Peace Hospice and Palliative Care Quality Measures (217), RAND’s Assessing Care of Vulnerable Elders (218), or the Measuring What Matters Initiative (129). However, few of these proposed measures have been endorsed by NQF, which may point to larger issues regarding the validity, importance and feasibility of some of these measures. Furthermore, most of these initiatives do not include domains or measures specific to behavioral health. At the same time, a 2015 review of several large national databases identified over 500 measures that address behavioral health, but only a limited number of those are endorsed by the National Quality Forum (NQF) (219). Furthermore, only about five percent of the items in the Measures Inventory maintained by the Centers for Medicare and Medicaid (CMS) focus on behavioral health (220) which points to the lack of suitable measures that could be applied to the interface of serious illness and behavioral health care in general.

The overall lack of suitable quality measures may be related to the inherent difficulties in measuring quality at the interface of behavioral and serious illness care, particularly with regard to defining meaningful outcomes for those suffering from behavioral health and serious illness care conditions. In addition, persons’ preferences along the care continuum can change over time. Another problem is the heterogeneity of the population served by serious illness care programs and the lack of a uniform definition for serious illness. Seriously ill people may suffer from serious and advanced illness with a high risk of mortality, chronic conditions, and limitations in cognitive and physical functioning. The clear definition of the population with serious illness including behavioral health issues, however, is essential to come up with a meaningful denominator, to target specific subpopulations, and to develop valid and meaningful measures and tools that can drive improvements of care.

While there may be few measures that could be implemented immediately in specific serious illness care settings, developments in other fields may provide some guidance. A recent Delphi study indicated that “mental health screening in general medical settings” is one of the measure concept that is ready for development, based on its importance, validity, and feasibility (1). Also, the National PACE (Programs of All-Inclusive Care for the Elderly) Association compiled a list of measures and toolkits for cognitive, mood, and substance use screening (222). However, some of the existing behavioral health screening measures and tools may need to be adapted to individuals with serious illnesses. Others have been developed or applied in the nursing home setting or in-home health (223)(224).

Serious illness care is often delivered across a low-to-high complexity/intensity care continuum and a multitude of settings and providers. Cross-cutting measures in cancer care may offer suggestions for measurement concepts that might be particularly relevant for a sub-population suffering from behavioral health issues. Those measurement concepts include “round-the clock

access to coordinated care and services", "adherence to clinical pathways", "adherence to prescribed (oral) drug therapy", "unexpected hospitalization/ emergency room visit rate", "patient reported health status (psychosocial health, pain, etc.), "patient reported symptom control", "patient reported participation in defining treatment goals", "patient reported assessment of meeting shared treatment goals", and "patient-reported change in psychosocial distress/financial toxicity" (225).

The concept of 'recovery' has gained increasing traction in the behavioral health field and may provide guidance for identifying additional meaningful quality measures particularly relevant at the interface of serious illness and behavioral health care. Potential measure domains may include *satisfaction with care* (communication, availability of needed services), *patient reported outcomes* (patient well-being, sense that goals are being met, sense that psychological symptoms are addressed, and goal-concordant care) and other domains traditionally not linked to clinical outcomes such as *quality of life, engagement in care and community, and economic stability and housing*.

Social risk factors such as income, education, race and ethnicity, employment, community resources, and social support play major roles in individuals' health. Significant gaps remain in health and life expectancy based on income, race, ethnicity, and community environment. Individuals with mental disorders have an all-cause mortality relative risk of 2.2 compared with the general population, with a median of 10 years of potential life lost (85).

Against this background, there is growing recognition of disparities for people with mental illnesses as compared to the general population, both in terms of access to needed health care services and overall health outcomes. While this discrepancy may be partially attributable to the symptoms and functional limitations resulting from (severe) mental illnesses, it is widely recognized that these trends also stem from discrimination, exclusion, and widespread stigma of individuals with mental illness. The creation of a new 'disparity category' by assessing healthcare quality separately for persons with behavioral health conditions could help better understand and address these issues at the practice, research and policy level (226)(221). This concept was considered important and valid in a recent Delphi study (221). The formal designation of mental illness as a disparities category could also encourage the development and implementation of quality measures for use in value-based payment models. This in turn could incent the development and application of evidence-based practices that improve the quality of care and ultimately, the lives of people suffering from behavioral health issues and serious illnesses.

## 5) Alternative payment models and payment barriers

The U.S. health care system is moving toward more integrated financing and delivery models that reward value instead of volume. Yet, among the various integrated payment models in Medicare (e.g., Medicare Advantage, Bundled Payments for Care Improvement Initiative, the Duals Financial Alignment Demonstration, and Program for All-Inclusive care for the Elderly,

PACE) only Medicare Accountable Care Organizations (ACOs) Demonstration Programs authorized under the Affordable Care Act cover hospice care.

New models and initiatives around the latter have generated some interest within the behavioral health field (Medicare Shared Savings and Pioneer ACO Programs (MSSP/Pioneer) and Blue Cross Blue Shield of Massachusetts Alternative Quality Contract (AQC)). Under these models, ACOs receive risk-based payments for the enrolled patient population. By passing either full or partial financial risks for total health care expenditures of the enrollees, payers seek to increase provider accountability, efficiency, and improve the integration of care.

However, there are challenges specific to behavioral health conditions that impede the development and uptake of value-based payment models, including privacy concerns (i.e., sensitivity issues, HIPAA, 42 CFR Part 2, Confidentiality of Substance Use Disorder Patient Records which restricts information sharing) in implementing these models in certain settings as well as sociodemographic variables, along with perceptions of mental disorder severity and need (227). Other challenges are related to often fragmented health care services, the lack of an overarching effective organizational and infrastructure framework that can track the quality of health care received, coupled with responsibility and accountability for patients' paths through the cycle of care. It is more challenging to define a cycle of care for complex long-term health conditions (e.g., a depressed patient after a stroke), when the need for health services related to these conditions extends over a long period of time and may involve different caregivers within different service levels and settings. In the specific context of behavioral health and serious illness care, the beginning and end of an episode of care is often difficult to define, along with health outcomes related to each episode that could help support the development of value-based health care and payment models.

As previously discussed, new quality measures throughout the entire cycle of care are needed to encourage coordination and the integration of health services across the cycle of care, create incentives for providers to share responsibility for each individual's health care needs across the behavioral health/serious illness care spectrum and to allow for transitioning to value-based care delivery and payment. These concepts of quality measurement and shared accountability need to be incorporated into managed care contracts as well.

Many value-based payment models target specific populations, but very few focus on the those with serious illness and behavioral health conditions. Two models have recently emerged that seek to address this gap by crafting a payment strategy that would support care teams in the delivery of effective, high-value care. The American Academy of Hospice and Palliative Medicine (AAHPM) developed the Patient and Caregiver Support for Serious Illness (PACSSI) Model, which would provide tiered monthly care management payments to support interdisciplinary palliative care teams as they deliver palliative care to patients and includes a quality and cost accountability framework to ensure that the care teams provide high-quality, high-value care (228). C-TAC's new Advanced Care Model (ACM) specifically targets Medicare beneficiaries with advanced chronic conditions in their last year of life. The model aims to better meet the needs

of these individuals by breaking down silos within the healthcare system, bridging traditional medical and social services, and creating comprehensive care management of an individual's healthcare needs consistent with the individual's goals and values. If fully implemented, the ACM would affect approximately 25% of Medicare expenditures and support over 1 million beneficiaries. Notably, this model explicitly builds upon the changing needs of individuals in terms of health, function (cognitive impairment, dementia, mental illness, addiction and trauma/ other psychosocial needs), and psychosocial status in light of disease severity and progression (127). Both payment models have received support from The Assistant Secretary for Planning and Evaluation (ASPE)'s Physician-Focused Payment Model Technical Advisory Committee (PTAC) and have been recommended to the HHS Secretary for urgent approval for a funded Medicaid demonstration (229).

## 6) Regulatory/Legal issues

Medico-legal aspects of serious illness care such as surrogate decision-making and advance care planning are largely defined by statutory law. In addition, the legal issues also inform competency and capacity in behavioral health care.

Individuals with comorbid serious medical illness and behavioral health issues have a significant stake in the regulation of advance care planning. Individuals with mental illness are less likely to be invited to participate in advance care planning, regardless of their capacity to do so (208). This is particular true given many serious medical illnesses are progressive diagnoses and that may require longitudinal, dynamic advance care planning that evolves over the illness trajectory. Universalized advance care planning (for example, laws mandating that Medicare-funded institutions must provide written information on ACP) may benefit individuals who would be otherwise left out. Within the behavioral health field, several initiatives aim to utilize psychiatric advance directives, and some examples exist of combined psychiatric-medical advance directives, for instance those disseminated by the National Resource Center on Psychiatric Advance Directives. However, little data exist on the adoption of such documents (230).

The vast majority of states have legal protocols allowing patients to avoid unwanted medical interventions, such as resuscitation. Additionally, most states have default surrogate consent laws, which enable a list of permissible surrogates to make medical decisions in the absence of advance directives. Significant differences in jurisdiction are given to surrogate decision-makers with respect to end-of-life decision-making across states, for instance, states vary widely in the authority given to surrogate decision-makers to withdraw life sustaining treatments (231). Despite the lack of consistency in advance care planning and surrogate decision-making, The Uniform Health Care Decisions Act is considered a model law combining both default surrogacy and advance directives with a high degree of flexibility. The legal and regulatory aspects of advance care planning remain dynamic. Physician orders for life sustaining treatment (POLST) refer to a formalized way for physicians to institute out-of-hospital orders regarding resuscitation and are an adjunct/component of broader advance care planning that is gaining traction since its inception in Oregon (232).

Additionally, a broader discussion about national standardization of advance care planning protocol may evolve in the coming years. It is important to note that statutory advance directive and surrogacy laws are not the only means of advance care planning; most end-of-life decisions take place informally through interactions between providers, patients, and family caregivers and most state laws (at least 33 states) sanction these (232). For example, The Conversation Project provides resources to guide individuals to start conversations about their end-of-life wishes (233). Of note, one driver of standardization may be the increasing recognition of advance care planning conversations as an element of billable care; for instance, Medicare recently introduced free-for-service billing codes for advance care planning conversations.

## VI. Conclusion and Further Opportunities

The goals of this study were to describe the scope of behavioral health needs among people with serious illness, identify gaps in current service provision and develop a model to support the integration of behavioral health provision into serious illness care. Using a mixed methods approach (peer and grey literature review, expert interviews and an advisory panel) we propose a model that builds upon two existing exemplars, the United Hospital Fund Continuum-Based Framework for Advancing Integration of Behavioral Health into Primary Care (126) and the Coalition to Transform Advanced Care (C-TAC) Serious Illness Program Design & Implementation Framework (127). The model advances this work by identifying a series of key components that serve as ‘building blocks’ to support behavioral health care integration into serious illness care, along the various stages of the advanced care continuum (130).

Implementation of this model and the successful shift toward more integrated, person-centered care will require a series of policy approaches outlined in this study. Addressing current barriers to implementation will require a focused research agenda targeted at clinical, organizational, and policy levels. Our study identified training, quality measurement, clinical assessment tools, and evidence base guidelines as priority areas to progress current efforts in this field. Successful strategies may include:

### **1) Reviewing screening and assessment tools and evaluating their strengths and limitations in the context of serious illnesses**

Screening tools generally used in behavioral health may be inappropriate for individuals with serious illnesses due to an overlap of symptoms. Additionally, there are screening tools for specific behavioral health diagnoses used in the specialty settings which contribute to fragmentation of behavioral health provision across sub-populations of seriously medically ill individuals. While clinicians have screening options, there is no broad, cross-diagnostic behavioral health screening method, including screening for SUD, for people with serious medical illnesses.

### **2) Compiling and summarizing selected guidelines for evidence-based interventions for individuals with comorbid behavioral health conditions that are adaptable to serious illness settings along the care continuum**

A review and synthesis of the published literature on guidelines for treatment of the most

common behavioral health conditions (e.g. depression, anxiety, delirium, cognitive impairment, agitation, including SUD) can help evaluate the comprehensiveness of these guidelines, identify gaps, and provide recommendations, particularly in the context of serious illness care. Furthermore, this information can be used to explore barriers to implementation of these practice guidelines in serious illness care settings across the care continuum.

### **3) Designing targeted training curricula for specific subsets of behavioral health professionals and non-behavioral health clinical staff working in serious illness care settings**

The training curriculum can be targeted to both professional schools preparing new cohorts of clinicians as well as settings where in-services could be delivered. Education on common skills at the interface of behavioral health and serious illness care is key for both behavioral health and medical providers to better meet demands. While all providers should be trained in general psychosocial care of seriously ill or dying individuals (i.e., goals-of-care discussions, advance care planning), our research revealed some major gaps in the training of the diverse workforce involved in the care of seriously ill people who also suffer from behavioral and substance use issues. Additionally, regardless of degree or discipline, all members of the team should be trained in risk management, de-escalation skills, and recognition of serious behavioral health pathology (193). The training curriculum may include suggestions for ongoing training of staff to address issues of retention of workforce and employee satisfaction. Online training courses addressing behavioral health needs in palliative care, such as the online clinical courses provided by Center to Advance Palliative Care (CAPC) (234) can provide guidance.

### **4) Establishing an agenda for quality measurement development at the interface of serious illnesses and behavioral health care**

There is a lack of meaningful quality measures (both within the behavioral health field, but also at the interface of general medical or serious illness care) to support alternative payment strategies based on the quality or value of care delivered. This agenda would initiate a systematic process to inform the development and application of measures that capture structure, process and outcomes (including patient's assessment of care) elements of care associated with best practices at the interface of serious illness and behavioral health care. There are also opportunities for accrediting organizations to set minimal standards for integrated behavioral health and serious illness care practices.

## Acknowledgements

We wish to thank **Sheri C. Gibson**, PhD, Director of Behavioral Health for Rocky Mountain Health Care Services; **Joanne Lynn**, MD, Director of the Program to Improve Eldercare; **Gary M. Rodin**, MD, Head of the Department of Supportive Care at Princess Margaret Cancer Centre; **Robyn I. Stone**, DrPH, Senior Vice President of Research and Co-Director of LeadingAge LTSS Center at the University of Massachusetts Boston; **Marian Grant**, DNP, Senior Regulatory Advisor for the Coalition to Transform Advanced Care; **Susan D. Block**, MD, Chair of the Department of Psychosocial Oncology and Palliative Care at the Dana-Farber Cancer Institute; **Haiden Huskamp**, PhD, 30th Anniversary Professor of Health Care Policy at the Department of Health Care Policy at the Harvard Medical School; **Diane E. Meier**, MD, Director of the Center to Advance Palliative Care; **Heather M. Young**, PhD, Professor and Dean Emerita of the Betty Irene Moore School of Nursing at the University of California Davis; and **Bruce Leff**, MD, Director of the Center on Aging and Health Program in Geriatric Health Services Research and Co-Director of the Elder House Call Program in the Division of Geriatric Medicine at the Johns Hopkins University School of Medicine; for their valuable contributions as advisory panelists to this project. We would also like to thank **Nicole Khauli**, MPH, for assisting with editing the final version of this report.



## References

1. Kelley AS, Covinsky KE, Gorges RJ, McKendrick K, Bollens-Lund E, Morrison RS, et al. Identifying Older Adults with Serious Illness: A Critical Step toward Improving the Value of Health Care. *Health Serv Res*. 2017 Feb;52(1):113–31.
2. Measuring care in the community for people with serious illness [Internet]. [cited 2018 Jun 15]. Available from: <https://www.moore.org/article-detail?newsUrlName=measuring-care-in-the-community-for-people-with-serious-illness>
3. Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life [Internet]. Washington, DC: The National Academies Press; 2015. Available from: <https://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near>
4. Centers for Disease Control and Prevention. Leading Causes of Death [Internet]. 2018 [cited 2018 Jul 17]. Available from: <https://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm>
5. Watkins DC, Assari S, Johnson-Lawrence V. Race and Ethnic Group Differences in Comorbid Major Depressive Disorder, Generalized Anxiety Disorder, and Chronic Medical Conditions. *J Racial Ethn Health Disparities*. 2015 Sep;2(3):385–94.
6. Miovic M, Block S. Psychiatric disorders in advanced cancer. *Cancer*. 2007 Oct 15;110(8):1665–76.
7. Ravi P, Karakiewicz PI, Roghmann F, Gandaglia G, Choueiri TK, Menon M, et al. Mental health outcomes in elderly men with prostate cancer. *Urol Oncol*. 2014 Nov;32(8):1333–40.
8. Caruso R, Nanni MG, Riba M, Sabato S, Mitchell AJ, Croce E, et al. Depressive spectrum disorders in cancer: prevalence, risk factors and screening for depression: a critical review. *Acta Oncol Stockh Swed*. 2017 Feb;56(2):146–55.
9. Clarke DM, Currie KC. Depression, anxiety and their relationship with chronic diseases: a review of the epidemiology, risk and treatment evidence. *Med J Aust*. 2009 Apr 6;190(7 Suppl):S54-60.
10. Daudt HML, Cosby C, Dennis DL, Payeur N, Nurullah R. Nutritional and psychosocial status of colorectal cancer patients referred to an outpatient oncology clinic. *Support Care Cancer Off J Multinatl Assoc Support Care Cancer*. 2012 Jul;20(7):1417–23.
11. Mercadante S, Aielli F, Adile C, Ferrera P, Valle A, Cartoni C, et al. Sleep Disturbances in Patients With Advanced Cancer in Different Palliative Care Settings. *J Pain Symptom Manage*. 2015 Dec;50(6):786–92.
12. Palmer SC, Taggi A, Demichele A, Coyne JC. Is screening effective in detecting untreated psychiatric disorders among newly diagnosed breast cancer patients? *Cancer*. 2012 May 15;118(10):2735–43.
13. Salvo N, Zeng L, Zhang L, Leung M, Khan L, Presutti R, et al. Frequency of reporting and predictive factors for anxiety and depression in patients with advanced cancer. *Clin Oncol R Coll Radiol G B*. 2012 Mar;24(2):139–48.

14. Stafford L, Judd F, Gibson P, Komiti A, Mann GB, Quinn M. Screening for depression and anxiety in women with breast and gynaecologic cancer: course and prevalence of morbidity over 12 months. *Psychooncology*. 2013 Sep;22(9):2071–8.
15. Lo C, Zimmermann C, Rydall A, Walsh A, Jones JM, Moore MJ, et al. Longitudinal study of depressive symptoms in patients with metastatic gastrointestinal and lung cancer. *J Clin Oncol*. 2010;28(18):3084–9.
16. Ng CG, Boks MPM, Zainal NZ, de Wit NJ. The prevalence and pharmacotherapy of depression in cancer patients. *J Affect Disord*. 2011 Jun;131(1–3):1–7.
17. Ahn MH, Park S, Lee HB, Ramsey CM, Na R, Kim SO, et al. Suicide in cancer patients within the first year of diagnosis. *Psychooncology*. 2015 May;24(5):601–7.
18. Wang S-M, Chang J-C, Weng S-C, Yeh M-K, Lee C-S. Risk of suicide within 1 year of cancer diagnosis. *Int J Cancer*. 2017 Dec 18;
19. Vyssoki B, Gleiss A, Rockett IRH, Hackl M, Leitner B, Sonneck G, et al. Suicide among 915,303 Austrian cancer patients: who is at risk? *J Affect Disord*. 2015 Apr 1;175:287–91.
20. Robson A, Scrutton F, Wilkinson L, MacLeod F. The risk of suicide in cancer patients: a review of the literature. *Psychooncology*. 2010 Dec;19(12):1250–8.
21. Delgado-Guay MO, Parsons HA, Li Z, Palmer LJ, Bruera E. Symptom distress, interventions, and outcomes of intensive care unit cancer patients referred to a palliative care consult team. *Cancer*. 2009 Jan 15;115(2):437–45.
22. Ng CG, Mohamed S, Kaur K, Sulaiman AH, Zainal NZ, Taib NA. Perceived distress and its association with depression and anxiety in breast cancer patients. *PloS One*. 2017;12(3):e0172975.
23. Kim YJ, Munsell MF, Park JC, Meyer LA, Sun CC, Brown AJ, et al. Retrospective review of symptoms and palliative care interventions in women with advanced cervical cancer. *Gynecol Oncol*. 2015 Dec;139(3):553–8.
24. Mehnert A, Koch U. Prevalence of acute and post-traumatic stress disorder and comorbid mental disorders in breast cancer patients during primary cancer care: a prospective study. *Psychooncology*. 2007 Mar;16(3):181–8.
25. Elsayem AF, Bruera E, Valentine AD, Warneke CL, Yeung S-CJ, Page VD, et al. Delirium frequency among advanced cancer patients presenting to an emergency department: A prospective, randomized, observational study. *Cancer*. 2016 Sep 15;122(18):2918–24.
26. Nagase M, Okamoto Y, Tsuneto S, Tanimukai H, Matsuda Y, Okishiro N, et al. A retrospective chart review of terminal patients with cancer with agitation and their risk factors. *J Palliat Med*. 2012 Nov;15(11):1185–90.
27. Rainsford S, Rosenberg JP, Bullen T. Delirium in advanced cancer: screening for the incidence on admission to an inpatient hospice unit. *J Palliat Med*. 2014 Sep;17(9):1045–8.

28. Takeuchi M, Takeuchi H, Fujisawa D, Miyajima K, Yoshimura K, Hashiguchi S, et al. Incidence and risk factors of postoperative delirium in patients with esophageal cancer. *Ann Surg Oncol*. 2012 Nov;19(12):3963–70.
29. Ho P, Rosenheck R. Substance Use Disorder Among Current Cancer Patients: Rates and Correlates Nationally in the Department of Veterans Affairs. *Psychosomatics*. 2018 Jun;59(3):267–76.
30. Bruera E, Moyano J, Seifert L, Fainsinger RL, Hanson J, Suarez-Almazor M. The frequency of alcoholism among patients with pain due to terminal cancer. *J Pain Symptom Manage*. 1995 Nov;10(8):599–603.
31. Broomfield NM, Quinn TJ, Abdul-Rahim AH, Walters MR, Evans JJ. Depression and anxiety symptoms post-stroke/TIA: prevalence and associations in cross-sectional data from a regional stroke registry. *BMC Neurol*. 2014 Oct 1;14:198.
32. Buijck BI, Zuidema SU, Spruit-van Eijk M, Geurts ACH, Koopmans RTCM. Neuropsychiatric symptoms in geriatric patients admitted to skilled nursing facilities in nursing homes for rehabilitation after stroke: a longitudinal multicenter study. *Int J Geriatr Psychiatry*. 2012 Jul;27(7):734–41.
33. Farner L, Wagle J, Engedal K, Flekkoy KM, Wyller TB, Fure B. Depressive symptoms in stroke patients: a 13 month follow-up study of patients referred to a rehabilitation unit. *J Affect Disord*. 2010 Dec;127(1–3):211–8.
34. Hirata S, Ovbiagele B, Markovic D, Towfighi A. Key Factors Associated with Major Depression in a National Sample of Stroke Survivors. *J Stroke Cerebrovasc Dis Off J Natl Stroke Assoc*. 2016 May;25(5):1090–5.
35. Kouwenhoven SE, Kirkevold M, Engedal K, Kim HS. Depression in acute stroke: prevalence, dominant symptoms and associated factors. A systematic literature review. *Disabil Rehabil*. 2011;33(7):539–56.
36. Santos CO, Caeiro L, Ferro JM, Figueira ML. A study of suicidal thoughts in acute stroke patients. *J Stroke Cerebrovasc Dis Off J Natl Stroke Assoc*. 2012 Nov;21(8):749–54.
37. Campbell Burton CA, Murray J, Holmes J, Astin F, Greenwood D, Knapp P. Frequency of anxiety after stroke: a systematic review and meta-analysis of observational studies. *Int J Stroke Off J Int Stroke Soc*. 2013 Oct;8(7):545–59.
38. von Vogelsang A-C, Forsberg C, Svensson M, Wengstrom Y. Patients Experience High Levels of Anxiety 2 Years Following Aneurysmal Subarachnoid Hemorrhage. *World Neurosurg*. 2015 Jun;83(6):1090–7.
39. Wong A, Lau AYL, Yang J, Wang Z, Liu W, Lam BYK, et al. Neuropsychiatric Symptom Clusters in Stroke and Transient Ischemic Attack by Cognitive Status and Stroke Subtype: Frequency and Relationships with Vascular Lesions, Brain Atrophy and Amyloid. *PLoS ONE* [Internet]. 2016 Sep 15 [cited 2018 Jan 2];11(9). Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5025073/>

40. Visser-Meily JMA, Rinkel GJE, Vergouwen MDI, Passier PECA, van Zandvoort MJE, Post MWM. Post-traumatic stress disorder in patients 3 years after aneurysmal subarachnoid haemorrhage. *Cerebrovasc Dis Basel Switz*. 2013;36(2):126–30.
41. Delville CL, McDougall G. A systematic review of depression in adults with heart failure: instruments and incidence. *Issues Ment Health Nurs*. 2008 Sep;29(9):1002–17.
42. Freedenberg V, Thomas SA, Friedmann E. Anxiety and depression in implanted cardioverter-defibrillator recipients and heart failure: a review. *Heart Fail Clin*. 2011 Jan;7(1):59–68.
43. Yohannes AM, Willgoss TG, Fatoye FA, Dip MD, Webb K. Relationship between anxiety, depression, and quality of life in adult patients with cystic fibrosis. *Respir Care*. 2012 Apr;57(4):550–6.
44. Shimizu Y, Suzuki M, Okumura H, Yamada S. Risk factors for onset of depression after heart failure hospitalization. *J Cardiol*. 2014 Jul;64(1):37–42.
45. Schweikert B, Hunger M, Meisinger C, Konig H-H, Gapp O, Holle R. Quality of life several years after myocardial infarction: comparing the MONICA/KORA registry to the general population. *Eur Heart J*. 2009 Feb;30(4):436–43.
46. Larsen KK, Agerbo E, Christensen B, Sondergaard J, Vestergaard M. Myocardial infarction and risk of suicide: a population-based case-control study. *Circulation*. 2010 Dec 7;122(23):2388–93.
47. Roberge M-A, Dupuis G, Marchand A. Post-traumatic stress disorder following myocardial infarction: prevalence and risk factors. *Can J Cardiol*. 2010 May;26(5):e170-175.
48. Feng H-P, Chien W-C, Cheng W-T, Chung C-H, Cheng S-M, Tzeng W-C. Risk of anxiety and depressive disorders in patients with myocardial infarction. *Medicine (Baltimore)* [Internet]. 2016 Aug 26 [cited 2018 Jan 2];95(34). Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5400317/>
49. Grace SL, Abbey SE, Irvine J, Shnek ZM, Stewart DE. Prospective examination of anxiety persistence and its relationship to cardiac symptoms and recurrent cardiac events. *Psychother Psychosom*. 2004 Dec;73(6):344–52.
50. Uguz F, Kayrak M, Cıçek E, Kayhan F, Ari H, Altunbas G. Delirium following acute myocardial infarction: incidence, clinical profiles, and predictors. *Perspect Psychiatr Care*. 2010 Apr;46(2):135–42.
51. Honda S, Nagai T, Sugano Y, Okada A, Asaumi Y, Aiba T, et al. Prevalence, determinants, and prognostic significance of delirium in patients with acute heart failure. *Int J Cardiol*. 2016 Nov 1;222:521–7.
52. Mangusan RF, Hooper V, Denslow SA, Travis L. Outcomes associated with postoperative delirium after cardiac surgery. *Am J Crit Care Off Publ Am Assoc Crit-Care Nurses*. 2015 Mar;24(2):156–63.
53. Atlantis E, Fahey P, Cochrane B, Smith S. Bidirectional associations between clinically relevant depression or anxiety and COPD: a systematic review and meta-analysis. *Chest*. 2013 Sep;144(3):766–77.

54. van den Bemt L, Schermer T, Bor H, Smink R, van Weel-Baumgarten E, Lucassen P, et al. The risk for depression comorbidity in patients with COPD. *Chest*. 2009 Jan;135(1):108–14.
55. Janssen DJA, Spruit MA, Leue C, Gijzen C, Hameleers H, Schols JMGA, et al. Symptoms of anxiety and depression in COPD patients entering pulmonary rehabilitation. *Chron Respir Dis*. 2010 Aug;7(3):147–57.
56. Kunik ME, Roundy K, Veazey C, Soucek J, Richardson P, Wray NP, et al. Surprisingly high prevalence of anxiety and depression in chronic breathing disorders. *Chest*. 2005 Apr;127(4):1205–11.
57. Mehta JR, Ratnani IJ, Dave JD, Panchal BN, Patel AK, Vala AU. Association of psychiatric co-morbidities and quality of life with severity of chronic obstructive pulmonary disease. *East Asian Arch Psychiatry Off J Hong Kong Coll Psychiatr Dong Ya Jing Shen Ke Xue Zhi Xianggang Jing Shen Ke Yi Xue Yuan Qi Kan*. 2014 Dec;24(4):148–55.
58. Zarowitz BJ, O’Shea T. Chronic obstructive pulmonary disease: prevalence, characteristics, and pharmacologic treatment in nursing home residents with cognitive impairment. *J Manag Care Pharm JMCP*. 2012 Oct;18(8):598–606.
59. Ouellette DR, Lavoie KL. Recognition, diagnosis, and treatment of cognitive and psychiatric disorders in patients with COPD. *Int J Chron Obstruct Pulmon Dis*. 2017 Feb 16;12:639–50.
60. Fan VS, Ramsey SD, Giardino ND, Make BJ, Emery CF, Diaz PT, et al. Sex, depression, and risk of hospitalization and mortality in chronic obstructive pulmonary disease. *Arch Intern Med*. 2007 Nov 26;167(21):2345–53.
61. Strid JMC, Christiansen CF, Olsen M, Qin P. Hospitalisation for chronic obstructive pulmonary disease and risk of suicide: a population-based case–control study. *BMJ Open* [Internet]. 2014 Nov 24 [cited 2018 Jan 2];4(11). Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4244413/>
62. Chung JH, Han CH, Park SC, Kim CJ. Suicidal ideation and suicide attempts in chronic obstructive pulmonary disease: The Korea National Health and Nutrition Examination Survey (KNHANES IV, V) from 2007–2012. *NPJ Prim Care Respir Med*. 2014 Oct 30;24:14094.
63. Blinderman CD, Homel P, Billings JA, Tennstedt S, Portenoy RK. Symptom distress and quality of life in patients with advanced chronic obstructive pulmonary disease. *J Pain Symptom Manage*. 2009 Jul;38(1):115–23.
64. Willgoss TG, Yohannes AM. Anxiety disorders in patients with COPD: a systematic review. *Respir Care*. 2013 May;58(5):858–66.
65. Abrams TE, Blevins A, Weg MWV. Chronic obstructive lung disease and posttraumatic stress disorder: current perspectives. *Int J Chron Obstruct Pulmon Dis*. 2015 Oct 15;10:2219–33.
66. Agganis BT, Weiner DE, Giang LM, Scott T, Tighiouart H, Griffith JL, et al. Depression and cognitive function in maintenance hemodialysis patients. *Am J Kidney Dis Off J Natl Kidney Found*. 2010 Oct;56(4):704–12.
67. Corruble E, Durrbach A, Charpentier B, Lang P, Amidi S, Dezamis A, et al. Progressive increase of anxiety and depression in patients waiting for a kidney transplantation. *Behav Med Wash DC*. 2010 Mar;36(1):32–6.

68. Roos E, Mariosa D, Ingre C, Lundholm C, Wirdefeldt K, Roos PM, et al. Depression in amyotrophic lateral sclerosis. *Neurology*. 2016 Jun 14;86(24):2271–7.
69. Atassi N, Cook A, Pineda CME, Yerramilli-Rao P, Pulley D, Cudkowicz M. Depression in amyotrophic lateral sclerosis. *Amyotroph Lateral Scler Off Publ World Fed Neurol Res Group Mot Neuron Dis*. 2011 Mar;12(2):109–12.
70. Stefanova E, Ziropadja L, Petrovic M, Stojkovic T, Kostic V. Screening for anxiety symptoms in Parkinson disease: a cross-sectional study. *J Geriatr Psychiatry Neurol*. 2013 Mar;26(1):34–40.
71. Bugalho P, da Silva JA, Cargaleiro I, Serra M, Neto B. Psychiatric symptoms screening in the early stages of Parkinson's disease. *J Neurol*. 2012 Jan;259(1):124–31.
72. Chen P, Kales HC, Weintraub D, Blow FC, Jiang L, Ignacio RV, et al. Depression in veterans with Parkinson's disease: frequency, co-morbidity, and healthcare utilization. *Int J Geriatr Psychiatry*. 2007 Jun;22(6):543–8.
73. Sampson EL, White N, Leurent B, Scott S, Lord K, Round J, et al. Behavioural and psychiatric symptoms in people with dementia admitted to the acute hospital: prospective cohort study. *Br J Psychiatry J Ment Sci*. 2014 Sep;205(3):189–96.
74. Teipel SJ, Thyrian JR, Hertel J, Eichler T, Wucherer D, Michalowsky B, et al. Neuropsychiatric symptoms in people screened positive for dementia in primary care. *Int Psychogeriatr*. 2015 Jan;27(1):39–48.
75. Forrester SN, Gallo JJ, Smith GS, Leoutsakos J-MS. Patterns of Neuropsychiatric Symptoms in Mild Cognitive Impairment and Risk of Dementia. *Am J Geriatr Psychiatry Off J Am Assoc Geriatr Psychiatry*. 2016 Feb;24(2):117–25.
76. Wetzels RB, Zuidema SU, de Jonghe JFM, Verhey FRJ, Koopmans RTCM. Course of neuropsychiatric symptoms in residents with dementia in nursing homes over 2-year period. *Am J Geriatr Psychiatry Off J Am Assoc Geriatr Psychiatry*. 2010 Dec;18(12):1054–65.
77. Chi S, Wang C, Jiang T, Zhu X-C, Yu J-T, Tan L. The prevalence of depression in Alzheimer's disease: a systematic review and meta-analysis. *Curr Alzheimer Res*. 2015;12(2):189–98.
78. Selbaek G, Engedal K, Benth JS, Bergh S. The course of neuropsychiatric symptoms in nursing-home patients with dementia over a 53-month follow-up period. *Int Psychogeriatr*. 2014 Jan;26(1):81–91.
79. Kessler RC, Berglund P, Demler O, Jin R, Merikangas KR, Walters EE. Lifetime prevalence and age-of-onset distributions of dsm-iv disorders in the national comorbidity survey replication. *Arch Gen Psychiatry*. 2005 Jun 1;62(6):593–602.
80. Passik SD, Theobald DE. Managing addiction in advanced cancer patients: why bother? *J Pain Symptom Manage*. 2000 Mar;19(3):229–34.
81. Chang Y-P, Compton P. Management of chronic pain with chronic opioid therapy in patients with substance use disorders. *Addict Sci Clin Pract*. 2013;8(1):21–21.

82. Elsayem AF, Bruera E, Valentine AD, Warneke CL, Yeung S-CJ, Page VD, et al. Delirium frequency among advanced cancer patients presenting to an emergency department: A prospective, randomized, observational study. *Cancer*. 2016 Sep 15;122(18):2918–24.
83. Siddiqi N, House AO, Holmes JD. Occurrence and outcome of delirium in medical in-patients: a systematic literature review. *Age Ageing*. 2006;35(4):350–64.
84. Cole MG, Ciampi A, Belzile E, Zhong L. Persistent delirium in older hospital patients: a systematic review of frequency and prognosis. *Age Ageing*. 2008;38(1):19–26.
85. Walker ER, McGee RE, Druss BG. Mortality in mental disorders and global disease burden implications: a systematic review and meta-analysis. *JAMA Psychiatry*. 2015;72(4):334–41.
86. Albert NM, Fonarow GC, Abraham WT, Gheorghiade M, Greenberg BH, Nunez E, et al. Depression and clinical outcomes in heart failure: an OPTIMIZE-HF analysis. *Am J Med*. 2009 Apr;122(4):366–73.
87. Damen NL, Versteeg H, Boersma E, Serruys PW, van Geuns R-JM, Denollet J, et al. Depression is independently associated with 7-year mortality in patients treated with percutaneous coronary intervention: results from the RESEARCH registry. *Int J Cardiol*. 2013 Sep 10;167(6):2496–501.
88. Celano CM, Millstein RA, Bedoya CA, Healy BC, Roest AM, Huffman JC. Association between anxiety and mortality in patients with coronary artery disease: A meta-analysis. *Am Heart J*. 2015 Dec;170(6):1105–15.
89. Atlantis E, Fahey P, Cochrane B, Smith S. Bidirectional associations between clinically relevant depression or anxiety and COPD: a systematic review and meta-analysis. *Chest*. 2013 Sep;144(3):766–77.
90. Kouwenhoven SE, Kirkevold M, Engedal K, Kim HS. Depression in acute stroke: prevalence, dominant symptoms and associated factors. A systematic literature review. *Disabil Rehabil*. 2011;33(7):539–56.
91. Hendrie HC, Tu W, Tabbey R, Purnell CE, Ambuehl RJ, Callahan CM. Health Outcomes and Cost of Care Among Older Adults with Schizophrenia: A 10-Year Study Using Medical Records across the Continuum of Care. *Am J Geriatr Psychiatry Off J Am Assoc Geriatr Psychiatry*. 2014 May;22(5):427–36.
92. Cukor D, Coplan J, Brown C, Peterson RA, Kimmel PL. Course of depression and anxiety diagnosis in patients treated with hemodialysis: a 16-month follow-up. *Clin J Am Soc Nephrol CJASN*. 2008 Nov;3(6):1752–8.
93. Kimmel PL, Peterson RA, Weihs KL, Simmens SJ, Alleyne S, Cruz I, et al. Multiple measurements of depression predict mortality in a longitudinal study of chronic hemodialysis outpatients. *Kidney Int*. 2000 May;57(5):2093–8.
94. Pinquart M, Duberstein PR. Depression and cancer mortality: a meta-analysis. *Psychol Med*. 2010 Nov;40(11):1797–810.
95. Kisely S, Crowe E, Lawrence D. Cancer-related mortality in people with mental illness. *JAMA Psychiatry*. 2013 Feb 1;70(2):209–17.

96. Khmour MR, Hawwa AF, Kidney JC, Smyth BM, McElnay JC. Potential risk factors for medication non-adherence in patients with chronic obstructive pulmonary disease (COPD). *Eur J Clin Pharmacol*. 2012 Oct;68(10):1365–73.
97. DiMatteo MR, Lepper HS, Croghan TW. Depression is a risk factor for noncompliance with medical treatment: meta-analysis of the effects of anxiety and depression on patient adherence. *Arch Intern Med*. 2000 Jul 24;160(14):2101–7.
98. Bautista LE, Vera-Cala LM, Colombo C, Smith P. Symptoms of depression and anxiety and adherence to antihypertensive medication. *Am J Hypertens*. 2012 Apr;25(4):505–11.
99. Johansson P, Nieuwenhuis M, Lesman-Leegte I, van Veldhuisen DJ, Jaarsma T. Depression and the delay between symptom onset and hospitalization in heart failure patients. *Eur J Heart Fail*. 2011 Feb;13(2):214–9.
100. Atzema CL, Schull MJ, Tu JV. The effect of a charted history of depression on emergency department triage and outcomes in patients with acute myocardial infarction. *CMAJ Can Med Assoc J J Assoc Medicale Can*. 2011 Apr 5;183(6):663–9.
101. Carney CP, Jones LE. The Influence of Type and Severity of Mental Illness on Receipt of Screening Mammography. *J Gen Intern Med*. 2006 Oct;21(10):1097–104.
102. Xiong GL, Bermudes RA, Torres SN, Hales RE. Use of cancer-screening services among persons with serious mental illness in Sacramento County. *Psychiatr Serv*. 2008;59(8):929–32.
103. Kisely S, Crowe E, Lawrence D. Cancer-related mortality in people with mental illness. *JAMA Psychiatry*. 2013 Feb 1;70(2):209–17.
104. Goldman ML, Spaeth-Rublee B, Pincus HA. The Case for Severe Mental Illness as a Disparities Category. *Psychiatr Serv Wash DC*. 2018 Feb 15;appips201700138.
105. Medicare C for, Baltimore MS 7500 SB, Usa M. NHE-Fact-Sheet [Internet]. 2018 [cited 2018 May 17]. Available from: <https://www.cms.gov/research-statistics-data-and-systems/statistics-trends-and-reports/nationalhealthexpenddata/nhe-fact-sheet.html>
106. Centers for Medicare & Medicaid Services. Physical and Mental Health Condition Prevalence and Comorbidity among Fee-for-Service Medicare-Medicaid Enrollees [Internet]. 2014 Sep [cited 2018 Jul 9]. Available from: [https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Downloads/Dual\\_Condition\\_Prevalence\\_Comorbidity\\_2014.pdf](https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Downloads/Dual_Condition_Prevalence_Comorbidity_2014.pdf)
107. Faces of Medicaid: Clarifying Multimorbidity Patterns to Improve Targeting and Delivery of Clinical Services for Medicaid Populations [Internet]. Center for Health Care Strategies. [cited 2018 May 17]. Available from: <https://www.chcs.org/resource/faces-of-medicaid-clarifying-multimorbidity-patterns-to-improve-targeting-and-delivery-of-clinical-services-for-medicaid-populations/>
108. Faces of Medicaid III: Refining the Portrait of People with Multiple Chronic Conditions [Internet]. Center for Health Care Strategies. [cited 2018 May 17]. Available from: <https://www.chcs.org/resource/the-faces-of-medicaid-iii-refining-the-portrait-of-people-with-multiple-chronic-conditions/>



109. Welch CA, Czerwinski D, Ghimire B, Bertsimas D. Depression and costs of health care. *Psychosomatics*. 2009 Aug;50(4):392–401.
110. Unutzer J, Schoenbaum M, Katon WJ, Fan M-Y, Pincus HA, Hogan D, et al. Healthcare costs associated with depression in medically ill fee-for-service medicare participants. *J Am Geriatr Soc*. 2009 Mar;57(3):506–10.
111. Subramanian S, Tangka FKL, Sabatino SA, Howard D, Richardson LC, Haber S, et al. Impact of chronic conditions on the cost of cancer care for Medicaid beneficiaries. *Medicare Medicaid Res Rev*. 2012;2(4).
112. Oosterveer DM, Mishre RR, van Oort A, Bodde K, Aerden LAM. Anxiety and low life satisfaction associate with high caregiver strain early after stroke. *J Rehabil Med*. 2014 Feb;46(2):139–43.
113. Braun M, Mikulincer M, Rydall A, Walsh A, Rodin G. Hidden morbidity in cancer: spouse caregivers. *J Clin Oncol*. 2007;25(30):4829–34.
114. Ferrara M, Langiano E, Di Brango T, De Vito E, Di Cioccio L, Bauco C. Prevalence of stress, anxiety and depression in with Alzheimer caregivers. *Health Qual Life Outcomes*. 2008 Nov 6;6:93.
115. Schulz R, Newsom J, Mittelmark M, Burton L, Hirsch C, Jackson S. Health effects of caregiving: the caregiver health effects study: an ancillary study of the Cardiovascular Health Study. *Ann Behav Med*. 1997;19(2):110–6.
116. Rumpold T, Schur S, Amering M, Kirchheiner K, Masel EK, Watzke H, et al. Informal caregivers of advanced-stage cancer patients: Every second is at risk for psychiatric morbidity. *Support Care Cancer Off J Multinatl Assoc Support Care Cancer*. 2016 May;24(5):1975–82.
117. Sallim AB, Sayampanathan AA, Cuttilan A, Chun-Man Ho R. Prevalence of Mental Health Disorders Among Caregivers of Patients With Alzheimer Disease. *J Am Med Dir Assoc*. 2015 Dec;16(12):1034–41.
118. National Alliance for Caregiving. Caregiving in the U.S. [Internet]. 2009 [cited 2018 Feb 6]. Available from: [http://www.caregiving.org/data/Caregiving\\_in\\_the\\_US\\_2009\\_full\\_report.pdf](http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf)
119. Merckaert I, Libert Y, Lieutenant F, Moucheux A, Farvacques C, Slachmuylder J-L, et al. Desire for formal psychological support among caregivers of patients with cancer: prevalence and implications for screening their needs. *Psychooncology*. 2013 Jun;22(6):1389–95.
120. Qualls SH, Williams AA. Caregiver family therapy: Empowering families to meet the challenges of aging. American Psychological Association; 2013.
121. Qualls SH. Caregiving families within the long-term services and support system for older adults. *Am Psychol*. 2016;71(4):283.
122. Unutzer J, Katon W, Callahan CM, Williams JWJ, Hunkeler E, Harpole L, et al. Collaborative care management of late-life depression in the primary care setting: a randomized controlled trial. *JAMA*. 2002 Dec 11;288(22):2836–45.

123. Druss BG, von Esenwein SA, Compton MT, Rask KJ, Zhao L, Parker RM. The Primary Care Access Referral, and Evaluation (PCARE) Study: A Randomized Trial of Medical Care Management for Community Mental Health Settings. *Am J Psychiatry*. 2010 Feb;167(2):151–9.
124. Wells KB. The design of Partners in Care: evaluating the cost-effectiveness of improving care for depression in primary care. *Soc Psychiatry Psychiatr Epidemiol*. 1999 Jan;34(1):20–9.
125. Alexopoulos GS, Katz IR, Bruce ML, Heo M, Have TT, Raue P, et al. Remission in Depressed Geriatric Primary Care Patients: A Report From the PROSPECT Study. *Am J Psychiatry*. 2005 Apr;162(4):718–24.
126. Henry Chung, Nina Rostanski, Hope Glassberg, Harold Alan Pincus. Advancing Integration of Behavioral Health into Primary Care: A Continuum-Based Framework. [Internet]. United Hospital Fund; 2016 Jul. Available from: <https://uhfnyc.org/publications/881131>
127. Toward a Serious Illness Program Design & Implementation Framework (hosted content) [Internet]. C-TAC. [cited 2018 May 17]. Available from: <https://www.thectac.org/toward-serious-illness-program-design-implementation-framework-hosted-content/>
128. American Academy of Hospice and Palliative Medicine. Expanding the Hospice and Palliative Care Workforce [Internet]. [cited 2018 Jul 10]. Available from: <http://aahpm.org/issues/workforce>
129. American Academy of Hospice and Palliative Medicine. Measuring What Matters [Internet]. [cited 2018 May 17]. Available from: <http://aahpm.org/quality/measuring-what-matters>
130. Advanced Care Project [Internet]. C-TAC. [cited 2018 May 3]. Available from: <https://www.thectac.org/key-initiatives/advanced-care-project/>
131. Ito T, Shimizu K, Ichida Y, Ishibashi Y, Akizuki N, Ogawa A, et al. Usefulness of pharmacist-assisted screening and psychiatric referral program for outpatients with cancer undergoing chemotherapy. *Psychooncology*. 2011 Jun;20(6):647–54.
132. Pituskin E, Fairchild A, Dutka J, Gagnon L, Driga A, Tachynski P, et al. Multidisciplinary team contributions within a dedicated outpatient palliative radiotherapy clinic: a prospective descriptive study. *Int J Radiat Oncol Biol Phys*. 2010 Oct 1;78(2):527–32.
133. Wakefield CE, Butow PN, Aaronson NA, Hack TF, Hulbert-Williams NJ, Jacobsen PB. Patient-reported depression measures in cancer: a meta-review. *Lancet Psychiatry*. 2015 Jul;2(7):635–47.
134. Mitchell AJ. Short screening tools for cancer-related distress: a review and diagnostic validity meta-analysis. *J Natl Compr Cancer Netw JNCCN*. 2010 Apr;8(4):487–94.
135. Vodermaier A, Millman RD. Accuracy of the Hospital Anxiety and Depression Scale as a screening tool in cancer patients: a systematic review and meta-analysis. *Support Care Cancer Off J Multinatl Assoc Support Care Cancer*. 2011 Dec;19(12):1899–908.
136. Oldenmenger WH, de Raaf PJ, de Klerk C, van der Rijt CCD. Cut points on 0-10 numeric rating scales for symptoms included in the Edmonton Symptom Assessment Scale in cancer patients: a systematic review. *J Pain Symptom Manage*. 2013 Jun;45(6):1083–93.

137. Richardson LA, Jones GW. A review of the reliability and validity of the Edmonton Symptom Assessment System. *Curr Oncol Tor Ont*. 2009 Jan;16(1):55.
138. Anderson J, Burney S, Brooker JE, Ricciardelli LA, Fletcher JM, Satasivam P, et al. Anxiety in the management of localised prostate cancer by active surveillance. *BJU Int*. 2014 Nov;114 Suppl 1:55–61.
139. Thombs BD, Magyar-Russell G, Bass EB, Stewart KJ, Tsilidis KK, Bush DE, et al. Performance characteristics of depression screening instruments in survivors of acute myocardial infarction: review of the evidence. *Psychosomatics*. 2007 Jun;48(3):185–94.
140. Schrag A, Barone P, Brown RG, Leentjens AFG, McDonald WM, Starkstein S, et al. Depression rating scales in Parkinson's disease: critique and recommendations. *Mov Disord Off J Mov Disord Soc*. 2007 Jun 15;22(8):1077–92.
141. Kellogg SH, McHugh PF, Bell K, Schluger JH, Schluger RP, LaForge KS, et al. The Kreek-McHugh-Schluger-Kellogg scale: a new, rapid method for quantifying substance abuse and its possible applications. *Drug Alcohol Depend*. 2003 Mar 1;69(2):137–50.
142. Jackson CB, Varon J, Ho A, Marks KM, Talal AH, Kreek MJ. Identification of substance use and dependence among patients with viral hepatitis. *Dig Liver Dis Off J Ital Soc Gastroenterol Ital Assoc Study Liver*. 2010 Sep;42(9):650–6.
143. Del Fabbro E. Assessment and management of chemical coping in patients with cancer. *J Clin Oncol Off J Am Soc Clin Oncol*. 2014 Jun 1;32(16):1734–8.
144. Watfa G, Husson N, Buatois S, Laurain MC, Miget P, Benetos A. Study of mini-mental state exam evolution in community-dwelling subjects aged over 60 years without dementia. *J Nutr Health Aging*. 2011 Dec 1;15(10):901–4.
145. Petersen RC, Stevens JC, Ganguli M, Tangalos EG, Cummings JL, DeKosky ST. Practice parameter: early detection of dementia: mild cognitive impairment (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. 2001 May 8;56(9):1133–42.
146. Pendlebury ST, Mariz J, Bull L, Mehta Z, Rothwell PM. MoCA, ACE-R, and MMSE versus the National Institute of Neurological Disorders and Stroke-Canadian Stroke Network Vascular Cognitive Impairment Harmonization Standards Neuropsychological Battery after TIA and stroke. *Stroke*. 2012 Feb;43(2):464–9.
147. Hoops S, Nazem S, Siderowf AD, Duda JE, Xie SX, Stern MB, et al. Validity of the MoCA and MMSE in the detection of MCI and dementia in Parkinson disease. *Neurology*. 2009 Nov 24;73(21):1738–45.
148. Stewart BJR, Turnbull D, Mikocka-Walus AA, Harley HAJ, Andrews JM. Acceptability of psychotherapy, pharmacotherapy, and self-directed therapies in Australians living with chronic hepatitis C. *J Clin Psychol Med Settings*. 2013 Dec;20(4):427–39.
149. McFarland DC, Johnson Shen M, Harris K, Mandeli J, Tiersten A, Holland J, et al. ReCAP: Would Women With Breast Cancer Prefer to Receive an Antidepressant for Anxiety or Depression From Their Oncologist? *J Oncol Pract*. 2016 Feb;12(2):172–4; e197-206.

150. Baker JM, Grant RW, Gopalan A. A systematic review of care management interventions targeting multimorbidity and high care utilization. *BMC Health Serv Res.* 2018 Jan 30;18(1):65.
151. Goodarzi Z, Mele B, Guo S, Hanson H, Jette N, Patten S, et al. Guidelines for dementia or Parkinson's disease with depression or anxiety: a systematic review. *BMC Neurol.* 2016 Nov 25;16(1):244.
152. Ostuzzi G, Matcham F, Dauchy S, Barbui C, Hotopf M. Antidepressants for the treatment of depression in people with cancer. *Cochrane Database Syst Rev.* 2015 Jun 1;(6):CD011006.
153. Breitbart W, Alici Y. Evidence-based treatment of delirium in patients with cancer. *J Clin Oncol Off J Am Soc Clin Oncol.* 2012 Apr 10;30(11):1206–14.
154. Chahine LM, Acar D, Chemali Z. The elderly safety imperative and antipsychotic usage. *Harv Rev Psychiatry.* 2010 Jun;18(3):158–72.
155. Okuyama T, Akechi T, Mackenzie L, Furukawa TA. Psychotherapy for depression among advanced, incurable cancer patients: A systematic review and meta-analysis. *Cancer Treat Rev.* 2017 May;56:16–27.
156. Fernandes-Taylor S, Adesoye T, Bloom JR. Managing psychosocial issues faced by young women with breast cancer at the time of diagnosis and during active treatment. *Curr Opin Support Palliat Care.* 2015 Sep;9(3):279–84.
157. Hoon LS, Chi Sally CW, Hong-Gu H. Effect of psychosocial interventions on outcomes of patients with colorectal cancer: a review of the literature. *Eur J Oncol Nurs Off J Eur Oncol Nurs Soc.* 2013 Dec;17(6):883–91.
158. Breitbart W, Rosenfeld B, Pessin H, Applebaum A, Kulikowski J, Lichtenthal WG. Meaning-centered group psychotherapy: an effective intervention for improving psychological well-being in patients with advanced cancer. *J Clin Oncol.* 2015;33(7):749–54.
159. Rodin G, Lo C, Rydall A, Nissim R, Malfitano C, Shnall J, et al. Managing cancer and living meaningfully (CALM): A randomized controlled trial of a psychological intervention for patients with advanced cancer. *American Society of Clinical Oncology;* 2017.
160. Sharpe M, Walker J, Holm Hansen C, Martin P, Symeonides S, Gourley C, et al. Integrated collaborative care for comorbid major depression in patients with cancer (SMaRT Oncology-2): a multicentre randomised controlled effectiveness trial. *Lancet Lond Engl.* 2014 Sep 20;384(9948):1099–108.
161. Semple C, Parahoo K, Norman A, McCaughan E, Humphris G, Mills M. Psychosocial interventions for patients with head and neck cancer. *Cochrane Database Syst Rev.* 2013 Jul 16;(7):CD009441.
162. Olazaran J, Reisberg B, Clare L, Cruz I, Pena-Casanova J, Del Ser T, et al. Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dement Geriatr Cogn Disord.* 2010;30(2):161–78.

163. Richards SH, Anderson L, Jenkinson CE, Whalley B, Rees K, Davies P, et al. Psychological interventions for coronary heart disease. *Cochrane Database Syst Rev* [Internet]. 2017;(4). Available from: <http://dx.doi.org/10.1002/14651858.CD002902.pub4>
164. Baraniak A, Sheffield D. The efficacy of psychologically based interventions to improve anxiety, depression and quality of life in COPD: A systematic review and meta-analysis. *Patient Educ Couns*. 2011 Apr 1;83(1):29–36.
165. Hackett ML, Anderson CS, House A, Xia J. Interventions for treating depression after stroke. *Cochrane Database Syst Rev* [Internet]. 2008;(4). Available from: <http://dx.doi.org/10.1002/14651858.CD003437.pub3>
166. Tsai HF, Chen YR, Chung MH, Liao YM, Chi MJ, Chang CC, et al. Effectiveness of music intervention in ameliorating cancer patients' anxiety, depression, pain, and fatigue: a meta-analysis. *Cancer Nurs*. 2014 Dec;37(6):E35-50.
167. Cooke M, Moyle W, Shum D, Harrison S, Murfield J. A randomized controlled trial exploring the effect of music on quality of life and depression in older people with dementia. *J Health Psychol*. 2010 Jul;15(5):765–76.
168. Jain S, Mills PJ. Biofield therapies: helpful or full of hype? A best evidence synthesis. *Int J Behav Med*. 2010 Mar;17(1):1–16.
169. Robison JG, Smith CL. Therapeutic Massage During Chemotherapy and/or Biotherapy Infusions: Patient Perceptions of Pain, Fatigue, Nausea, Anxiety, and Satisfaction. *Clin J Oncol Nurs*. 2016 Apr;20(2):E34-40.
170. Wilkinson S, Barnes K, Storey L. Massage for symptom relief in patients with cancer: systematic review. *J Adv Nurs*. 2008 Sep;63(5):430–9.
171. Mishra SI, Scherer RW, Snyder C, Geigle P, Gotay C. The effectiveness of exercise interventions for improving health-related quality of life from diagnosis through active cancer treatment. *Oncol Nurs Forum*. 2015 Jan;42(1):E33-53.
172. Danhauer SC, Addington EL, Sohl SJ, Chaoul A, Cohen L. Review of yoga therapy during cancer treatment. *Support Care Cancer Off J Multinatl Assoc Support Care Cancer*. 2017 Apr;25(4):1357–72.
173. Oh P-J, Kim SH. The effects of spiritual interventions in patients with cancer: a meta-analysis. *Oncol Nurs Forum*. 2014 Sep;41(5):E290-301.
174. Ross S, Bossis A, Guss J, Agin-Liebes G, Malone T, Cohen B, et al. Rapid and sustained symptom reduction following psilocybin treatment for anxiety and depression in patients with life-threatening cancer: a randomized controlled trial. *J Psychopharmacol (Oxf)*. 2016;30(12):1165–80.
175. Irwin KE, Henderson DC, Knight HP, Pirl WF. Cancer care for individuals with schizophrenia. *Cancer*. 2014 Feb 1;120(3):323–34.
176. Reisfield GM, Wasan AD, Jamison RN. The prevalence and significance of cannabis use in patients prescribed chronic opioid therapy: a review of the extant literature. *Pain Med Malden Mass*. 2009 Nov;10(8):1434–41.

177. Oliver J, Coggins C, Compton P, Hagan S, Matteliano D, Stanton M, et al. American Society for Pain Management nursing position statement: pain management in patients with substance use disorders. *Pain Manag Nurs*. 2012;13(3):169–83.
178. O'Brien CP. Managing patients with a history of substance abuse. *Can Fam Physician*. 2014 Mar;60(3):248–50.
179. Scott K, Lewis CC. Using Measurement-Based Care to Enhance Any Treatment. *Cogn Behav Pract*. 2015 Feb;22(1):49–59.
180. Fortney JC, Unützer J, Wrenn G, Pyne JM, Smith GR, Schoenbaum M, et al. A Tipping Point for Measurement-Based Care. *Psychiatr Serv*. 2016 Sep 1;68(2):179–88.
181. Hibbard JH, Greene J. What The Evidence Shows About Patient Activation: Better Health Outcomes And Care Experiences; Fewer Data On Costs. *Health Aff (Millwood)*. 2013 Feb 1;32(2):207–14.
182. Committee on Approaching Death: Addressing Key End of Life Issues; Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. [Internet]. Washington (DC): National Academies Press (US); 2015. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK285681/> doi: 10.17226/18748
183. Dixon LB, Lucksted A, Medoff DR, Burland J, Stewart B, Lehman AF, et al. Outcomes of a randomized study of a peer-taught Family-to-Family Education Program for mental illness. *Psychiatr Serv Wash DC*. 2011 Jun;62(6):591–7.
184. Evangelista LS, Stromberg A, Dionne-Odom JN. An integrated review of interventions to improve psychological outcomes in caregivers of patients with heart failure. *Curr Opin Support Palliat Care*. 2016 Mar;10(1):24–31.
185. Porter LS, Keefe FJ, Garst J, Baucom DH, McBride CM, McKee DC, et al. Caregiver-Assisted Coping Skills Training for Lung Cancer: Results of a Randomized Clinical Trial. *J Pain Symptom Manage*. 41(1):1–13.
186. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. *JAMA*. 2014 Mar 12;311(10):1052–60.
187. Christakis NA, Escarce JJ. Survival of Medicare patients after enrollment in hospice programs. *N Engl J Med*. 1996;335(3):172–8.
188. Shear MK, Ghesquiere A, Glickman K. Bereavement and complicated grief. *Curr Psychiatry Rep*. 2013 Nov;15(11):406.
189. Shear MK. Complicated Grief. *N Engl J Med*. 2015 Jan 7;372(2):153–60.
190. Nam IS. Effects of psychoeducation on helpful support for complicated grief: a preliminary randomized controlled single-blind study. *Psychol Med*. 2016;46(1):189–95.
191. Dobbins MI, Thomas SA, Melton SLS, Lee S. Integrated Care and the Evolution of the Multidisciplinary Team. *Prim Care*. 2016 Jun;43(2):177–90.

192. Raine R, Wallace I, Nic a' Bháird C, Xanthopoulou P, Lanceley A, Clarke A, et al. Improving the effectiveness of multidisciplinary team meetings for patients with chronic diseases: a prospective observational study [Internet]. Southampton (UK): NIHR Journals Library; 2014 [cited 2018 Feb 27]. (Health Services and Delivery Research). Available from: <http://www.ncbi.nlm.nih.gov/books/NBK260189/>
193. Irwin SA, Ferris FD. The opportunity for psychiatry in palliative care. *Can J Psychiatry Rev Can Psychiatr*. 2008 Nov;53(11):713–24.
194. Irwin SA, Montross LP, Bhat RG, Nelesen RA, von Gunten CF. Psychiatry resident education in palliative care: opportunities, desired training, and outcomes of a targeted educational intervention. *Psychosomatics*. 2011 Dec;52(6):530–6.
195. Tait GR, Hodges BD. End-of-life care education for psychiatric residents: attitudes, preparedness, and conceptualizations of dignity. *Acad Psychiatry J Am Assoc Dir Psychiatr Resid Train Assoc Acad Psychiatry*. 2009 Dec;33(6):451–6.
196. Macleod ADS. Palliative medicine and psychiatry. *J Palliat Med*. 2013 Apr;16(4):340–1.
197. Health Leads. Health Leads Screening Toolkit [Internet]. Health Leads. [cited 2018 Jul 10]. Available from: <https://healthleadsusa.org/tools-item/health-leads-screening-toolkit/>
198. Camden Coalition of Healthcare Providers. Care Planning for Patients with Frequent Hospitalizations Toolkit [Internet]. 2016. Available from: [https://www.camdenhealth.org/wp-content/uploads/2016/12/Care-Planning-Toolkit\\_final.pdf](https://www.camdenhealth.org/wp-content/uploads/2016/12/Care-Planning-Toolkit_final.pdf)
199. Andrews AO, Bartels SJ, Xie H, Peacock WJ. Increased risk of nursing home admission among middle aged and older adults with schizophrenia. *Am J Geriatr Psychiatry Off J Am Assoc Geriatr Psychiatry*. 2009 Aug;17(8):697–705.
200. Karen Davis, Amber Willink, Cathy Schoen. Medicare help at home [Internet]. Health Affairs Blog. Available from: <https://www.healthaffairs.org/do/10.1377/hblog20160413.054429/full/>
201. Aspen Institute Health Strategy Group. Improving care at the end of life [Internet]. 2016. Available from: <https://www.aspeninstitute.org/publications/improving-care-end-life/>
202. Centers for Medicare & Medicaid Services (CMS), HHS. Medicare Program; Contract Year 2019 Policy and Technical Changes to the Medicare Advantage, Medicare Cost Plan, Medicare Fee-for-Service, the Medicare Prescription Drug Benefit Programs, and the PACE Program. 4120-01-P, 42 CFR Parts 405, 417, 422, 423, 460 , and 498.
203. NCQA's Serious Illness Care Measures Project Awarded [Internet]. NCQA. [cited 2018 Jul 23]. Available from: <http://www.ncqa.org/newsroom/details/ncqa%E2%80%99s-serious-illness-care-measures-project-awarded?ArtMID=11280&ArticleID=86&tabid=2659>
204. NQF: NQF's Serious Illness Care Initiative [Internet]. [cited 2018 Aug 9]. Available from: [http://www.qualityforum.org/NQP/Transforming\\_Advanced\\_Illness\\_Care.aspx](http://www.qualityforum.org/NQP/Transforming_Advanced_Illness_Care.aspx)
205. Chochinov HM, Martens PJ, Prior HJ, Kredentser MS. Comparative health care use patterns of people with schizophrenia near the end of life: a population-based study in Manitoba, Canada. *Schizophr Res*. 2012 Nov;141(2–3):241–6.
206. Shalev D, Brewster K, Arbuckle MR, Levenson JA. A staggered edge: End-of-life care in patients with severe mental illness. *Gen Hosp Psychiatry*. 2017 Feb;44:1–3.

207. Martens PJ, Chochinov HM, Prior HJ. Where and how people with schizophrenia die: a population-based, matched cohort study in Manitoba, Canada. *J Clin Psychiatry*. 2013 Jun;74(6):e551-557.
208. Foti ME, Bartels SJ, Van Citters AD, Merriman MP, Fletcher KE. End-of-life treatment preferences of persons with serious mental illness. *Psychiatr Serv*. 2005;56(5):585–91.
209. Candilis PJ, Foti MEG, Holzer JC. End-of-life care and mental illness: a model for community psychiatry and beyond. *Community Ment Health J*. 2004 Feb;40(1):3–16.
210. Jones D, Macias RL, Gold PB, Barreira P, Fisher W. WHEN PARENTS WITH SEVERE MENTAL ILLNESS LOSE CONTACT WITH THEIR CHILDREN: ARE PSYCHIATRIC SYMPTOMS OR SUBSTANCE USE TO BLAME? *J Loss Trauma*. 2008 Jul 1;13(4):261–87.
211. Foti ME. " Do It Your Way": A Demonstration Project on End-of-Life Care for Persons with Serious Mental Illness. *J Palliat Med*. 2003;6(4):661–9.
212. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand*. 1983 Jun;67(6):361–70.
213. Park J-Y, Wu L-T. Prevalence, reasons, perceived effects, and correlates of medical marijuana use: A review. *Drug Alcohol Depend*. 2017 Aug 1;177:1–13.
214. Hill KP. Medical marijuana for treatment of chronic pain and other medical and psychiatric problems: A clinical review. *JAMA*. 2015 Jun 23;313(24):2474–83.
215. Facts and Statistics - Certificates issues through December 31, 2017 [Internet]. American Board of Psychiatry and Neurology. [cited 2018 Jul 19]. Available from: <https://www.abpn.com/about/facts-and-statistics/>
216. Community-Based Guidelines (2018) | NCP | NCHPC [Internet]. [cited 2018 May 14]. Available from: <https://www.nationalcoalitionhpc.org/ncp-guidelines-2018/>
217. Schenck AP, Rokoske FS, Durham D, Cagle JG, Hanson LC. Quality measures for hospice and palliative care: piloting the PEACE measures. *J Palliat Med*. 2014 Jul;17(7):769–75.
218. Monica 1776 Main Street Santa, California 90401-3208. Health Indicators Address Quality of Care in Older Adults [Internet]. [cited 2018 May 17]. Available from: <https://www.rand.org/health/projects/acove.html>
219. Patel MM, Brown JD, Croake S, Lewis R, Liu J, Patton L, Potter DE, Scholle SH. The current state of behavioral health quality measures: where are the gaps?. *Psychiatric Services*. 2015 Jun 15;66(8):865-71.
220. Medicare C for, Baltimore MS 7500 SB, Usa M. CMS Measures Inventory [Internet]. 2018 [cited 2018 May 14]. Available from: <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityMeasures/CMS-Measures-Inventory.html>
221. Pincus HA, Li M, Scharf DM, Spaeth-Rublee B, Goldman ML, Ramanuj PP, et al. Prioritizing quality measure concepts at the interface of behavioral and physical healthcare. *Int J Qual Health Care J Int Soc Qual Health Care*. 2017 Aug 1;29(4):557–63.



222. Quality Improvement | National PACE Association [Internet]. [cited 2018 May 17]. Available from: <https://www.npaonline.org/member-resources/quality-improvement>
223. Tjia J, Lemay CA, Bonner A, Compher C, Paice K, Field T, et al. Informed family member involvement to improve the quality of dementia care in nursing homes. *J Am Geriatr Soc*. 2017;65(1):59–65.
224. Unroe Kathleen T., Stump Timothy E., Effler Shannon, Tu Wanzhu, Callahan Christopher M. Quality of Hospice Care at Home Versus in an Assisted Living Facility or Nursing Home. *J Am Geriatr Soc*. 2018 Feb 10;66(4):687–92.
225. Valuck T, Blaisdell D, Dugan DP, Westrich K, Dubois RW, Miller RS, et al. Improving Oncology Quality Measurement in Accountable Care: Filling Gaps with Cross-Cutting Measures. *J Manag Care Spec Pharm*. 2017 Feb;23(2):174–81.
226. Goldman ML, Spaeth-Rublee B, Pincus HA. Quality indicators for physical and behavioral health care integration. *Jama*. 2015;314(8):769–70.
227. Ferguson A, Yates C, Tilford JM. Value-based insurance designs in the treatment of mental health disorders. *Am J Manag Care*. 2016 Jan 1;22(1):e38-44.
228. American Academy of Hospice and Palliative Medicine. Proposal for a Physician-Focused Payment Model - Patient and Caregiver Support for Serious Illness (PACSSI) [Internet]. 2017 Aug. Available from: <https://aspe.hhs.gov/system/files/pdf/255906/ProposalAAHPM.pdf>
229. Physician-Focused Payment Model Technical Advisory Committee. Report to the Secretary of Health and Human Services: Comments and Recommendations on Advanced Care Model (ACM) Service Delivery and Advanced Alternative Payment Model & Patient and Caregiver Support for Serious Illness (PACSSI) [Internet]. 2018 May. Available from: <https://aspe.hhs.gov/system/files/pdf/255906/PTACCommentsRecommendationAAHPMCTAC.pdf>
230. NRC PAD | National Resource Center on Psychiatric Advance Directives [Internet]. [cited 2018 Jul 18]. Available from: <https://www.nrc-pad.org/>
231. Clint Parker J, Goldberg DS. A Legal and Ethical Analysis of the Effects of Triggering Conditions on Surrogate Decision-Making in End-of-Life Care in the US. *HEC Forum Interdiscip J Hosp Ethical Leg Issues*. 2016 Mar;28(1):11–33.
232. Sabatino CP. Advance Directives and Advance Care Planning: Legal and Policy Issues [Internet]. Washington, D.C: U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy; 2007 Oct. Report No.: #HHS-100-03-0023. Available from: <http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.pdf>
233. 5 Years of The Conversation Project [Internet]. The Conversation Project. 2018 [cited 2018 May 8]. Available from: <https://theconversationproject.org/tcp-blog/5-years-of-the-conversation-project/>
234. Center to Advance Palliative Care. CAPC Palliative Care CME/CNE/CE Courses. [Internet]. CAPC. [cited 2018 Jul 10]. Available from: <https://www.capc.org/providers/courses/>

## Serious Illness Care Population: Behavioral Health Issues in Serious Illness Care

| Categories of Behavioral Health Issues in Serious Illness Care  | Clinical Scenarios  |
|---|---|
| <ul style="list-style-type: none"><li>• Pre-existing behavioral health conditions</li><li>• Newly developed behavioral health problems, including:<ul style="list-style-type: none"><li>- Disorders as a direct manifestation of medical illness</li><li>- Disorders as a complication of medical treatment</li><li>- Disorders in the context of psychosocial stressors and disability</li></ul></li></ul> | <ul style="list-style-type: none"><li>Anxiety</li><li>Confusion/Delirium</li><li>Cognitive impairment</li><li>Depression</li><li>Existential/spiritual crisis</li><li>Prolonged grief disorder</li><li>Interpersonal/family conflict</li><li>Personality disorders</li><li>Substance use disorders</li><li>Serious mental illnesses</li><li>Trauma-related conditions</li><li>Other behavioral health scenarios</li></ul> |

# Model for Behavioral Health Care in Serious Illness Care Settings

## Guiding Principles

|  |                                   |                                 |                              |
|--|-----------------------------------|---------------------------------|------------------------------|
| Person/Family-oriented care reflecting individual goals, values, preferences, concerns | Interdisciplinary team-based care | Coordinated and integrated care | Value-based accountable care |
|--|-----------------------------------|---------------------------------|------------------------------|

## Key Components/ Domains

| Key Components               |  |  | Examples and Elaboration   |
|------------------------------|--|--|--|
| 2. Clinical Functions        | Provider/ Person communication                             | Ensuring shared decision-making that incorporates behavioral health issues   | <ul style="list-style-type: none"> <li>• Pro-active communication to address person’s concerns/fears</li> <li>• Infrastructure for robust provider and person communication across care processes</li> <li>• Culturally appropriate communication among persons and providers</li> <li>• Continuous exploration and alignment with person’s care preferences across all domains, including behavioral health</li> </ul>  |
|                              | Case finding, screening, and referral to care              | Providing screening, initial assessment, and follow up   | <ul style="list-style-type: none"> <li>• Screening with standardized behavioral health measures (e.g., Hospital Anxiety and Depression Scale, Beck Depression Inventory-II, Generalized Anxiety Disorder-7, Patient Health Questionnaire-9/ Patient Health Questionnaire-2, substance use disorder screening audit, etc.) adapted to serious illness settings paired with a periodic activity (e.g. oncological follow-up treatment) in addition to standard history of behavioral health conditions/relevant medications and pain assessment</li> <li>• Assessment by behavioral health-trained personnel</li> <li>• Standardized protocols for appropriate and timely follow up</li> <li>• Goal-setting and comprehensive advanced care planning to assure care is in concordance with person’s goals and preferences</li> </ul> |
|                              |  | Facilitating and tracking referral   | <ul style="list-style-type: none"> <li>• Establish network for behavioral health referral with formalized arrangements for “greasing” referral pathways, sharing information pre/post-referral</li> <li>• Patient preparation and tracking to assure successful referral connection across different care settings and providers if a referral is needed</li> </ul>  |
| Longitudinal care management | Coordinating, communicating, and following up relentlessly | <ul style="list-style-type: none"> <li>• Assuring appropriateness and timeliness of behavioral health and other services</li> <li>• Transitional care and care coordination</li> <li>• Prevention of unnecessary emergency department visits/hospitalizations due to untreated behavioral health issues</li> <li>• Mapping person’s behavioral health needs over time and across settings</li> </ul> |  |

## Key Components/ Domains *(continued)*

| Key Components           |  |   | Examples and Elaboration  |
|--------------------------|--|---|---|
| 2. Clinical Functions    | Longitudinal care management   | Managing clinical crises or any severe or sudden change of behavior   | <ul style="list-style-type: none"> <li>• Protocols for managing suicidality</li> <li>• Protocols for managing agitation/delirium</li> <li>• Protocols for assessment of capacity to refuse/consent to treatments or diagnostics</li> <li>• Protocols for managing behavioral health symptom flares</li> <li>• Protocols for managing disruption of social support</li> </ul>  |
|                          | Integrated evidence-based and measurement-based behavioral health care     | Providing access to evidence-based psychopharmacological and evidence-based psychosocial interventions  | <ul style="list-style-type: none"> <li>• Preventive services to reduce occurrence or severity of behavioral health issues</li> <li>• Psychiatric medication management (especially in context of complex co-morbidities)</li> <li>• Psychosocial interventions (e.g., cognitive-behavioral, motivational enhancement, problem solving, trauma-related therapies, palliative care psychotherapies including meaning centered therapy and dignity-conserving therapy)</li> <li>• Complementary treatments (e.g., music therapy, acupuncture)</li> <li>• Attention to spiritual concerns</li> <li>• Treatment of severe mental illness (e.g., schizophrenia, bipolar disorder)</li> <li>• Pain and other physical symptom management</li> <li>• Treatment of substance use disorder</li> </ul> |
|                          |  | Measurement-based, stepped care   | <ul style="list-style-type: none"> <li>• Incorporate tools and guidelines in clinical workflow/health information technologies</li> <li>• Access to informal (“curbside”) consultation with behavioral health specialists</li> </ul>  |
|                          | Self-management support to address behavioral health issues                | Promoting patient activation/engagement   | <ul style="list-style-type: none"> <li>• Educational materials and technologies regarding behavioral health</li> <li>• Health coaching</li> <li>• Self-care and caregiver training in behavioral health issues</li> <li>• Support for discussions about goals of care</li> <li>• Peer support</li> </ul>  |
|                          |  | Promoting health literacy to achieve symptom control and personal goals   |   |
| Family caregiver support | Providing tools and interventions to support and educate family caregivers | <ul style="list-style-type: none"> <li>• Formal and informal treatments and supports for family caregivers including:               <ul style="list-style-type: none"> <li>- Health coaching/care training for caregivers in recognizing/responding to depression, cognitive deficits, etc. in family members (and themselves)</li> <li>- Informal emotional support; referral to behavioral health provider if indicated</li> <li>- Appropriate toolkits to support/ education for goals of care discussions</li> <li>- Home health aides with behavioral health training</li> <li>- Respite care</li> <li>- Bereavement/Prolonged grief disorder interventions</li> </ul> </li> </ul> |   |

## Key Components/ Domains *(continued)*

| Key Components                              |  |  | Examples and Elaboration  |
|---|--|--|---|
| 3. Workforce to Support Clinical Functions  | Interdisciplinary teams                                      | Including generalist/ specialist/palliative care physicians, psychiatrists, psychologists, nurse practitioners, physician assistants, nurses, social workers, chaplains, behavioral health care managers, patients, caregivers/peers, etc. | <ul style="list-style-type: none"> <li>• Embedded or formalized network relationship with trained prescribers of psychiatric medications</li> <li>• Embedded or formalized network relationship with psychologist, nurse, social worker or other behavioral health specialists</li> <li>• Embedded or formalized network relationship to support care coordination (“lead point of contact on the healthcare team”)</li> <li>• Formal/ informal linkage to social support services</li> <li>• Formal/informal linkage to spiritual care providers</li> <li>• Working milieu that promotes staff satisfaction and consistency to reduce staff burnout</li> </ul>   |
|   | Competencies   | Providing training, supervision and assessment to assure competencies in evidence-based practices  | <ul style="list-style-type: none"> <li>• Training and supervision for general medical/palliative care providers to develop behavioral health competencies</li> <li>• Training and supervision for behavioral health providers to develop competencies in serious illness care</li> <li>• Training and supervision in facilitating advance care planning and goals of care conversations and maintaining patient treatment alliance</li> <li>• Training and supervision in effective methods to facilitate communication across medical silos between general medical and behavioral health providers</li> <li>• Knowledge and competencies in social services and other needs for patients and connecting patients to those services</li> </ul> |
| 4. Structures to Support Clinical Functions | Health information technologies and other technology support | Commissioning and maintaining systematic tracking of clinical information and exchange among team members across settings  | <ul style="list-style-type: none"> <li>• Incorporating behavioral health concepts and terms in HIT systems</li> <li>• Electronic health records with registry functionality to support longitudinal care management for behavioral health issues</li> <li>• Data sharing platform including secure mobile devices to connect all care team members</li> <li>• Policies and support to guide discussions with patients about privacy and sharing of information among providers</li> <li>• Telemedicine capacity to assure access to behavioral health care for patients with limited mobility</li> <li>• Easy access to co-located psychosocial information in electronic health records</li> </ul>   |

## Key Components/ Domains *(continued)*

| Key Components  |  |   | Examples and Elaboration  |
|---|--|---|---|
| 4. Structures to Support Clinical Functions                 | Systematic quality improvement           | Using quality metrics and other improvement strategies targeted to behavioral health care   | <ul style="list-style-type: none"> <li>• Formal quality improvement targeting behavioral health care through:               <ul style="list-style-type: none"> <li>- Behavioral health workforce competencies</li> <li>- Integrated electronic health records for behavioral health and serious illnesses</li> <li>- Delivering evidence-based behavioral health care</li> </ul> </li> <li>• Implementing quality measures for monitoring and evaluation</li> </ul>   |
|   | Linkages with community/ social services | Initiating and maintaining formal arrangements with housing, entitlement, and other social support services tailored to persons' behavioral health needs (especially severe mental illness) | <ul style="list-style-type: none"> <li>• Home Safety and Access Adaptations through home maintenance and modification programs</li> <li>• Housing support services</li> <li>• Transportation</li> <li>• Meals on Wheels</li> <li>• Home maker services</li> <li>• Personal care (e.g., assistance for dependence)</li> <li>• Physical and financial abuse assessment and response</li> </ul>  |
| 5. Policies to Enhance and Incent Effective Integrated Care | Accountability                           | Sharing responsibility among team members to meet performance standards for all care, including behavioral health   | <ul style="list-style-type: none"> <li>• Development of validated behavioral health quality measures specifically designed to encourage integration and improvement in serious illness contexts:               <ul style="list-style-type: none"> <li>- Structure measures</li> <li>- Process measures</li> <li>- Outcomes measures (symptom management , personalized goal achievement, quality of life)</li> <li>- Patient/caregiver/staff experience measures</li> <li>- Efficiency measure</li> </ul> </li> <li>• Create a shared-accountability model between physical and behavioral health providers to monitor and assure access and quality</li> </ul> |
|   | Payment                                  | Incorporating behavioral health-related costs in payment models that encourage efficiency and quality   | <ul style="list-style-type: none"> <li>• Development of sustainability strategies to support behavioral health services:               <ul style="list-style-type: none"> <li>- Capitated payment</li> <li>- Value-based payment models</li> <li>- Fee-for-service environments</li> </ul> </li> </ul>  |