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**Psycho-Oncology: Psychosocial Support and Mental Health Care for Cancer Patients**

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## Abstract

Psycho-oncology is a multidisciplinary sub-specialty of medical psychiatry or psychosomatic medicine which has grown from its beginning in the mid-1970s to an established evidence-based field addressing the psychiatric, psychological, social, and emotional well-being of cancer patients, families and caregivers (Jacobsen, Holland, & Steensma, 2012). As the public and healthcare professionals continue to have greater awareness of the impact of cancer diagnosis and treatment, with its high levels of associated stress, loss and adjustment, and as our population ages, there is a growing need for psycho-oncology care. The Institute of Medicine published a report in 2008 “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs” stressing the effectiveness of psychotherapy, self-care, health education and promotion, and psychopharmacological treatment in benefitting these patients (Jacobsen et al., 2012). Based on this report, the American College of Surgeons Commission on Cancer (CoC), added psychosocial distress screening and referral as a standard of care for all CoC accredited cancer centers as of 2015 (Lazenby et al., 2015). There is a need for psycho-oncology programs in community hospitals, but there may be a lack of both trained mental health professionals and funding. A study of the current breadth and availability of psycho-oncology services is proposed. The methods to be used to examine these topics will be a review of the literature using electronic data bases accessed through the Harley French Medical Library at the University of North Dakota covering medical, nursing, life sciences and allied health literature by using databases of PubMed, CINAHL, and PsycInfo. The search will cover the development of the field of psycho-oncology, current research on psycho-social needs and interventions, standards of care and clinical practice guidelines, training of psycho-oncology professionals, barriers to psycho-social care implementation, services available in large cancer centers relative to smaller community

hospitals and psycho-oncology program development. Consultation with an expert working in the specialty of psycho-oncology regarding developing, implementing and funding a psycho-oncology program and the roles of psychiatric mental health nurse practitioners is also an objective of the study. The goal of this inquiry was to determine what a psycho-oncology program can offer to improve care and quality of life for cancer patients. Cancer patients can benefit greatly from access to the psychosocial support and mental health services of psycho-oncology. The transactional model of stress and coping is examined as a framework for understanding the coping responses to the stressor of cancer. The most critical aspects that make up a successful program are identified as screening for distress with appropriate response and follow-up, excellent communication, assessment and care provided with empathy in calming surroundings. These measures enable identification of patients in need of referral and work to ensure that patients will not be facing the challenges of cancer alone. Many factors contribute to the growth of psycho-oncology services at this time. Psycho-oncology care is provided most extensively in large cancer centers, but is increasingly implemented and funded in more rural community settings.

## **Psycho-oncology: Psychosocial Support and Mental Health for Cancer Patients**

### **Introduction**

Cancer is the second-leading cause of death in the United States (Centers for Disease Control [CDC], 2016) with approximately 40% of Americans being diagnosed with cancer during their lives (Adler & Page, 2008; National Cancer Institute [NCI], 2016), as one out of every two men and one out of every three women will be diagnosed (American Cancer Society [ACS], 2016). Thirty-five thousand children are currently being treated for childhood cancers (Bass, 2014). Early diagnosis and improved treatments resulting in greater survival times, combined with an aging population, mean cancer diagnoses will be increasingly common (Meyer, Erlich, & Peteet, 2009). In 2016, researchers expect an estimated 1,685,210 new diagnoses (an incidence of 454.8/100,000) with 595,690 deaths (a mortality of 171.2/100,000; NCI, 2016), and this number is expected to rise from 1.6 million per year to 2.3 million per year by 2030, a 45% increase (National Academies, 2013). Currently, 15.5 million Americans have a history of cancer—excluding carcinoma-in-situ and basal/squamous cell skin cancers (ACS, 2016). Cancer is now viewed as a chronic disease with a greater focus on the long term well-being of the patient (Bass, 2014), quality of life issues, and psychosocial adjustment during and after cancer treatment (American College of Surgeons [ACoS], 2011).

Psycho-oncology is a multidisciplinary specialty field of psychiatrists, psychologists, social workers, nurses, and others, and it is closely related to health psychology, medical psychiatry, psychosomatic medicine and includes any psychosocial and mental health care of cancer patients. The clinical and research work in psycho-oncology has demonstrated evidence over the last 30 years of significant psychological impact on patients and families as a consequence of cancer and its treatment, which may result in psychiatric disorders and

psychosocial suffering (Holland, 2002). A cancer experience can worsen existing psychological and social problems and create new ones and is an important time to protect and promote mental health. There has been increasing recognition, evident through reports, standards of care, and practice guidelines, of the necessity of providing for cancer patients' mental health, quality of life, and psychosocial distress. Surbone and others (2010) noted that many organizations, including the World Health Organization (WHO), Oncology Nursing Society, International Psycho-Oncology Society, American Society of Clinical Oncology, and more, have all endorsed standards that integrate psychosocial care for patients and families. A key 2008 Institute of Medicine (IOM) report called for psychosocial care to be incorporated into all routine oncology care and stated there could be no quality cancer care without support of psychological needs and recommended actions to ensure implementation (Adler & Page, 2008). The American College of Surgeons Commission on Cancer (ACoS CoC, 2012) report identified requirements for cancer centers to "develop and implement a process to integrate and monitor on-site psychosocial distress screening and referral for provision of psychosocial care" (p.77) to be accredited as of 2015.

However, indications are that widespread screening, assessment, and treatment from diagnosis through survival care and beyond may not be widely available throughout many regions of the country. The 2008 IOM report noted that care often focuses on medical treatment, and oncologists may tend to underestimate patients' distress. Significant evidence indicates that cancer patients have unmet psychosocial needs (Fann, Ell, & Sharpe, 2012), and researchers express concern that psycho-oncology experts tend to be available primarily in larger metropolitan cancer centers and are limited elsewhere (Leykin et al., 2012; Turner, 2015). This study will examine psycho-oncology practices, barriers to their implementation, current focuses

in service/program implementation, and innovations in the dissemination of psycho-oncology care.

### **Purpose**

Psycho-oncology is a broad multidisciplinary field with distinctive niches for health educators, clergy, social workers, psychologists, and more. This literature search will seek to glean material useful to the clinical health care professional's perspective, especially assessment, intervention, and program development roles of the advanced practice nurse, providing patient-centered care to adults in an inpatient or outpatient setting. Child and adolescent cancer psychosocial care is ahead of adult psycho-oncology in survivorship programming and emotional follow-up care (Bass, 2014), and due to its uniqueness, is beyond the scope of this paper.

Psycho-oncology encompasses all psychological aspects related to cancer, including their role in cancer prevention and health behaviors prior to a diagnosis. For the purposes of this paper, only the psychosocial factors associated with diagnosis and beyond will be included. While it is understood that the family caregivers and members have psychological needs and are included as part of the patient unit of care, the focus of this literature review will be programs and interventions with the cancer patient.

Cancer care is complex, involving treatment by a number of specialists—often seen in a variety of settings. An individual's cancer experience may be described as her journey, course, or trajectory, indicating that the experience is not static. The goal will be a broad overview examining this cancer experience, from diagnosis onward, with the purpose of determining what is known about identifying patient emotional distress, unmet mental health needs, supportive follow-up care after treatment, and connecting patients to needed services.

### Significance

Despite its relatively short history—it began in the 1970s—psycho-oncology is now an established field with dedicated professional societies, scientific meetings, and journals (Jacobsen, Holland, & Steensma, 2012). Many factors converged prior to that time to give rise to psycho-oncology: psycho-somatic research; improved cancer treatments with long-term remissions and new chemotherapies; patients' rights; and new science on cancer causation, stress, and the immune system (Holland, 2002). Before these changes, cancer diagnoses carried a strong stigma and were equated with a death sentence; also, doctors considered it a cruelty to inform a patient of the diagnosis which offered only hopelessness. Illustrating a shift in attitudes are the survey statistics from 1961—over 90% of physicians would not tell a patient they had cancer—compared with 1978—over 90% would (Holland, 2002). Once it became routine to give a patient the diagnosis, the opportunity emerged to learn about the impact on patients, and interventions to improve hope and provide support began to be developed.

As patient and professional awareness increased, the development of psycho-oncology kept pace (Jacobsen et al., 2012). Patients increasingly sought holistic, complementary, and alternative therapies; interventions out of the mainstream developed in cancer wellness communities and became integrated into medical cancer care. Cancer stigma has improved although certain kinds of cancer, such as lung cancer, still carry it. Mental health continues to have a stigma; in the same way cancer equated death, insanity was thought to be untreatable and permanent (Holland, 2002). Holland, a prominent pioneering psychiatrist in psycho-oncology, noted that the stigma of mental illness is a factor in the sometimes low response rates to psychological support services as patients do not want to be labeled or associated with anything that may carry a negative connotation of defect, failure, or weakness.



Substantial evidence indicates that cancer patients are greatly impacted psychosocially by their diagnosis and treatment (Fann et al., 2012) in nearly every aspect of their lives (Surbone et al., 2010), with one in four reporting reduced quality of life (ACS, 2016; Hamann & Kendall, 2013). Both the diagnosis and treatment can be life-threatening, disruptive, or invasive, with a third to a half of patients experiencing emotional distress related to fatigue, anxiety, pain, or depression (Fann et al., 2012; See Appendix A). The most common psychiatric diagnosis is adjustment disorder, with a prevalence range of 10% to 36% (NCI, 2015). Researchers estimate that 40% of those with cancer experience significant distress with distress being identified as the sixth vital sign (Allen, Zebrack, Wittmann, Hammellef, & Morris, 2014; NCI, 2015; Turner, 2015).

Most psychiatric disturbances are directly related to cancer or its treatment with 66% of the diagnoses being for adjustment disorder (Breitbart & Alici, 2009). These emotional and behavioral issues in turn impact treatment adherence (ACoS CoC, 2012), increase somatic symptoms such as pain and sleep problems (Adler & Page, 2008), exacerbate anticipatory nausea and vomiting, are associated with delays or neglect in screening or treatments (NCI, 2015), and predict increased medical expenses and worsened self-management (Fann et al., 2012). Non-adherence to treatment is three times higher when a patient is depressed (Meyer et al., 2009), and suicides rates are doubled in the cancer population, with risk factors being depression, poorly controlled pain, certain cancers, and being a White single male (Breitbart & Alici, 2009; Meyer et al., 2009, 2012; Yuppa, Braun, & Meyer, 2014).

While most patients experience an adjustment, the majority do not have a diagnosable mental illness but fall somewhere along a continuum from normal adjustment (meeting some criteria) to the upper end of the spectrum, where patients meet diagnostic criteria for specific

mental disorders like major depressive disorder or cancer-related PTSD (NCI, 2015). Researchers clearly understand that psychosocial factors are determinants of health and poor mental health is associated with poor physical health (WHO, 2016). Documented, effective, evidence-based interventions of supportive and psychological services to improve coping, improve adherence, and reduce distress have been developed (Meyer et al., 2009; Schuyler, 2004). Psycho-oncological care is considered an integral part of comprehensive care, and patients today should expect their psychosocial needs to be attended with their biomedical needs; to not provide this treatment is to extend life without consideration of the quality of life (Fann et al., 2012).

Research currently focuses on studies that address practical application, technological innovation, and clinical implementation of known interventions to address the questions of how to meet needs in the most cost-effective, timely manner, with efficient best-use of existing resources and how to provide services to areas that are less likely to be served by psychiatrists (Hamann & Kendall, 2013; Jacobsen et al., 2012; McCabe, 2008). Answers to these questions will increase the abilities of practitioners to provide patients access to appropriate services and achieve good usage rates. Barriers to this goal—time and access limitations, short patient visits, limited numbers of professionals with experience and training in mental health related to cancer in non-urban areas—provide challenges to overcome.

### **Theoretical Framework**

Cancer can be viewed as special and severe form of stress (Grassi, Caruso, Sabato, Massarenti, & Nanni, 2015). The diagnosis and treatment of cancer typically involves many new stressors for patients and their entire families. Two major tasks of adjustment are coping with uncertainty and dealing with a changed reality (Folkman, 2010). With tasks of this magnitude, it

is understandable that adjustment disorder is the most frequent mental health diagnosis associated with cancer. Recommendations, practice guidelines, and accreditation standards all have *distress screening* as a first step in psychosocial care, and it has become the focus of clinical intervention implementation (Grassi et al., 2015). Distress was chosen for the screening terminology because it was perceived to have the least stigma and greatest acceptance. Distress is a dimension of stress that produces negative physical and emotional outcomes (Allen et al., 2014). The risk of cancer-related distress has been identified to be greatest at diagnosis, during transitions in treatment such as having surgery or moving from chemotherapy to radiotherapy, and when treatment is finished (ACoS CoC, 2012). Each of these transitions requires new adjustments and often decision-making.

Making treatment decisions—which may be “life or death” decisions—under time constraints with thoughts of potential disability, pain, disfigurement, or death requires all available coping skills. Coping abilities play an important role in patient follow-through in complex treatment regimens (Green, 2014). Coping with cancer is an attempt to maintain balance between what the illness demands and one’s ability to meet those demands (Schuyler, 2004). Holland (2002) explains that cancer patients face struggles on many fronts throughout the treatment process as they deal with extreme side effects, psychological responses, possible body image issues, and concerns for the future. Frequently, cancer can precipitate an existential crisis as well, with social and spiritual sequelae. Patients’ emotional and psychological well-being depends on their ability to control anxiety, fear, or depression responses and make needed decisions and take needed actions (ACS, 2016).

Since Richard Lazarus published his work *Psychological Stress and Coping* in 1966, the transactional model of stress and coping has served as a framework for the social and health

disciplines to study stress (Folkman, 2010; Lyon, 2012). The model defines stress as a transaction process that changes over time between the environment and the individual. By including key constructs of stress, appraisal, coping, and adaptation, the framework accounts for the complexities of individuality, circumstances, perceptions, and availability of resources. Appraisal or evaluation of the stressor is what causes stress to be perceived as stress, and a person must determine if it is significant enough to exceed one's resources to manage it. If this appraisal determines there is some potential for gain, it is no longer perceived as a stressor or a threat, but as a challenge; appraisal serves as the mediator between the individual and the environment (Lyon, 2012). Folkman (2010) identified two kinds of appraisal: *primary*—which evaluates the stressor—and *secondary*—which evaluates available resources to respond. Primary appraisal is affected by individual beliefs and values that assess the situation's impact on well-being to determine if it is a potential threat or an actual threat. Secondary appraisal evaluates coping options (psychological, physical, social, spiritual, and material resources) to respond to the threat. *Reappraisal* is the term for the process of continuing evaluation in changing circumstances. The appraisal/reappraisal process sorts the demands vs. resources and is influenced by availability of resources, social support, intensity and duration of the stress, and the level of ambiguity in the threat (Lyon, 2012).

Rather than an automatic response, coping is a process that changes to accommodate appraisals/reappraisals and consists of all the thoughts and behaviors used in efforts to manage the stress that is overwhelming available resources (Lyon, 2012). Folkman (2012) identified three types of coping. *Problem-focused coping* involves direct action to change the situation; it is action-oriented. *Emotion-focused coping* attempts to decrease emotional distress and control emotional symptoms—more palliative. A third, more recent coping type, is *meaning-focused*

*coping*, which involves positive emotions that occur along with the stress. Positive emotion can allow some aspects of the stress to be perceived as a challenge, with some type of gain resulting from the negative experience. This type of coping can be seen when patients make statements such as “Cancer has caused me to get my life priorities straight.” People use all three coping focuses, and they work together. For example, a patient may practice calming down (emotion-focused) in order to gather some information (problem-focused) while looking on the bright side by reframing the situation (meaning-focused).

Psycho-oncology seeks to facilitate coping strategies to reduce patient suffering and improve quality of life and mental health as a core goal (Holland, 2002). The demands from the environment, cancer-related in psycho-oncology, require a reaction to adjust and maintain balance. A patient responds to cancer as a life event stressor by an appraisal of the situation, which results in distress and coping efforts to solve the problem (e.g., implementing action-focused coping mechanisms such as getting a second opinion and determining prognosis, etc.) and manage emotions (e.g., exercising emotion-focused coping skills such as venting, meditating, exercising, etc.). Appraisal of the threat is a process in which psych-oncology interventions—such as exploring understanding of treatment options or prognosis—can be implemented to determine if the patient has the necessary information to accurately appraise the cancer threat. Secondary appraisal assesses access to medical care, psychosocial support, and financial and other resources in which psycho-oncology is able to actively engage (Hoffman, Lent, & Raque-Bogdan, 2013).

Psychosocial interventions based on the stress and coping theory support individuals’ coping abilities by assisting their attempts to modify distress and increase their use of coping resources. Psycho-oncology researchers affirm that to increase effective coping and reduce

distress, screening for coping must be done with attention to the coping process and to barriers and facilitators of patients' use of coping resources (Allen et al., 2014). Barriers may include healthcare beliefs, accessibility and acceptability of services, coordination of care, and quality of patient provider communication and relationship (Allen et al., 2014). Normal cancer adjustment attempts to gain mastery over the disruption that is cancer. Healthy adjustment is characterized by regulation of emotions, continued involvement in life with minimal disruption of roles, while helplessness, disengagement and overwhelming emotions are seen with complicated adjustments (Schuyler, 2004). Psychosocial stressors and mental health disorders have been associated with maladaptive coping, poor social relationships and family dysfunction, lower quality of life, longer rehabilitation times, and decreased treatment adherence (Grassi et al., 2015).

The therapies developed for use with cancer patients align with the stress and coping framework. Cognitive behavioral approaches used in cancer settings focus on present concerns the patient is facing and can help in the appraisal, coping, and reappraisal processes to correct unhelpful thoughts and improve adjustment (Breitbart & Alici, 2009; Green, 2014). Meaning-focused coping is the foundation for meaning-based therapy, which has been found to be beneficial with cancer patients, especially in advanced cancers, to identify priorities, revise goals and meanings, and enable growth so that the patient may live life to the fullest in the remaining time (ACS, 2016; Green, 2014; Holland & Weiss, 2010).

Psycho-oncology uses this theoretical framework to facilitate coping through a number of interventions, because ideal psycho-oncology treatment uses multiple interventions simultaneously to reduce as many stressors as possible (Breitbart & Alici, 2009; Meyer et al., 2009). Cancer centers are increasingly adding more supportive services to meet psychosocial needs; one example was a pilot program at Duke Cancer Center (Printz, 2012). The Duke

program sought to decrease distress by focusing on coping skills using a program called Pillars4Life, which is based on seven aspects of personal recovery: meaning, support, resilience, balance, self-care, spirituality, and hope. The pilot program found improved coping, improved social support, and improved self-efficacy, all correlated with decreased stress. The program director noted that routine distress screening and assessment were essential to the program and were basically asking the right questions at the right time. How these pillars align with the stress and coping transactional model can be clearly seen.

### Definitions

The ACoS CoC (2012) implemented key changes in its 2012 standards for accreditation for cancer programs requiring palliative care services, genetic counseling/referral, navigation programs, survivorship care plans, and psychosocial distress screening as part of comprehensive cancer care. Survivorship planning and distress screening have become important areas of interest in psycho-oncology research and patient care. The National Comprehensive Cancer Network (NCCN, 2016) chose the term *distress* when it published its first guidelines in 1999. The current distress management guidelines explain that the term was preferable to emotional or psychiatric terms as it involves less stigma and can be measured by self-report. The NCCN (2016) defines *distress* as a “multifactorial unpleasant emotional experience of psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment” (p. 2); further, the guidelines explain that distress occurs along a continuum from common temporal feelings to disabling symptoms, experienced at varying levels by most cancer patients at some time.

The term *survivor* refers to anyone who has had a cancer diagnosis at some time in his or her life, and *survivorship* refers to the time from completion of treatment and forward through

the rest of the survivor's life (Adler & Page, 2008; Sunbone et al., 2010). The early survivorship period has been identified as a time of increased distress for patients due to loss of active care, expectations to resume previous roles (Jacobsen et al., 2012), concerns about continuity of care, continuing side effects of treatment, loss of function (both physical and cognitive), adjustment issues, uncertainty, fear of recurrence, existential concerns, surveillance decisions (Hamann & Kendall, 2013; Turner, 2015), weakened immune system, PTSD (Meyer et al., 2009), and less social support (ACS, 2016). Research and development on survivorship programs have shown recent exponential growth (Hamann & Kendall, 2013; Hebdon, Abrahamson, McComb, & Sands, 2014).

Survivorship care is primarily concerned with the medical outcomes of surveillance and screening (McCabe, 2008) but incorporates psycho-oncology care for unmet psychosocial needs and ongoing distress (Sunbone et al., 2010). The diagnosis of cancer can precipitate a hypervigilant response for some patients, and many experience increased anxiety surrounding their rechecks and scheduled tests as they wait to find out if they are cancer-free (Schuyler, 2004). The growing number of cancer survivors challenges psycho-oncology programs to carry their service provision beyond active treatment into long-term chronic care delivery (Hamann & Kendall, 2013; Hebdon et al., 2014). Survivorship care plans will be required at the conclusion of treatment to provide a written document with a complete treatment summary and important plans for follow-up to promote continuity.

Survivorship programs like Survivor Training and Rehabilitation (STAR) provide physical therapy, occupational therapy, mental health counseling, speech and cognitive therapy; they address the consequences of cancer and treatment that can leave patients with ongoing issues, disabilities, and reduced quality of life (Personal communication, Director of STAR



Program-Essentia Health, June, 2016). Program goals are premature death prevention, early recognition of recurrence, and improvement in communication to prevent fragmentation when care involves so many specialists (Bass, 2014; Middleton, 2014). Many patients do not get anything in writing from their doctors to take with them, and one recent national study indicated only 20% of oncologists completed care plans for the most common cancers (ACS, 2016; Bass, 2014).

## **Literature Review**

### **Distress**

Cancer-related distress and distress screening is a frequent topic in the psycho-oncology literature, as are implementation and follow-up of screenings. NCCN guidelines recommend use of a distress thermometer (DT), a rapid 0 to 10 scale screen paired with a problem list, which initiates a discussion that may not otherwise happen. In a cross-sectional study using data from a large sample of adult cancer survivors ( $n = 1,777$ ), only 40.2% reported having a discussion with their provider on cancer's psychological, emotional, and relational impact (Forsythe et al., 2013). More than half (55.1%) reported no discussion and no counseling or support group participation. Extrapolated, that would represent nearly 7 million cancer patients having no discussion of the psychosocial impact of cancer. Survivors who had any discussion were more likely to report being *very satisfied* in having their needs met.

The cross-sectional survey limited any inferred causation and was also limited by self-reported responses, which might be subject to recall bias. Future screening for distress should serve as a tool for more integrated psycho-oncologic care. Accredited cancer centers will be required to have services available on site or by referral with a process in place to inform patients of the services (ACoS CoC, 2012). Jacobsen et al., (2010) found chart documentation for pain

assessment in 87% of reviewed charts, while emotional distress assessment was documented less frequently (52%) in the charts. This emotional assessment was negatively associated with age with a 1.5% decrease in assessment for every year increase in age. Clinicians have missed the symptoms so that distress has gone unrecognized and unresolved (Deshields, Zebrack, & Kennedy, 2013). This unrecognized distress could be a factor in the increase in alternative and complementary therapies for cancer patients, who sought help and attempted to get their needs met in alternative ways (Holland, 2002).

The challenge has been to implement screening, determine how, where, by whom, and how to follow it up. Guidelines recommend follow-up with a social worker, mental health professional, or spiritual counselor for DT scores equal to or greater than 4. Scores of 7 show sensitivity of .81 and specificity of .85 for detecting depression and the need for evaluation for treatment (NCI, 2015). In practice, the screening may involve three steps when assessment follows screening and is then confirmed by diagnostic interview; the DT and problem list differs from a psychological screen as it includes concerns like transportation and finances (Hess & Chan, 2014). Implementing screening alone has not led to increased use of services or increased referrals (Leykin et al., 2012) and resources should be identified before screening. Recommendations are for the DT screen to be completed upon diagnosis and again whenever there is a transition in care or change in patient status—recurrence or personal crisis, for example—and for there to be integration and coordination of medical and psychological care interventions (Andersen et al., 2014; Fann et al., 2012).

Implementation of screening has been a slow process. A survey of American Psycho-Oncology Society members showed only 51% of the respondents were routinely screening (Deshields et al., 2013). This survey ( $n = 233$ ) had only a 27% response rate, which may not

have resulted in a representative sample of the 850 surveys mailed. Lazenby and others (2015) collected quantitative and qualitative data from healthcare professionals and administrators from 70 institutions who applied to a distress screening education program. The data indicated that at 14 months before the accreditation deadline, fewer than half (41%) of the institutions had started screening and 53% had psycho-oncology programs. The study identified uncertainty about procedures and seeing the screening as an extra burden as barriers to implementation. It also identified a need for support from oncologists, including surgeons, and all cancer team members. A clinician's preference for clinical assessment and therapeutic discussions may cause resistance to distress screening, and short appointment times already filled with other assessments may be a barrier as well. Further, low uptake may be seen among patients who may prefer not to share, who do not want to be seen as complainers, or who may just expect suffering as part of cancer (Howell, Hack, Green, & Fitch, 2014). Patients' needs exceeding resources, funding concerns, EMR systemization, time constraints, prioritization of medical treatment, and uncertainty about how to incorporate psychosocial care in the medical setting are all identified as barriers to screening (Association of Community Cancer Centers [ACCC], 2015; Clark et al., 2012).

Many researchers view screening as the first step to integrating psycho-oncology into patient care and identified screening as a key to mitigating coping and adjustment issues. In 2011, Kendall, Glaze, Oakland, Hansen, and Parry examined data from 1,281 distress screenings from a community center in Colorado for intensity and frequency of distress. Patients received the DT and problem list, along with a list of support people available should they wish to request to see them. Worry and financial concerns were the most common problems; 59% (755 patients) reported emotional concerns, and 32% (423 patients) scored above the distress threshold requiring assessment for referral. Mean distress intensity was 2.47, and 45% of patients reported

zero for distress. The most frequently requested support person was the dietician. Kendall et al. (2011) hypothesized that worry about diagnosis motivated patients to seek nutritional support as dietary problems had not been indicated on the problem list.

A retrospective review and analysis of the EMRs from seven cancer clinics of two tertiary cancer centers examined whether medical records contained documentation of distress screens and responses (Zebrack et al., 2015). Results showed great variation. Eleven charts showed multiple visits with no patient distress screening done at any point. Adherence to screening was lowest where it had been implemented most recently. DT screens with scores of 8 to 10 had higher documentation of contact following screenings and more referrals, but a psycho-oncologic response was absent in 25% to 30% of patient cases for high distress and absent in 45% to 50% of patient cases for moderate distress. About 50% to 75% of patients had their distress addressed. A limitation of the study was a lack of clarity about whether an actual follow-up was missing or the documentation of the follow-up. In the end, the effect is the same. Compliance cannot be demonstrated and risks for liability and litigation increase if screening documents distress, yet no follow up is completed. The patients' distress is likely increased as well when they report their distress without acknowledgement. This study also surveyed staff on the acceptability of screening and found adherence, responsiveness, and acceptability were all greater when the cancer team included a psycho-oncology team member present in clinic to consult and respond versus needing a referral to off-site care (Zebrack et al., 2015).

### **Communication**

*Communication* is another theme frequently found in the psycho-oncological literature. Effective empathetic interactions are part of the therapeutic relationship and provide the basis for important assessments and trust. Communication of concern and commitment to care enables

patients to sense their providers care for them—making treatment therapeutic (McFarland, Hamilton, Fox, & Holland, 2014). Routine interactions wherein all medical caregivers show caring and support are associated with less stress and sense of trauma (Li, Fitzgerald, & Rodin, 2012). Access to support—integrated into care—reflects the need of the patient to communicate with caregivers (Turner, 2015). Communication is especially important in cancer care where patients and caregivers experience strong emotions, loss and grief are common, and 15% of patients report leaving their doctor's office without information they need (Adler & Page, 2008). High stress levels can prevent intake and processing of information, and in turn increases stress. At the time of diagnosis, shock and denial may be present as well. Solutions for this situation include encouraging another person to be at appointments with patients (Breitbart & Alici, 2009), strongly encouraging two-way communication (Allen et al., 2014), and providing written communication to take home or recording appointments so the patient can re-listen later (Fuller et al., 2016; Middleton, 2014).

There is institutional support for communication skills training (CST) because communication has been associated with lower patient stress and anxiety, better health outcomes, fewer malpractice claims, and positive changes in behavior (Jacobsen et al., 2012). It is known to affect patient status and is considered a necessary requisite to being a healthcare provider. The psycho-oncologist has a potential role in CST for cancer staff team and also for resolving communication problems of mixed messages or incomplete information between providers and patients that could improve care (Meyer et al., 2009).

Diagnosis is an emotional time when most patients present without any familiarity with the terminology and yet must make decisions; how the doctor communicates the diagnosis can have a lasting impact and be remembered the rest of a patient's life (Fujimori et al., 2014;

Middleton, 2014). Emotional support may increase a patient's acceptance and processing of the information provided by the medical personnel (Fuller et al., 2016). There may be no good or easy way to give bad news, but there may be better ways than some patients have described: "He was so blunt! Thus began my love-hate relationship with my oncologist" or "He read the radiology report to me word-for-word, then walked out of the room."

A Cochrane review of 15 random clinical trials (RCT) of CST for real interactions involving 1,147 total providers found that improved communication for health care providers correlated with reduced psychological stress for cancer patients (Moore, Mercado, Artigues, & Lawrie, 2013). High quality evidence indicated that six studies demonstrated consistent effect for improved empathy shown to patients and moderate effect for increased use of open-ended questions to gather information. Reviewers were unable to determine lasting effects and not enough of the RCTs looked at similar patient outcomes to determine effects for them. However, CST, using experiential methods and taught by experienced teachers, can help health care providers to improve empathy and information gathering skills, according to evidence-based practice (Moore et al., 2013).

A CST program based on factors that influence how patients receive news has been used to train providers. The acronym SHARE stands for the factors: S—setting up supportive environment for meeting, H—how to deliver the news, A—additional information available, R—reassurance and respond to, E—emotions (Fujimori et al., 2014). A random trial of 30 oncologists and 1,192 adults with cancer in outpatient clinics that administered specialized CST to 15 of the oncologists in a two-day workshop, which involved surveys, video-recording, and blinded coders, showed positive results for both patients and doctors. Doctor confidence, emotional support skills, and behaviors all improved, and they demonstrated increased use of

silence and checking of patients' understanding and increased use of preamble. The preamble serves to prepare the patients, so they do not report communications such as the following:

The doctor said, "Well, it looks like you've got leukemia. That's a cancer of the blood."

He said, "I'm going off shift now. The next doctor coming in will tell you what you need to do next." Then he walked out of the room. It was that blunt. . . . There was no, "I'd like to talk to you alone." (Nissim et al., 2013, Section 3.3)

The patients who received communication from trained caregivers experienced reduced psychological distress and increased trust in oncologists. CST is an indirect intervention to improve patient care, and it is worth investment of resources. An exciting finding in Fujimori et al.'s study was that improved communication, better delivery, and offering emotional support did not take doctors any more time than their usual procedures. The positive results of CST will help not only those seeking support or getting bad news but also will potentially impact all the patients coming for medical care (Heron-Speirs, Harvey, & Baken, 2013).

## **Treatments**

Many therapies have been successful with cancer patients, and researchers seek to identify which patients benefit from which interventions. Meta-analysis of 146 prospective controlled trials concluded education on coping is helpful, relaxation (progressive muscle relaxation) is useful in cancer-related anxiety, cognitive behavioral therapy (CBT) is especially effective for depression, and expressive supportive therapies demonstrate good effect (Heron-Speirs et al., 2013). Supportive expressive-based support groups have been used since the 1970s and have provided lasting positive effect on quality of life, coping, and patient satisfaction (Meyer et al., 2009). Support groups have been used most extensively with breast cancer patients and are attended predominantly by women. Three factors predict increased support group use:

undergoing more cancer treatments, not being employed, and having an emotion-oriented coping style (Sautier, Mehnert, Hocker, & Schilling, 2014).

Li and others (2012) reported cancer-related depression differs from primary depression in a number of ways: fewer depressive thoughts, increased hopelessness and demoralization that is not a true depression, equal incidence in men and women, and greater physiologic involvement. Tumor cells and tissue destruction can produce a cytokine-induced depression when pro-inflammatory cytokines act on neurotransmitter and neuro-endocrine physiology to produce depressive symptoms. Depression treatment needs to include pain and symptom management, discussion of the illness experience and the relationships with care providers and support systems.

Li et al.'s (2012) literature review of original studies, systematic reviews, and meta-analytic studies found psychosocial and psychopharmacologic treatments (Sertraline, escitalopram, citalopram have the fewest interactions with chemotherapeutic drugs) reduce depression in cancer patients with many therapies demonstrating effectiveness. Therapies that work best for new cancers and mild to moderate depression are psycho-education, relaxation training, problem-solving therapy, and CBT. For patients with later-stage cancers, manualized therapies like dignity therapy, meaning-centered therapy, Cancer and Living Meaningfully (CALM), mindfulness-based meditation, Re-creating your Life, and the Healing Journey—all created for this population—have proved helpful (Breitbart et al., 2015; Li et al., 2012; Meyer et al., 2009).

Meaning-centered therapy serves extensively as a supportive expressive therapy with many protocols and manualized programs and was developed at Memorial Sloan-Kettering Cancer Center for patients with late stage cancer experiencing existential and loss of meaning



difficulties (Breitbart et al., 2015). One study divided 253 Stage 4 cancer patients randomly into two treatment support groups. One group, a meaning-centered group therapy (MCGT) group focused on meaning, and the other group focused on support. Both groups showed improvement from baseline at two and four months, but the MCGT had more significant results especially in spiritual well-being, quality of life, and reduction of hopelessness. Meaning-centered therapy is the basis for CALM, a cancer-specific psychotherapy (Lo et al., 2015) which is developing into an online version, e CALM, for underserved patients without face-to-face support (Zernicke et al., 2013).

The Pillars4Life intervention is a strength-based coping skills psychosocial educational program founded on positive psychology, coping theory, and resilience theory (Smith et al., 2015). This program views coping not as a trait but as a learned process and targets coping resources and self-efficacy. It is associated with statistically and clinically significant improvements both in-person and when scaled up ( $n = 130$ ) for online and virtual group formats, adding to the number of studies that have documented effective Internet interventions.

Technology has exploded the intervention options. Leykin et al. (2012) reviewed the literature to develop recommendations for Internet interventions (II) for mental health during cancer care. Leykin et al. identified three types of cancer sites: informational sites, mutual support sites, and evidence-based II sites. The first two are widely used by cancer patients but do not offer treatment, as II has potential to do. It has been asked, “If we build it, will they come?” Exploring online support groups and blog sites suggests patients are building their own websites faster than can be followed. Private support groups, matching mentor sites (Firefly), and well-developed communication sites (CaringBridge) can be resources to which psycho-oncologists can direct patients. Patients can use CaringBridge in ways that best suit them—communicating

updates, sharing expressive writing, or preventing isolation. An expressive writing RCT (Mosher et al., 2012) found that women ( $n = 87$ ) who wrote their deepest emotions about cancer also exhibited greater use of mental health services (55% vs. 26%, odds ratio 3.40) than the control group who wrote factual details. The study scored 348 essays and had 100% retention.

Internet interventions are expected to grow and expand; they hold potential for closing service gaps and offering benefits such as a sense of improved confidentiality, decreased stigma, convenience, efficiency, and cost-effectiveness. IIs are an unlimited resource—they can be consumed over and over; they are updatable, provide access to the best-trained specialists for consistent treatment, and can be used by the majority (Leykin et al., 2012; Stephen et al., 2011). Also, tracking is available so providers can monitor use and progress. Leykin et al. (2012) noted the importance of clarifying what II is and what it is not; II is self-guided intervention that attempts to change awareness and understanding. Individuals use IIs on their own, unlike online or telemedicine resources, online support groups or e-counseling, which are other technological opportunities. Internet interventions should be secure sites with sound health materials and interactive components that build skills with practice tools and homework. Most are CBT-based and can be viewed as similar to a self-help book; these interventions are not helpful for some patients and are preferred by others (Leykin et al., 2012).

Telemedicine has potential, as numerous studies have documented. Kroenke et al. (2010) conducted a representative study (RCT,  $n = 405$  cancer patients with pain and depression, 202 used telecare management, 203 relied on usual care). Kroenke et al. described the tele-management at 16 cancer clinics in rural and mid-sized towns in Indiana. Regularly scheduled nurse calls monitored care, and automated call triggers notified nurses to call patients if they did not complete computer surveys weekly or if scores for pain or depression were high. Twelve

patients were referred for more care for pain and 11 for depression. Both pain and depression showed improvement, and one intervention allowed the oncologist and the psycho-oncologist to collaborate for improved care. A cost analysis of this study found the tele-managed patients had 60.3 depression-free days at a cost of \$19.72 per depression-free day or \$1,189 per patient—comparable to or less expensive than many common interventions (Yoo, Nyman, Cheville, & Kroenke, 2014).

Technology in record keeping for psycho-oncology care has potential to improve care. City of Hope, a leading cancer center in California, uses SupportScreen, a touchscreen assessment tool that screens mental and physical symptoms while it responds with education materials, automatic triage, and clinic alert referrals all at once. It is HIPPA compliant and privacy protected, an automated, comprehensive program for increasing numbers of services (Clark et al., 2012).

### **Psycho-Oncology Staffing and Delivery**

Examining models of psycho-oncology practices for staffing and organization is another objective of this review. The American Society of Clinical Oncology mailed 1,000 surveys to randomly selected oncologists from its 17,000 member list asking questions about their practices and how they addressed their patients' psychosocial needs (Muriel et al., 2009). Responses ( $n = 448$ ) determined that 50% (on average, 39% to 75% range) of the oncology practices were affiliated with mental health service, and oncologists referred more often when they were affiliated. The professionals staffing the mental health care for referral were 47% social workers, 26% psychologists, 17% psychiatrists, and 8% psychiatric mental health nurse practitioners (PMHNPs). Oncologists made referrals most often to support groups (69%), social workers (64%), and psychiatrists (54%).

A 2016 electronic survey of cancer centers that make up the National Comprehensive Cancer Network aimed to determine optimal staffing and services for psycho-oncology (Deshields, Kracen, Nanna, & Kimbro, 2016). Case workers and managers were most often social workers. Most psycho-oncology programs were institutionally funded, supplemented by grants and fee-for-services. Wide variety existed in services, scope of programs, and staff size and structure. Volunteers supported the programs at 56% of the institutions. Recommendation is for patient uptake of services to be tracked for annual numbers of contacts as information for numbers of patient contacts or services provided could not be obtained as they were not being tracked, limiting knowledge of activities in which various staff were involved.

A model program would have seamless biopsychosocial programs and services sharing site, staff and information to integrate care for the whole person (Loscalzo, Bultz, & Jacobsen, 2010). Cancer care was originally inpatient, but when cancer care moved to outpatient setting for the majority, the psychological care did not move with oncology --one consequence of this shift was that to refer patients out for psychological care is to have that care appear “other,” stigmatizing it, and patients may not follow the referral (Holland & Weiss, 2010). Cancer patients already have so many treatment appointments, one more may be too many. Organization of the care can integrate it or fragment it. Fann et al. (2012) sees organization of care as one of the biggest problems in receiving psycho-oncology care. The two main models seen in the literature are the integrated model and the psychiatric consultant-liaison model. Integrated care shares a site, has a biopsychosocial focus, can increase early detection and improve management of distress, and can be costly, while the consultant model has both a medical model and a psychiatric model which can become compartmentalized but may be more cost-effective as all

patients do not receive both (Fann et al., 2012; Hamann & Kendall, 2013; Loscalzo et al., 2010; Meyer et al., 2009).

The best programs offer clinical care, education, and research (Loscalzo et al., 2010). The research aspect can tie other institutions into the program and bring in outside funding. The educational component instructs the staff, supports family caregivers, and trains oncology practitioners. A large program may have post-doctoral health psychologist training and medical psychiatry or psychosomatic fellowships. Different descriptions exist for psycho-oncology qualifications: a mental health practitioner who has cancer expertise for differential diagnosis, psychotherapy, and psychopharmacology is one definition (Yuppa et al., 2014). Accreditation standards state psycho-oncology services coordinators can be oncology social workers, clinical psychologists, or mental health professionals trained in the psychosocial aspects of cancer care (ACoS CoC, 2012). Blenkiron, Brooks, Dearden, and McVey (2014) reported one group described their practice as three clinical psychologists and one liaison psychiatrist who saw 8% of all cancer patients at their cancer center, 85% on an outpatient basis. Therapies of CBT, mindfulness, and brief intervention are their most commonly used; liaison with staff and support for family is a part of most of their days, and it takes an average of 16 days to get an appointment (Blenkiron et al., 2014).

In trendsetting hospitals right now, psychiatrists are being embedded in medical programs, working alongside other physicians in ICU and other inpatient and outpatient settings. An article in the *Wall Street Journal* stated that traditionally, when problems arose, a psychiatrist would be consulted, but now the direction is to have a psychiatric person doing rounds, assessments, and co-managing care because as one doctor stated, “When the body breaks down the mind is affected” (Lagnado, 2016, para. 7). The hospitals are engaged in research to

determine the impact of this approach on length of hospital stays, health outcomes, and cost savings. Yale and Johns Hopkins are both staffing their programs using PMHNPs. These trends may lend good support to psycho-oncology which may have a head start in this direction.

### **Availability of Psycho-Oncology Services**

As disparate access to mental health specialists is a general concern across healthcare, so it is in psycho-oncology. Few mental health professionals with experience and training in psycho-oncology work outside of urban areas (Yuppa et al., 2014), yet most patients are treated in community-based settings, not large comprehensive centers (Hamann & Kendall, 2013; McCabe, 2008). All the counties in Minnesota-- outside of the seven county metro-area—are designated health professional shortage areas in mental health services. It is a goal of psycho-oncology to increase availability of service (Jacobsen et al., 2012).

The rural United States has 20% of the population but less than 11% of the physicians, with mental health professionals underrepresented (Aylward et al., 2012). Psychosocial care is the standard, but rural patients have less access to services. Health care resources are typically scarce where population is low. Aylward et al. (2012) surveyed 63 women with breast cancer in rural northern California; they lived 50 to 150 miles from a city. Aylward et al. found over 17% had to travel more than 100 miles to get cancer treatment and that 38% met criteria for depression.

Through questionnaires and interviews, 116 rural and nonrural Kentucky cancer survivors were compared for mental health functioning as part of a preliminary study (Burris & Andrykowski, 2010). Assessments included DT, Hospital Anxiety and Depression Scales (HADS), a life satisfaction scale, a 17-item benefit finding, and a 41-item quality of life measure. Rural patients reported worse outcomes in all areas (mean effect = .50). When results were

adjusted for education and physical functioning, the magnitude of effects were reduced, but the results remained. The prevalence of depression was 10% higher for rural patients and the prevalence for anxiety 11% higher. The sample was small and further research is needed to examine if the worse mental health is related to the burden of travel to care, lack of mental health care and support groups, or other variables.

The services at large centers are extensive and providers include psychiatrists, rehabilitation therapists, music therapists, art therapists, dieticians, dermatologists, specialists in sexual health and fertility, support groups by cancer type and stage, and more, while they may be nonexistent in rural areas (Appendix B). Available technology can provide access to some of these services, and patients can be directed to these online resources when none are locally available. The Cancer Support Community—which has merged with Gilda’s Clubs to become the largest support community in North America—is meeting some of these disparate needs by providing online support to 750,000 people with cancer (Cancer Support Community, n.d.). Efforts to bring mental health providers and services to underserved areas are key as well.

### **Methods**

The electronic data bases CINAHL, PsycINFO, and PubMed were searched for possible English language sources pertaining to adults. Keywords used were “psycho-oncology,” (“psycho-oncology” and “guidelines”), (“psycho-oncology” and “program development”), (“psycho-oncology” and “services” or “interventions”), (“psycho-oncology” and “psychosomatic medicine”), (“Psycho-oncology” and “psycho-therapeutic interventions”), (“psychosocial interventions” and “cancer” or “neoplasms” or “oncology”). Also those three terms for cancer were searched with “psychosocial factors” and “psychological factors,” “support,” “psychosocial care” and “psychosocial programs,” “quality of life” “psycho-education” and

“survivor.” Once a psycho-oncology book and three articles on the history of psycho-oncology were obtained, materials were limited to journal articles published in the last ten years and available online or through interlibrary loan.

The most productive search in PubMed was for (“psycho-oncology” AND “psychosocial interventions”) with 224 results and 10 articles chosen to review. The PubMed search using the keywords “psycho-oncology” and “psycho-somatic medicine” had 49 results and three articles chosen to review. The search in PsycINFO using “psycho-oncology programs” had 261 results and six articles chosen. CINAHL had the greatest number of relevant articles. The search (“psycho-oncology” AND “psycho-social services”) had 23 results with six articles selected, “psycho-oncology” yielded 35 results with five chosen; (“psycho-oncology” AND “interventions” AND “cancer”) had 32 results with five chosen and also five more chosen from the CINAHL search combining (“cancer,” “support,” “psychological factors”). There was much information available with 133 abstracts read, 90 articles reviewed and 40 chosen. These 40 articles were chosen to be read for background and for possible inclusion in the study based on broad generalizability and size of the studies with consideration given to include quantitative and qualitative data, RCTs, systematic reviews, a Cochrane review, meta-analysis and a variety of journals. Ancestry searches were done for these articles resulting in 18 more articles.

## **Results**

The information obtained through the literature review was shared with several individuals and small groups from a variety of backgrounds (somewhat similar to a multi-disciplinary psycho-oncology team). Two meetings with PowerPoint presentation were planned and then were canceled—the first due to peoples’ scheduling conflicts and the second due to severe weather. Multiple smaller meetings were held with individuals or small groups in which



the pre-test (Appendix C) was used as a basis for creating interest and presenting the material. The total audience (all took the pre-test, some viewed the PowerPoint) included two registered nurses (one an oncology/hospice nurse), one clergy member, one counselor, a health educator, a psychology student, a health- studies student, an educator with graduate background in psychology, three cancer survivors, a young man who lost a family member to cancer last year, and one fourth- year medical student who is also the professional student government subcommittee chair for mental health for the University of Minnesota, for a total of thirteen individuals. There may be an opportunity to present the PowerPoint to a group yet this summer.

Much of the information was new for all of these people. No one got all the questions correct on the pre-test. Surprise was expressed by several that there was significant distress, psychiatric diagnoses, and higher suicide associated with cancer even though most had been impacted in some way by cancer. This is consistent with the consensus that distress is often underestimated and missed. One statement was “I can’t imagine PTSD associated with cancer. How could that be anywhere near as traumatic as combat?” There was some surprise at the statistics of cancer being diagnosed in one out of two men and one out of three women. Lack of awareness of resources and of the variety of supportive therapies was common. The information was well received and several people in the early stages of their careers said this would be useful information to their work. It was expressed that psycho-oncology care is needed and that growth of the field is a positive direction for care for patients with cancer.

### **Discussion and Implications for Nursing**

In some large cancer centers in urban areas of the United States psycho-oncology departments are well established. In smaller more rural areas psycho-oncology may be in early stages—just implementing distress screening with a social worker available for follow-up—but

growing quickly. It is not identified by the same terminology everywhere and may not be a “program” at all, but an awareness, consideration of the research of psycho-oncology and interest in developing more services are likely found. One large university cancer center has a “PsychOncology” department which has a nice sound to it—perhaps preferable and less confusing than the double *O*s, hyphen, and the word “psycho.” PsychOncology brings important perspectives to holistic patient care, addressing the emotional issues unique to cancer. As one of the program’s videos says—we don’t treat cancer—we treat patients (PsychOncology Program, 2014). That is the difference PsychOncology can make. As the same site states, it can help people feel they are living with cancer- not dying from cancer. So much cancer terminology is borrowed from battle analogies. PsychOncology is to the patient what morale would be to the troops-giving hope in place of hopelessness and courage knowing that one will not face it all alone.

A number of factors make it likely that psycho-oncology may be a growing field. A large number of cancer survivors and caretakers can act as a driver for increased care; greater awareness of psycho-oncology as essential to care, more advocacy groups for cancer, and an increase in professional organizations all act to promote it (Loscalzo et al., 2010). The aging population, the passage of the Affordable care and Mental Health Parity Acts, and the limited number of medical psychiatrists available in many areas are other factors. Many cancers are increasingly treated as chronic diseases; there is greater focus on survivorship. Accreditation requirements, practice guidelines for psychiatric assessment and management for cancer patients, and cancer centers developing staff positions to meet IOM recommendations (Loscalzo et al., 2010) may all contribute to there being opportunities for mental health providers to work with cancer patients. Outpatient cancer care also contributes to greater need for patient

family/caregiver support. Estimates a decade ago-likely greater now- were that there were 24 million homes in the U.S. where care was provided for a chronically ill patient (Holland, 2002). David Spiegel, M.D., a Stanford psychiatrist working in psycho-oncology for decades has stated the field is a growth area for psychiatrists (Arehart-Treichel, 2012) so it may be likely that it is a field that may have opportunities for PMHNPs as well. With a nursing background and advanced pathophysiology, pharmacology, psychopharmacology and health assessment, PMHNPs would be well suited to work with medically ill patients who are also experiencing psychiatric symptoms –caring for patients’ physical, mental and emotional needs.

Having a mental health specialist in cancer care provides support to oncology staff in caring for patients with mental health concerns and also provides support for staff themselves. The PMHNP working in cancer care can increase patient acceptance of psychological care by being an integrated part of the team-reducing stigma and the necessity for off- site referral. Distress, missed psychiatric diagnoses, and staff stress/burnout/compassion fatigue all have potential to be decreased. The PMHNP would be ideally positioned for staff education, patient psych-education, and program development. Doing psychological assessments and counseling patients to help redefine hopeful meaning in their lives may be beyond the time constraints and scope of many oncology nurses, but the nurse specialist with assessment, diagnostic, and therapy skills could fill that role (Middleton, 2014 ).Some programs integrate a clinician into cancer appointments as a team member or others include them as a referral for direct patient care and as liaison consultation for other team members. Different models of care can be successfully adapted to the patients served and available resources of the institution and the community.

The practice implications and the practical applications of the specialized body of knowledge for psycho-oncology are well illustrated by a new cancer center that had its grand

opening in June of 2016. The new facility was built for the primary purpose of providing cancer care close to home to remove the burden of traveling an hour away to the nearest city and to keep patients in their community for proximity to the support of family and friends. Evidence-based research, the recommendations of experienced staff, and the preferences of cancer survivors—through a patient advisory council—combined to inform the design, building, furnishing, and decoration of the new 12 million dollar facility (T. K., Director of cancer center, personal communication, July 19, 2016). There are no waiting rooms; patients go directly to private treatment/exam rooms. Schedulers come to the rooms to see patients to make their next appointment to reduce stress and provide privacy. The 39 large exam rooms accommodate family and four consultation rooms provide pleasant surroundings for discussions. These rooms were designed and are used based on psycho-oncologic data indicating that patients retain 60% more information when they are taken out of exam rooms and seated comfortably for consultations (“Cancer Center and Clinic,” 2016).

The cancer center director explained that the private treatment rooms that look out over a Healing Garden will eventually have benches and walkways. The center does not look like a clinic; rather the colors, woodwork, and artwork were all chosen based on researched criteria for therapeutic effects in cancer care. Much of the carefully selected artwork reflects the proximity of Lake Superior and is very calming. The architects even camouflaged the concrete vault of the linear accelerator as they incorporated back-lit nature scene art panels. The ten chemotherapy infusion chairs are equipped with heat, massage, and warm blankets. IPADs with “Playaways” that stream soothing music and meditations are provided. The cancer center is stocking their resource center and have a hospital social worker available as needed. The director says her ultimate goal is to hire a PMHNP to provide psychological support and survivorship care (T. K.,

personal communication, July 19, 2016). This is a picture of a brand new cancer center in a town of with a population of just over 8,000, and it reflects the work and influence of psycho-oncology. Funding was available for these investments based on strong evidence of the importance of holistic cancer care to patients' quality-of-life and the psychological impact cancer has on patients.

Funding for services can be through an institution's general operating funds, philanthropic donations, grants, and charging fee-for-service (Deshields et al., 2013). Creativity in funding is seen such as cancer programs raising money and partially funding themselves for years through dragon boat races where the teams raise money and have names like Dragons of Hope, Survivor's Sisterhood, and Chemo Savvy.

Holding community classes to promote education and communication can increase patient interest in and support for services. Extending support to family and caregivers—who may be unprepared for and overwhelmed by the demands on them and receptive to support—can be an area for promoting effective coping skills and providing services. PsychOncology staff can put together training programs for professionals from other clinics and communities providing CEUs and charging for the programs (Hamann & Kendall, 2013). Projects that have received funding include touch-screen patient screening, community and patient education, navigation and survivorship programs, creative arts, music therapy (Badger, Henry, & McCorkle, 2010 ) and communication skills training (Fujumori et al., 2014). Funding will not be available for programs where there are questions about the quality or value of the deliverable services (Badger et al., 2010 ). Interventions with benefits to the patients and to the institution—such as fewer hospitalizations or emergency room visits, greater adherence to treatment—that are clearly identified and communicated with documented measurable outcomes will get funding and

support from institutions (Hamann & Kendall, 2013; Zebrack et al., 2015). Identification of funding sources and documentation of outcomes and patient satisfaction can help to demonstrate the value and cost-effectiveness of psychOncology care.

It is important to document psychosocial assessments; case discussions and patient progress notes can go beyond treatment progress to include quality-of-life measures, coping status and family adjustment (Surbone et al., 2010 ). Addressing the total patient, integrating biopsychosocial assessments that take in the full spectrum of needs may promote policies that lessen the stigma related to mental health issues. Health care providers can support policies that reduce organizational barriers (lack of referral, disruption of care continuity, etc.) and cultural barriers (minimizing emotional care, stigmatizing mental illness, etc.) to psychological care (Dilworth, Higgins, Porter, Kelly & Turner, 2014). The Multinational Association Of Supportive Care In Cancer identified three policies in their position paper: greater inclusion of mental health professional in cancer care, implementation of increased psychosocial care from diagnosis through post-treatment, and greater uniformity of psychosocial care with fewer geographic disparities (Surbone et al., 2010).

Patients expect to be fully assessed and hopefully it will be an infrequent complaint that “No one ever asked how I was doing.” Yet, patients conversely can expect to feel terrible and may assume depression and distress are part of having cancer and therefore untreatable, so may not seek help or follow-up with referrals (Fann et al., 2012). Opening up discussions, offering anticipatory guidance, and proactively providing support and resources are all actions that can improve psycho-oncology care. How therapies are presented can impact receptivity; calling them meetings or coaching sessions can lessen stigma and resistance—especially for men (Heron-Speirs et al., 2013).

Recommendations for research in general are: that it include greater collaboration amongst disciplines, that small centers take part in trials/studies of large centers—benefitting them both (Hamann & Kendall, 2013 ),and that it have greater focus on patient reported outcomes, quality-of-life and incorporate mental health integration with biomedical care—combining medicine and psychiatry (Breitbart & Alici, 2009). It is interesting to note that as much psycho-oncology research as there is—it is a very small portion of the overall cancer research. Psychosocial and mental health research in cancer represents 0.26% of all oncology research publications and 0.51% of all mental health publications (McFarland et al., 2014 ).

Recommendations for research made in the literature were for a large number of topics. Some of them are research on the prevention of delirium (with paraneoplastic syndromes, advanced cancers, and brain metastasis all associated with this), prevention of cognitive symptoms “chemo-brain” which can be associated with up to 50% of some cancer types (Meyer et al., 2009 ), prevention of central nervous symptom damage from chemo and immune therapies (Meyer et al., 2009), research on drug interactions between chemotherapeutic agents and psychotropic medications (Arehart-Treichel, 2012), and research on the psychological impact and adherence for oral chemotherapies as they are taken for long periods and can be self-administered (McFarland et al., 2014).

Recommendations for interventions research include: trials to assess Internet interventions, tele-psychiatry and other technologies, comparisons of models of care delivery and use of medical homes in psycho-oncology (Fann et al., 2012), more research on the impact of coping, resilience, and social support on mortality and on the psychological consequences of survivorship (Meyer et al., 2009), best practices for management of the survivorship period of cancer (McCabe, 2008), and continued research on best practices for distress screening and tools

to elicit concerns effectively. Research is recommended for the needs and treatment of subpopulations, especially geriatric and cultural minorities (Breitbart & Alici, 2009 ), to give age-appropriate and culturally competent care. Under-represented groups have not been studied for ethnic and cultural considerations and greater understanding of patient and family responses to cancer are needed (Grassi et al., 2015; Hamann & Kendall, 2013; Surbone et al., 2010).

One other recommended subject for research is a new area that is related to new cancer treatments. Research on newly-created populations such as the psycho-emotional distress state of *previvors*—those identified as high risk genetically for cancer. Another new group consists of those receiving *targeted therapies* . Targeted therapies represent a new era in cancer treatment—moving from a cytotoxic approach to molecular targeting based on a patient’s own gene expression with new implications for psychosocial assessment (McFarland et al., 2014). McFarland et al. noted that with gene testing there is an emotional/psychological response to having the “right gene” that is similar to winning the lottery, with expectations for trial therapies disproportionately high relative to the actual data.

Educational implications of PsychOncology for oncology professionals—and healthcare education in general—reflect the need for greater psychosocial focus and emphasis on holistic patient care with mental health care given parity with biomedical care. Many health professionals working in oncology report lacking confidence in their communication skills—especially on difficult topics (Middleton, 2014) and not all feel comfortable assessing mental health and lack the training to recognize some psychiatric symptoms.

PsychOncology specialist training has evolved differently for the various disciplines involved. Certification for oncology social workers is at the graduate level and can be general or focused on a specific cancer population (pediatric, geriatric, bone-marrow transplant, hospice,



etc.) (Loscalzo et al., 2010 ). For psychologists, post-doctoral fellowships are a key route to being trained in psycho-oncology (Hamann & Kendall, 2013 ). Large cancer centers have post-graduate clinical and research training programs in which hundreds have participated (Holland & Weiss, 2010 ). Most of the programs reviewed on-line are for medical students, residents, or fellows in psycho-somatic medicine, integrated medicine, medical psychiatry through psychiatric or psychOncology departments, or are for post-doctoral health psychologists through these same departments. Some training is available for oncology nurses to obtain psychOncology training. There are not enough nurses with psychOncology education to meet the needs of cancer patients, survivors and their families (Loscalzo et al., 2010 ).

The majority of PMHNPs work in psych with patients with mental health concerns, not in oncology with patients with cancer, but oncology and psycho-oncology may be increasingly hiring some PMHNPs to provide the services recommended by the IOM and to meet accreditation requirements. Internships in psycho-oncology are an opportunity for PMHNPs to learn the specialty. The International Psycho-Oncology Society (IPOS) has developed an on-line training program called the International Multilingual Core Curriculum (IPOS, n.d.). It is available on-line at no cost and covers the basics of comprehensive care delivery with full webcasts and power points in many cases delivered by the original researchers—an excellent resource.

An exciting implication for psycho-oncology care is that it can serve as a blueprint for working with patients who have other life-threatening illnesses, chronic illnesses or chronic pain that disrupt functioning and quality-of-life (Badger et al., 2010). Type I diabetes and myocardial infarction are two health conditions that are associated with depression, to which the principles of psycho-oncology for biopsychosocial care can be applied. There is great potential for working

with children and families managing T1DM, muscular dystrophy, patients with renal dialysis and patients with many other serious diseases which have not fully had their psychosocial and mental health needs met. PsychOncology has led the way—and is leading the way—for improvement in holistic patient care that addresses both the physical and related mental aspects of disease processes and their impact on patients' lives.

### **Summary and Conclusions**

The ability to cope and function in the midst of stress are foundational to mental health. Much can be done to support coping for those experiencing the unique stress of cancer. Supporting patients' coping can look very different in different cases. Providing information and resources and emphasizing treatment decision-making can empower certain patients, but overwhelm others. For example, when diagnosis is unexpected and sudden and treatment is inpatient and immediate—such as with many leukemias and lymphomas—it has been found patients tend to cope best by surrendering control to the medical team and limiting information on prognosis (Nissim et al., 2013). Trusting the medical staff and using a present-oriented time frame can decrease anxiety, decrease a sense of responsibility and feelings of being overwhelmed and improve patient's emotional well-being.

Psycho-oncology is a complex and growing sub-specialty with much to learn for providers and much to offer for patients. The research over the last thirty years has built a large evidence-based body of knowledge that needs to be more fully integrated into practice. A knowledgeable confident provider is associated with greater patient hopefulness (Middleton, 2014). Knowledge about survivor distress, stigma, guilt and anger associated with *preventable cancers*, paraneoplastic presentations, psychopharmacologic and chemotherapeutic medical

interactions, demoralization syndrome, and so much more, are needed to provide holistic care to patients with cancer.

This care is not uniformly available in all areas as screening recommendations are newly implemented in some areas and trained psycho-oncology specialists are not widely available in many community cancer centers. A range of effective psycho-oncologic interventions have been developed with implementation and integration in progress, yet there is much room to grow and improve care services, especially in non-urban communities. The use of technologies such as tele-psychiatry and Internet interventions show good potential for use in patient assessment and support.

Integration of mental health services and greater delivery of psychosocial /emotional support can positively affect patient quality-of- life and medical outcomes. There is great potential for application of the psycho-oncologic principles of psychosocial/psychiatric care and medical care integration for the medical care of patients with many other serious illnesses. Medical illness can be a key time for mental health care providers to intersect patients' lives as it is often a time that patients may be highly motivated to improve their health through behavior change.

Cancer care has vastly improved over the last few decades and one of the improvements has been the evolution of psycho-oncology. The biomedical-psychosocial care of patients is needed to optimize cancer care. Biomedical services and mental health services should both be of the highest quality and both need to be available to all patients with cancer.

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**Appendix A. Potential Psychosocial Responses and Stresses  
Experienced Related to Cancer Diagnosis and Treatment**

- Disbelief/shock/denial
- Fear of death
- Overwhelming stress
- Isolation/withdrawal
- Sadness & depression
- Helplessness
- Anxiety
- Hopelessness
- Appointment overload/time constraints
- Relationship & role changes
- Apprehension/fear of treatment and side effects
- Information needs
- Disruption of life/sense of loss of control
- Existential questions –
- Worry/sense of vulnerability
- Residual treatment effects –
- Anticipatory loss & toxicities
- Fear of recurrence
- Shifts in priorities
- Anger
- Worries about family
- Anhedonia
- Cancer-related PTSD
- Pain & extreme fatigue
- Stress of decision-making
- Nausea & vomiting
- Decisional conflict
- Altered body image
- decreased functional status/disability
- Confusion/Suicidal thoughts (completed suicide is double that of non-cancer population)
- Cognitive changes/“chemo fog”
- Financial worries/employment or insurance issues
- Guilt, feeling responsible for illness or responsible to get well
- Sexuality concerns

### **Appendix B. Sample of Current Supportive Services and Interventions Used With Cancer Patients and Survivors**

- Support groups
- Classes
  - educational classes & materials for individual cancer types
  - exercise for caregivers/families
  - yoga, meditation
  - bereavement
  - mindfulness, guided imagery
- Peer support networks
- Navigation services
- Survivorship programs with rehabilitation, physical therapy, occupational therapy
- Pastoral/spiritual care
- Cognitive retraining
- Genetic counseling
- Financial & employment counseling
- Fertility counseling
- Nutritional counseling
- Transportation/ housing assistance

### **Therapies Successfully Used for Patients with Cancer**

- Writing therapy
- Individual psychotherapy
- Music therapy
- Cognitive behavioral therapy
- Art therapy
- Meaning-centered therapy
- Gardening therapy
- Desensitization therapy
- Family therapy



### **Appendix C. Pre-Test**

#### **True or False:**

Cancer is associated with more psychiatric disorders than any other chronic illness.

Women with cancer experience greater prevalence of depression than men.

Cancer is a physical illness associated with completed suicide.

Support groups are attended predominantly by women.

#### **Multiple Choice:**

Which is recommended to be done at first appointment and at each transitional point of care

- a.) Distress Screening
- b.) Hospital Anxiety & Depression Scale
- c.) Neurological assessment

Patients report this cancer-related physical symptom to be the most distressing

- a.) Pain
- b.) Nausea and vomiting
- c.) fatigue

The most common cancer-related psychiatric diagnosis is

- a.) Post-traumatic stress disorder
- b.) Adjustment disorder
- c.) Delirium

#### **Short answer:**

Which cancer has the greatest stigma associated with it?

Which cancers are associated with the greatest amount of distress?

What do these therapies—meaning-centered therapy, dignity therapy, The Healing Journey—have in common?

**Matching:**

- |  |                            |
|--|----------------------------|
| ___1. Percentage can be as high as___ of patients reporting “chemo-brain” or “chemo-fog.”    | a) 50%                     |
| ___2. Percentage of patients referred for psychological evaluation & counseling.             | b) 40%                     |
| ___3. Percentage of Americans diagnosed with cancer during their lives.                      | c) 32%                     |
| ___4. Percentage of leukemia/lymphoma patients that meet criteria for acute stress disorder. | d) 10%                     |
|  |                            |
| ___1. A mentor matching program for women with breast cancer.                                | a) Support groups          |
| ___2. Website for communicating updates and for blogging interventions.                      | b) Internet                |
| ___3. Primarily expressive supportive-based.   | c) CaringBridge            |
| ___4. Primarily based on cognitive behavioral therapies.                                     | d) American Cancer Society |
| ___5. Part of the largest CA support community in North America.                             | e) Firefly                 |
| ___6. Founded in 1913.   | f) Gilda’s Club            |

Appendix D. PowerPoint Presentation

# Psycho-Oncology

Psychosocial Support and Mental Health Care for Cancer Patients