DISTRESS SCREENING IN THE PATIENT WITH CANCER

A DOCTORAL PROJECT

Submitted in Partial Fulfillment of the Requirements

For the degree of

DOCTOR OF NURSING PRACTICE

By

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ABSTRACT

The Institute for Medicine identifies distress screening as an essential aspect of comprehensive cancer care. Unfortunately, because of limited resources, not all community cancer sites consistently screen for distress. This quality improvement project implemented distress screening in a community based cancer support setting. Applying the Plan-Do-Study-Act (PDSA) framework, twenty-one participants of a Cancer Support Community (CSC) affiliate were screened with the CancerSupportSource® (CSS) during an intake interview. The CSS® is a validated 15-item distress screening instrument in an innovative touch-screen tablet format introduced by the CSC in 2014. The distress screening was valuable in opening sensitive communication between author and participants. The author found that the screening process provided an opportunity to discuss emotional topics that may have been overlooked without the screening instrument. Approximately 62% of participants (13 of 21 participants) screened positive for depression and two participants were found seriously depressed providing evidence that screening for distress is imperative. Screening facilitated referral to appropriate support groups, supportive activities within the community, and individual therapy. The PDSA provided a useful framework for guiding this successful community based quality improvement project. Nurses are valuable in bringing distress screening to community settings in order to meet the psychosocial needs of cancer survivors.
# TABLE OF CONTENTS

ABSTRACT ................................................................................................................... iii

LIST OF TABLES ......................................................................................................... vi

LIST OF FIGURES ....................................................................................................... vii

ACKNOWLEDGMENTS ............................................................................................. viii

INTRODUCTION ......................................................................................................... 1

BACKGROUND ........................................................................................................... 2

  Problem Statement .................................................................................................. 3
  Purpose Statement .................................................................................................. 4
  Supporting Framework ............................................................................................ 4
    Distress Screening in Cancer Patients Utilizing the PDSA Model ................ 7

REVIEW OF LITERATURE ........................................................................................ 10

  Overview ............................................................................................................... 10
  Important Principles Related to Distress .............................................................. 11
  Distress in Patients with Cancer ........................................................................... 12
  Distress Screening .................................................................................................. 15
  Barriers to Screening ............................................................................................ 16
  Interventions for Distress ...................................................................................... 17
  Conclusion ............................................................................................................ 19

METHODS .................................................................................................................... 20

  Design ................................................................................................................... 20
  Sample .................................................................................................................. 20
  Ethical Considerations ......................................................................................... 21
  Setting ................................................................................................................... 21
  Instrument ............................................................................................................. 22
  Procedures ............................................................................................................. 25
  Analysis ................................................................................................................ 26
  Proposed Project ................................................................................................... 26
REFERENCES .......................................................................................................................... 27
APPENDIX A: CANCERSUPPORTSOURCE® ........................................................................ 32
APPENDIX B: PERMISSION LETTER FROM CANCER SUPPORT COMMUNITY ....................... 40
APPENDIX C: INSTITUTIONAL REVIEW BOARD ................................................................. 41
APPENDIX D: MANUSCRIPT SUBMITTED TO CLINICAL JOURNAL OF ONCOLOGY NURSING ................................................................................................. 43
APPENDIX E: AUTHOR GUIDELINES FOR CJON ............................................................... 66
LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Characteristics of Patient Distress</td>
<td>14</td>
</tr>
</tbody>
</table>

vi
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Model for Improvement</td>
<td>5</td>
</tr>
<tr>
<td>2.</td>
<td>PDSA Cycle</td>
<td>7</td>
</tr>
</tbody>
</table>
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Many thanks to the professors and peers who made this journey a fruitful one. A special acknowledgment for my Chair, Dr. Joy Goebel, for believing in me.
INTRODUCTION

The experience of cancer brings forth psychological, social, and practical challenges, which can contribute to patient distress. Detecting distress can lead to improved patient outcomes, increased quality of life, and early intervention can avoid patients experiencing unmet needs (O'Connor, Tanner, Miller, Watts, & Musiello, 2017). This Capstone project is focused upon the detection of distress for improving the referral process for participants of a Cancer Support Community affiliate. As an oncology nurse and cancer survivor, this project is the culmination of interest in identifying distress in patients in order to ensure that the emotional impact of cancer is addressed and that patients have appropriate and adequate resources to support them in the tumultuous challenges brought forth by the experience.

This paper builds on the content that was used in the initial proposal defense for the Southern California CSU Doctor of Nursing Practice Consortium. The project results, tables, figures and discussion are found at the end of this report in a paper being drafted to submit for publication to the Clinical Journal of Oncology Nursing. The present Capstone project is a continuation of my passion for meeting the emotional needs of patients with cancer.
BACKGROUND

The journey across the cancer trajectory usually brings distress for patients and families due to the threat of mortality and the unforeseen treatments that ensue. Distress in the context of cancer has been defined as an "unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment" (National Comprehensive Cancer Network [NCCN], 2017, DIS-2). The causes of distress are multifactorial and can occur anywhere along the cancer continuum (diagnosis, treatment, end-of-treatment, recurrence, and end-of-life care) and may change over time (Gao, Bennett, Stark, Murray, & Higginson, 2010). Distress can range from normal feelings of fear, vulnerability, and sadness, to more serious symptoms of "depression and anxiety, panic, social isolation, and existential and spiritual crisis" (NCCN, 2017, DIS-2). Research has found that patient distress is associated with reduced quality of life, poor response and adherence to treatment, poor self-management, higher healthcare costs, and higher mortality (Estes & Karten, 2014; Fann, Ell, & Sharpe, 2012; Gao et al, 2010). It is estimated that one third to one half of patients receiving outpatient cancer care have symptoms of distress due to pain, fatigue, insomnia and depression (Fann et al., 2012).

The IOM report Cancer Care for the Whole Patient in 2008 outlined the deleterious effects of unmet needs and identified the beneficial effects of providing psychosocial services to patients in need (Adler & Page, 2008; Jacobsen & Wagner, 2012). The IOM report in 2013 Delivering High-Quality Cancer Care stressed that an attribute of patient-centered care included the provision of emotional support as needed,
such as relieving fear and anxiety and addressing mental health issues (Levit, Balogh, Nass, & Ganz, 2013). Distress has been given the title of the 6th vital sign to increase attention to it (Mitchell, 2015). Unfortunately, the literature suggests that the routine screening for distress is not universal across settings (Jacobsen & Wagner, 2012). Without adequate screening, many will suffer silently when effective interventions are unavailable to prevent the negative sequelae of unmitigated distress.

**Problem Statement**

Distress screening should be carried out on all patients experiencing cancer at vulnerable points in the cancer trajectory (Mitchell, 2015). Patients referred to the Cancer Support Community (CSC) are seeking support groups, education, and interventions such as yoga, journaling, etc., to assist them in coping with their disease process. The CSC is the largest professionally led nonprofit network of supportive resources worldwide with affiliates across the United States. The location of the CSC for this project covers the areas of the San Fernando Valley, Ventura, and Santa Barbara, California. The philosophy of the CSC is "dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community" (CSC, 2017, p. 1). In addition to providing emotional and social support for patients and families, the National CSC has a Research and Training Institute that carries out psychosocial, behavioral, and survivorship research, of which the CancerSupportSource® tool was developed.

The Valley/Ventura/Santa Barbara Wellness Community, now called the Cancer Support Community, did not currently use the CancerSupportSource® (Appendix A) tool due to limited resources available to train staff and implement the tool. The Board of
Directors, administrative staff, and therapists identified a need to implement this screening tool to assist in identifying the needs of each individual patient and to refer patients appropriately to support resources.

**Purpose Statement**

The purpose of this quality-improvement project was twofold:

1) To implement a standardized distress screening method for a population of patients with cancer at the Cancer Support Community, using the tool CancerSupportSource®, and

2) To improve referral to resources for a population who screen positive for distress at the Cancer Support Community.

**Supporting Framework**

Quality improvement projects such as the one proposed by the author benefit from the use of a conceptual model to ensure a systematic approach to implementation and evaluation of the practice change. The Plan-Do-Study-Act model is an effective method of supporting healthcare organizations to initiate change, reach quality goals, and structure improvement work (Crowl, Sharma, Sorge, & Sorensen, 2015). The PDSA acronym stands for the "plan, do, study, act" process (see Figure 1). Three essential questions clarify the purpose of the improvement process, suggest measures to ascertain and evaluate the change, and identify the changes involved in the project (Crowl et al., 2015). These three questions are: 1) What are we trying to accomplish? 2) How will we know if a change is an improvement? and, 3) What changes can we make that will result in improvement? (Crowl et al., 2015).
Initially developed for business and industry, this model has been adapted by healthcare for use in quality improvement projects. Agencies such as the Centers for Medicare and Medicaid Services (CMS) have promoted use of the model "…to reduce the gap between what organizations know about quality improvement and what organizations do to improve quality" (Crowl et al., 2015, p. 366).

*Figure 1. Model of Improvement (based on information from Langley et al., 2009)*

Application of the PDSA cycle begins by identifying what is to be accomplished. It is an explicit statement that is both measurable and time-specific and defines the system or population of interest. Crowl et al (2015) assert that it is imperative to apply quantitative goals in order to provide specificity for measurement. The next question addresses the need to define the measures and identify the changes to be made. Three types of measures should be addressed: *outcome measures, process measures,* and
balancing measures. Outcome measures address how the system influences the value that patients put on their health and well-being (Crowl et al., 2015). Process measures evaluate whether the improvement initiated will have a positive impact on the system and balancing measures ensure that by applying change or improvement in one part of the system does not cause disruption in another part of the system (Crowl et al., 2015).

Lastly, the change to be made is identified with the goal being overall improvement in the system.

The PDSA is cyclical in nature—a process of planning for the change, implementing the change, observing and studying the results, then acting on what is learned (see Figure 2). The first step or plan needs to specify the objective of the change to be implemented, predict what will happen, and develop a course of action to evaluate the change (Crowl et al., 2015). The part of the cycle also addresses the 5 W's—who, what, where, when, and why. Plans for data collection are addressed here too. Change implementation occurs during the "do" stage and any complications or unexpected observations are recorded along with positive results. In the "study" phase, data is analyzed, compared to predictions, and reflection upon what has been learned occurs. Finally, the "act" stage consists on making necessary changes and modifications in order to prepare for the next PDSA cycle. "Just as a circle has no end, the combinations of these four steps should be continually repeated as cycles of improvement (Crowl et al., 2015, p. 369).
Distress Screening in Cancer Patients Utilizing the PDSA Model

The purpose of this quality-improvement project was twofold: to implement distress screening for a population of patients with cancer at the Cancer Support Community (CSC) using the CancerSupportSource®, and improve access to resources for a population who screen positive for distress. There was no standardized screening method at the Valley/Ventura/Santa Barbara CSC setting. Therefore, it was difficult to identify those at-risk patients who may be suffering psychological distress. In addition, a standardized distress screening could inform the choice of resources offered to each patient. For example, information from screening may influence the choice of support group and what additional CSC resources (e.g., yoga, journaling club, psychoeducational programs) could be offered. If the participant is identified to have distress (anxiety, depression, or other symptomatic issue), referral to CSC or outside resources (e.g., psychotherapist) could be offered.
Since no formalized screening method was currently used in this CSC affiliate, the site stakeholders (President and CEO, Program Director, therapists) identified a need to formalize the screening process using the CancerSupportSource® Integration of this tool in the participants' intake interview process would be beneficial to identify at-risk patients for distress in addition to providing the best evidence-based practice treatment. The "My Support Care Plan" produced by the CancerSupportSource® would help to determine what supportive services at the CSC would be most beneficial for the individual participant. The My Support Care Plan also provides a list of Internet resources available to address any concerns identified from the distress screening tool. Lastly, distress screening can help identify any individual who is in need of additional resources that the CSC cannot provide, e.g., psychotherapy for pharmacotherapy. Follow-up or rescreening using the same tool planned to be carried out 30 days later to determine any changes in distress scores after the participant had attended support group or other CSC activity.

Application of PDSA cycles established a framework for the project. The "Plan" phase of the project consisted of the 5 W's—the identification of who—the cancer patient—what—CancerSupportSource®, when—intake interview—where—Cancer Support Community—why—to identify those at-risk patients who are experiencing distress. The "Do" phase of the project began by carrying out the screening process to a minimum of 3 participants at the intake interview with the purpose of gathering information related to time-effectiveness and patient responses to administration of the tool, e.g., difficulty in using the touch screen tablet. Inter-rater reliability was carried out by 2 therapists observing administration of the tool to determine if the interview process
was consistent. Once this introductory process was finalized, the CancerSupportSource®
was administered to all patients during the intake interview. Participants were then
assigned to a support group and/or other resources within the CSC. If a participant was
identified as having distress, the patient was appropriately referred for six free individual
therapy sessions at CSC or to outside resources if warranted, e.g., psychotherapist. A list
of psychotherapists was developed and available for the practitioner to identify an
appropriate referral.

The "Study" component of the project analyzed descriptive data including: 1) demographies of the population who were successfully screened, 2) initial distress
scores, 3) risk for depression, and 3) identification and referral of high-risk participants.
The final "Act" phase considered what changes needed to be made within the system to
integrate distress screening to each individual participant who comes to the CSC for
assistance with their coping needs.
REVIEW OF LITERATURE

Overview

A systematic review of the literature is the foundation of a Doctorate of Nursing Practice (DNP) and served to guide all aspects of the methods and evaluation to improve practice. The focus of this quality improvement project was distress screening in the patient with cancer. A review of literature was carried out using the following electronic databases: PubMed, CINAHL, and PsychInfo. Key search terms utilized included distress, distress screening, distress in cancer, depression in cancer, anxiety in cancer, and symptom distress in cancer. Symptom distress was limited to the following symptoms that are major contributing factors to emotional distress: pain, fatigue, insomnia, anorexia, and relationship/role changes. Other search terms included coping with cancer, adaptation to cancer, and quality of life in cancer. Only peer-reviewed journal publications were chosen for review and for those articles chosen a review of article references was carried out to identify other pertinent research studies. In addition, national guidelines pertaining to distress and distress screening were included, e.g., National Comprehensive Cancer Network (NCCN) Distress Guidelines.

Searching was carried out for articles published starting in January 2006 to the present day unless there was seminal research identified before these dates. Search limitations were peer-reviewed journals and the English language. For the purpose of this project, distress was defined as an unpleasant emotional response to the cancer experience interfering with coping, adaptation, and quality of life. Results that were only abstracts or case studies were eliminated from the final literature review. The articles
were then organized into four categories: 1) distress, 2) distress screening, 3) anxiety and depression, and 4) symptoms related to emotional distress.

Review articles provided general information regarding the state of distress screening in the oncology population. This included important principles related to distress, distress in patients with cancer, screening and interventions for distress.

**Important Principles Related to Distress**

The Institute of Medicine (IOM) seminal release *Cancer Care for the Whole Patient* in 2008 changed cancer care. It recommended that services such as identification of patient distress be integrated into routine cancer care (Adler & Page, 2008). The goal of care is to maximize the patient's quality of life, not just the quantity of life (Fann et al., 2012; Jacobsen & Wagner, 2012). Once patient needs are identified, appropriate services and interventions (pharmacologic and nonpharmacologic) can be offered (Fann et al., 2012).

Distress is a clinically significant phenomenon that represents several mood disorders (Carlson, Waller, & Mitchell, 2012). The term "distress" was reported to be chosen by NCCN (2017) for cancer screening, assessment, and care because it is less stigmatizing than terms such as "psychiatric," "psychosocial," or "emotional." It is more useful than psychiatric terms such as anxiety or depression (Carlson et al., 2012) and it can be defined and easily measured by self-report (NCCN, 2017). Standards for distress management have been developed by the NCCN (2017) and other organizations (Institute of Medicine, Canadian Association of Psychosocial Oncology, American Society of Clinical Oncology/Oncology Nursing Society, American College of Surgeons, Commission on Cancer) in recent years (Jacobsen & Wagner, 2012; Oncology Nursing
The NCCN (2017) standards state that distress should be assessed and managed according to clinical practice guidelines.

NCCN (2017) standards suggest that quality cancer care is dependent upon a multidisciplinary approach including disciplines such as chaplains and mental health professionals along with cancer care professionals such as physicians, nurses and social workers. The multidisciplinary team can identify and treat distress in addition to the incorporation of educational and training programs to ensure that all health care professionals in cancer care obtain the necessary knowledge and skills. The American College of Surgeons Commission on Cancer (ACoS CoC), an accrediting body of hospitals, set new standards for patient-centered care that requires the development and implementation of distress screening and referral for services (Jacobsen & Wagner, 2012). Even so, Jacobsen and Wagner (2012) stress that there are concerns that the wider community of oncology professionals are not cognizant of these initiatives for care.

**Distress in Patients with Cancer**

Distress can occur anywhere along the cancer continuum. Patients recently diagnosed experience normal fears and feelings of vulnerability (Mitchell, 2015). The treatment phase unleashes its own set of emotional challenges as well as physiological states such as pain and insomnia can induce distress. When treatment ends, Mullen (1984) described the "re-entry phase" when patients often express fears of being abandoned by the treatment team. Advances in cancer care have improved survival rates yet survivors may experience long-term effects of disease and treatment. Symptoms such as pain, fatigue, anxiety and depression are frequently reported as interfering with activities of daily living, in turn, negatively affecting quality of life long after treatment.
ceases (NCCN, 2017). If patients have a comorbid psychiatric disorder, it may be exacerbated by a cancer diagnosis and interfere with treatment and cancer recovery (NCCN, 2017).

Patients at increased risk for distress and the periods of increased vulnerability have been identified (NCCN, 2017). Table 1 presents these risk factors and points of vulnerability. Any histories of prior psychiatric disorders or substance abuse are noted to increase the risk of distress as well as uncontrolled symptoms such as pain. Cognitive impairment and comorbid illnesses are recognized as increasing distress and social issues such as inadequate social support or communication barriers may also increase the occurrence of distress. Research has identified those persons with certain cancers such as lung, brain, and pancreatic are more likely to be distressed. These patients are more likely to have poorer quality of life (QoL), disability, and ongoing unmet needs (Carlson et al., 2012). The prevalence of psychological distress is highest among patients with advanced disease and a poor prognosis (Holland & Alici, 2010).

Patients with unmet needs are also at risk for distress. Unmet needs are defined as a mismatch between the care that a patient receives and the care necessary to achieve optimal well-being (Waller, Boyes, Carey, & Sanson-Fisher, 2015). Recent studies suggest that experiencing unmet needs is associated with being female, socially disadvantaged, being younger, having less social support, and not being in remission (Waller et al., 2015).
Table 1.

Patient Characteristics of Distress

<table>
<thead>
<tr>
<th>Increased Risk Factors for Distress</th>
<th>Points of Vulnerability</th>
</tr>
</thead>
<tbody>
<tr>
<td>● History of psychiatric disorder/substance abuse</td>
<td>● Finding a suspicious symptom</td>
</tr>
<tr>
<td>● History of depression/suicide attempt</td>
<td>● Diagnostic work-up</td>
</tr>
<tr>
<td>● Cognitive impairment</td>
<td>● Diagnosis</td>
</tr>
<tr>
<td>● Communication barriers</td>
<td>● Treatment</td>
</tr>
<tr>
<td>● Severe comorbid illnesses</td>
<td>● Symptoms related to treatments</td>
</tr>
<tr>
<td>● Ineffective coping</td>
<td>● End of treatment</td>
</tr>
<tr>
<td>● Insomnia</td>
<td>● Transition to survivorship</td>
</tr>
<tr>
<td>● Social issues</td>
<td>● Medical follow-up and surveillance</td>
</tr>
<tr>
<td>□ Family/caregiver conflicts</td>
<td>● Recurrence/progression</td>
</tr>
<tr>
<td>□ Inadequate social support</td>
<td>● Advanced cancer</td>
</tr>
<tr>
<td>□ Living alone</td>
<td>● End of life</td>
</tr>
<tr>
<td>□ Financial problems</td>
<td></td>
</tr>
<tr>
<td>□ Limited access to medical care</td>
<td></td>
</tr>
<tr>
<td>□ Younger age</td>
<td></td>
</tr>
<tr>
<td>□ Female</td>
<td></td>
</tr>
<tr>
<td>□ History of abuse (physical, sexual)</td>
<td></td>
</tr>
<tr>
<td>□ Other stressors</td>
<td></td>
</tr>
<tr>
<td>● Spiritual/religious concerns</td>
<td></td>
</tr>
<tr>
<td>● Uncontrolled symptoms (pain, fatigue)</td>
<td></td>
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</tbody>
</table>

Note. Based on information from National Comprehensive Cancer Network (2017)

Periods of increased vulnerability for distress are associated with transitional stages along the cancer continuum including at the time of diagnosis, new or re-entry into treatment, cancer recurrence, and advancing cancer. The pre-diagnosis phase of finding a
suspicious symptom begins an often roller-coaster ride of fear and apprehension for what the future holds. In some patients, distress, anxiety, and significant complications such as pain and fatigue remain elevated months or years after initial diagnosis (Waller et al., 2015). In a grounded theory investigation of the perceptions of distress in women with ovarian cancer, many patients experienced an "existential assault" across the cancer trajectory. For participants, distress was experienced within a psychological, psychosocial, and existential context (DellaRipa et al., 2015).

Distress Screening

The International Psycho-oncology Society stated in 2009 that distress screening should be carried out and documented just as temperature, blood pressure, pulse, respiratory rate, and pain (Bultz, Loscalzo, & Holland, 2015). This movement follows closely after pain became the fifth vital sign in 1999 when the Joint Commission on Accreditation of Healthcare Organizations (TJC) required screening, documentation, and management of pain (Bultz et al., 2015). The sixth vital sign requires that patient distress be screened using standardized subjective measures and managed using evidence-based interventions (Bultz et al., 2015).

Screening for distress should be done at major points of transition across the cancer trajectory and reevaluation of distress symptoms is always imperative (Vitek et al., 2007). Screening should begin by identifying if the patient has any psychiatric history and treatment. In addition, it is important to determine if any underlying symptoms of disease and treatment (e.g., uncontrolled pain) are contributing to distress. Accurate assessment of distress can often be challenging as symptoms of distress are often difficult to distinguish from disease symptoms and treatment side-effects (Estes & Karton, 2014).
Screening for mild to severe distress includes identifying the following emotions or behaviors: excessive fears or worries that interfere with coping or carrying out activities of daily living, feelings of sadness, despair, or hopelessness, difficulty concentrating, religious crises, or dysfunction in relationships (e.g., family issues) (Vitek et al., 2007). Underlying psychiatric disorders such as generalized anxiety disorder (GAD), dementia, delirium, adjustment disorder, substance abuse, or personality disorder may underlie distressful emotions and behaviors (Vitek et al., 2007). Identification of comorbid illnesses (e.g., diabetes) is also important as stress is associated with chronic illness and may exacerbate the patient's distress level (Petty & Lester, 2014). Distress in the elderly patient often presents as somatic symptoms that can be attributed to the cancer or treatment therefore missed during screening (Cohen & Bankston, 2011). Few studies have focused upon minorities or have identified how low socioeconomic status impacts distress in patients with cancer yet some studies have identified differences in coping strategies used by different ethnicities (Cohen & Bankston, 2011) and some evidence suggests that QoL is compromised in ethnic minorities diagnosed with cancer relative to their white counterparts (Stanton, 2012). Therefore, an important objective for routine screening is to meet the needs of all underserved populations such as those with low income, ethnic minorities, and psychosocially distressed individuals (Carlson et al., 2012).

### Barriers to Screening

Barriers to screening include patient level, clinician level, and system level barriers (Cohen & Bankston, 2011). It is disingenuous to state that distress associated with the cancer experience is inevitable. Clinician level barriers to screening include a
lack of knowledge of psychosocial issues, a reticence to intervene, and poor communication skills. Clinicians may prefer to focus their care on interventions that have concrete patient outcomes (e.g., lab values) (Cohen & Bankston, 2011). In a study exploring the views of cancer professionals regarding accountability for the detection and management of emotional distress, many subjects noted the importance of detection but were uncertain of their roles and responsibilities, often turning to the expert clinician (e.g., clinical nurse specialist) to be responsible for assessment and management (Absolom et al., 2011). One research study identified barriers associated with the implementation of the NCCN-DT. These included time, concern about the increased demand for referrals, lack of knowledge about how to screen for and then manage distress, and no benefit of screening (Tavernier, 2014). System barriers include the lack of staff training for assessment and diagnosis, the lack of reimbursement for services, and a lack of communication between professionals across settings (e.g., inpatient, outpatient, primary care) (Cohen & Bankston, 2011). Loscalzo, Clark, & Holland (2011) emphasize that to implement a successful screening program, key stakeholders must find benefits to the organization. Finally, a barrier to distress screening could simply be the absence of a screening implementation strategy (Loscalzo, Clark, Pal, & Pirl, 2013).

**Interventions for Distress**

For patients with mild distress, expected feelings (e.g., fear) should be normalized for the patient allowing them to understand that distress is common at different transitions across the cancer continuum. Patients with moderate or severe distress may be experiencing mood or adjustment disorder (mixed anxiety and depressive symptoms) that demand immediate attention. Patients must be assessed for a range of psychiatric
conditions that often exist in the oncology setting (Holland & Alici, 2011; Mehta & Roth, 2015) and safety of the patient and others become a priority. Patients experiencing mood and adjustment disorders can develop suicidal tendencies and/or may be a danger to themselves and to others making psychiatric consultation warranted (NCCN, 2017). Overall, it is important to remember that psychiatric disorders in the cancer setting are usually direct responses to the illness or treatment, whereas others may be preexisting psychiatric problems that are exacerbated by the illness (Mehta & Roth, 2015).

Mild distress is often expected with a cancer diagnosis and treatment and can easily be handled by the specialized oncology team. Most often when physical side-effects are treated (e.g., insomnia), distress is decreased. Interventions for mild distress include carrying out education to inform the patient of what to expect from treatment, using appropriate medications for symptom control, and using nonpharmacologic interventions such as relaxation and guided imagery (Vitek et al., 2007). Stanton (2012) discusses the results of randomized trials to support that interventions offered at re-entry/survivorship can be effective. These interventions include cognitive behavioral strategies, stress management (e.g., relaxation and mindfulness), and psychoeducational approaches. Other interventions include pharmacologic and supportive approaches; individual and group or family therapies (Clark et al., 2012).

Interventions should be discussed collaboratively with patients, and any plan should address the management of physical health problems, psychological, social, and spiritual consequences of the cancer experience (Clark et al., 2012). Re-administration of any screening tools utilized and reevaluation of interventions is vital to determine if the patient's level of distress has improved or whether an intervention needs to be modified.
or replaced (Clark et al, 2012). Finally, documentation of interventions is of importance to demonstrate that interventions have been carried out (Clark et al., 2012).

**Conclusion**

Distress is a common response to cancer and frequently occurs along the major transitional points of care. Assessment and screening for distress is now a standard of quality patient care (e.g., the sixth vital sign) across all oncology settings. Although mild distress may be normal, it is difficult for patients and should be addressed by the oncology support team. Both physiologic and psychological factors contribute to distress and need to be treated to improve patient outcomes (e.g., effective coping). The nurse caring for the patient with cancer is in a unique position to identify distress because holistic care is inherent in the role of nursing. Nurses build therapeutic and trusting relationships with their patients thus providing a safe place for patients to express their fears and emotions. Therefore, nurses play a vital role on the multidisciplinary team and are in a prime position to carry out successful distress screening, referral, and follow-up.
METHODS

The purpose of this QI project was to implement distress screening using the CancerSupportSource™ on a population of participants at the Cancer Support Community, Valley/Ventura/Santa Barbara site during the intake interview (Appendix A). Prior to the implementation of the screening tool a referral list was formalized and updated to utilize if a participant was highly distressed and required CSC or outside referral, e.g., psychotherapy. Following implementation of distress screening, a one page educational resource was developed that can be used for training. Follow-up screening using email 30 days after the initial assessment was carried out for participants to identify changes in distress scores. Descriptive analysis was performed on all distress screening data to identify demographics, disease, stage, distress score, and risk of depression.

Design

This was a QI project to implement an effective process of distress screening and referral at the CSC. The goal was to institute the CancerSupportSource® as a routine standard of practice at the Valley/Ventura/Santa Barbara site. Tools to ensure time-effectiveness, referral and educational resources were developed.

Sample

A convenience sample of patients (referred to as "participants") who had attended the CSC orientation program and desired to have an intake interview to join the CSC were screened with the CancerSupportSource™ from July 2016 to January 2017. A total of 21 patients over a 7-month period were recruited to be screened. Participants that were English speaking, who could read, and were male or female over 18 years of age were included in the project.
Ethical Considerations

A permission letter to carry out the project was obtained from the CEO of the CSC at this site (Appendix B). Institutional Review Board (IRB) approval from California State University, Long Beach (CSULB) was obtained prior to project initiation (Appendix C). Identification of participants was kept in a HIPPA-secure site and the QI investigator received the extracted de-identified aggregate data from the CSC National headquarters. Agreement to complete the tablet screening was considered consent.

Setting

The project was carried out at one of the Cancer Support Community (CSC) affiliates covering the San Fernando, Ventura, and Santa Barbara counties. It is located in Westlake, California. The CSC is a not-for-profit cancer organization that provides psychological and social support for people with cancer and their families. Services of the CSC include weekly support groups, stress management programs, educational workshops, and social activities. These services are free to participants. Financial support is obtained through tax-deductible contributions from businesses, charitable foundations, and fundraising. The National CSC is located in Washington, D.C. and affiliates are all over the country. Participants hear about the CSC through brochures in physician offices, advertisements in local newspapers, and by other healthcare professionals familiar with the services provided. All support groups are led by licensed marriage and family therapists (MFCs) or licensed social workers (LSWs).

The CSC has a research center that ensures that all of its programs are evidence-based such as the CancerSupportSource®. The philosophy of the Valley/Ventura/Santa Barbara site is that adults and children impacted by cancer are "empowered by
knowledge, strengthened by action, and supported by community” (https://www.cancersupportvvsb.org/, n.d.). This site is housed in a small building that has a home-like atmosphere. There is a small waiting area upon entering the CSC with a volunteer present at all times to greet participants and visitors. There is a large living room area and kitchen for psychoeducational programs, social events, and activities such as yoga. Three group rooms are decorated with comfortable couches and chairs for group therapy sessions. Any of these rooms are used for the interview process.

The CancerSupportSource® was currently being administered in other CSC affiliates around the country but not at this site due to limited resources for staff training and a lack of an implementation plan. This QI project outlined a process using the PDSA cycle to implement the distress screening tool at this site.

**Instrument**

The CancerSupportSource® is a validated distress screening tool that can be used at community-based hospitals, physician practices, and advocacy organizations such as the CSC (www.CancerSupportCommunity.org/CancerSupportSource). The initial tool was a 36-item community-based problem-related distress screening tool tested on 319 cancer survivors across 14 affiliates of the CSC. The distress tool demonstrated high internal consistency (Cronbach's alpha = 0.91) and strong test-retest reliability (ICC > 0.75) (Miller et al., 2013). The distress tool demonstrated high internal consistency (Cronbach's alpha = 0.91) and strong test-retest reliability (ICC > 0.75) (Miller et al., 2013). The tool correlated with the FACT-G (Functional Assessment of Cancer Therapy-General Well-Being Scale) \(R(2) = 0.58, p < 0.001\), the CES-D (Center for Epidemiologic Studies Depression Scale) \(R(2) = 0.48, p < 0.001\), and the DT
(Distress Thermometer) \( R(2) = 0.35, p < 0.001 \) indicating strong concurrent validity. Researchers concluded that the distress screening tool demonstrated strong psychometric properties to screen for psychological distress related to social, emotional, and physical problems (Miller et al., 2013). Following extensive research to determine the discriminatory power of a 25-item distress screening tool (Miller et al., 2012; Miller et al., 2014) the tool is now a fifteen-item assessment that identifies physical distress (e.g., pain or physical discomfort), social distress (e.g., impaired role functioning, financial issues), and psychological distress (anxiety, depression) (Buzaglo, Miller, Gayer, Morris, & Galant, 2013).

The 15-question survey touch-screen tablet enables patients to rate their concerns and to identify what specific assistance they want. Patients are asked to rate their concerns by the question "Today, how concerned are you about . . . ?" Responses are based on a five-point scale (0 Not at all, 1 Slightly, 2 Somewhat, 3 Seriously, 4 Very Seriously). Following each question the participant is prompted to reply how the CSC can help them, "Please let us know how we can help you . . . " and are asked to mark all that apply (e.g., have a staff person talk with you, connect you with online resources, give written information, or no action needed). Demographic and clinical information is also recorded including disease site, stage, and treatments. The tool is scored automatically by computer once the data is submitted.

Once completed, the CancerSupportSource® provides two additional resources: 1) the "My Support Care Plan" that provides educational and resource information to the participant based upon their individual screening results, and 2) the "Distress Screening Report," a reference for the healthcare provider that outlines the participants needs for
support. The CancerSupportSource® provides a vehicle to identify the unique needs of every patient.

There are four questions on the CancerSupportSource® that correlate heavily with a psychometric measure called the CES-D (Center for Epidemiologic Studies Depression Scale), a depression tool. If a participant answers moderate to very seriously (3 or above) on any one of those four items, there is the possibility that the person may be at risk for depression. A red flag will appear on the "Distress Screening Report" and trigger an email to the Program Director. The participant can also take a copy of the "Distress Screening Report" to his/her doctor. The red flag does not prohibit the participant from joining the community or attending programs.

Prior to screening a list of psychotherapeutic and community resources was available if the participant screened at risk for depression or anxiety and required CSC or outside referral, e.g., for pharmacotherapy. The CSC provides six free individual sessions for participants who screen at risk for depression. After implementation of distress screening on 21 participants, an educational one-page resource was developed to instruct staff on implementation of the tool to all participants coming into the CSC. Distress screening also demanded that the intake interview form be updated to reflect the results of participant screening. A journal was kept by the QI coordinator to identify problems/concerns that arose with tool implementation, time-effectiveness, and participant responses to tool administration. This will be used to develop a final report to CSS stakeholders at this site.
Procedures

Each participant is required to attend the CSC orientation program prior to an intake interview for participation. If after attending the orientation program, they are interested in becoming a member of the community then they must have an intake interview. This interview introduces the participant to the resources available at the CSC and is used to identify which supportive groups/programs are best suited for them. It was estimated that the entire interview with administration of the CSS would take forty-five minutes but actually averaged a minimum of one hour. A 90-minute time slot was allotted for interviews and screening in case the participant needed more time to discuss concerns. There were a total of 21 participants interviewed from July 2016 to January 2017.

Once a patient expressed a desire to join the community, the interviewer introduced the project, invited participation and obtained verbal informed consent, then led the participant into one of the private support group rooms for the interview. The CancerSupportSource® was administered by the QI coordinator at the time of, but prior to, the interview process. The tool is completed on a touch-screen tablet and results are automatically integrated into a HIPPA-secured computer site. The "My Support Care Plan" was printed out and reviewed with the patient during the interview process. Screening assisted in the assignment of the participant to the appropriate support group and available programs. If the patient scored at risk for depression or anxiety, the participant was referred to a therapist in CSC for six-free individual therapy sessions or referred outside the community appropriately, e.g., psychotherapy, using the developed resource list. A copy of the interview form completed by the QI coordinator was placed
along with the "Distress Screening Report" in the assigned therapist's box in a sealed envelope. Notes were transcribed in the distress screening journal/notebook to identify any problems/concerns that occurred during each process.

**Analysis**

Nonparametric statistics will describe demographic information and distress scores (samples and measures).

**Proposed Project**

The product of my doctoral work will be a manuscript to be submitted to the *Clinical Journal of Oncology Nursing*. I will carefully review the author guidelines for the journal, and work with my committee to submit a publishable manuscript describing the evidence to support distress screening in a community cancer support setting.
REFERENCES


Cancer Support Community. (2017). Retrieved from
http://www.cancersupportcommunity.org/mission-vision-and-history

CancerSupportSource®. (2016). Retrieved from
http://www.cancersupportcommunity.org/find-support/distress-screening


INTRODUCTION
Distress is an unpleasant emotional state that can affect how we think, feel and act. Everyone with cancer experiences distress at some point in time. This brief questionnaire is designed to help you talk about your worries and concerns so that we can better understand what kind of information and supportive services might be most helpful at this time. CancerSupportSource® has been tested in many studies and many people with cancer have found it to be helpful.
As you participate in this program, you understand that this questionnaire and the resources you will receive are provided as an informational service only. Your responses will be collected and stored in a highly secure electronic database. You understand that the results of this questionnaire will be used to help you identify your level of distress. Your responses will be used to create My Support Care Plan© which is a personalized report that you will receive after you answer the questions. Please complete the questionnaire and a staff person will review the results with you and provide the information you requested. We hope that you will find this tool to be helpful in your cancer journey.

Today, how CONCERNED are you about…..
Feeling irritable? Please select one of the choices below, then continue.

1 2 3 4 5
Not at all Slightly Moderately Seriously Very seriously
**Feeling irritable:** please let us know how we can help you.
Please circle as many of the choices below as apply, then continue.

Have a staff person talk with you  Provide me additional information  No action needed

Today, how CONCERNED are you about…..

**Sleep problems?** Please select one of the choices below, then continue.

1 2 3 4 5
Not at all  Slightly  Moderately Seriously  Very seriously

**Sleep problems:** please let us know how we can help you.
Please circle as many of the choices below as apply, then continue.

Have a staff person talk with you  Provide me additional information  No action needed

Today, how CONCERNED are you about…..

**Changes or disruption in work, school or home life?** Please select one of the choices below, then continue.

1 2 3 4 5
Not at all  Slightly  Moderately  Seriously  Very seriously

**Changes in work, school or home life:** please let us know how we can help you.
Please circle as many of the choices below as apply, then continue.

Have a staff person talk with you  Provide me additional information  No action needed

Today, how CONCERNED are you about…..

**Feeling sad or depressed?** Please select one of the choices below, then continue.

1 2 3 4 5
Not at all  Slightly  Moderately  Seriously  Very seriously

**Feeling sad or depressed:** please let us know how we can help you.
Please circle as many of the choices below as apply, then continue.

Have a staff person talk with you  Provide me additional information  No action needed

Today, how CONCERNED are you about…..

**Pain and/or physical discomfort?** Please select one of the choices below, then continue.

1 2 3 4 5
Not at all  Slightly  Moderately  Seriously  Very seriously
**Pain and/or physical discomfort:** please let us know how we can help you. Please circle as many of the choices below as apply, then continue.

<table>
<thead>
<tr>
<th>Choice</th>
<th>Description</th>
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<tbody>
<tr>
<td>1</td>
<td>Have a staff person talk with you</td>
</tr>
<tr>
<td>2</td>
<td>Provide me additional information</td>
</tr>
<tr>
<td>3</td>
<td>No action needed</td>
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</tbody>
</table>

Today, how CONCERNED are you about…..

**Body image and feelings about how you look?** Please select one of the choices below, then continue.

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Not at all</td>
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<tr>
<td>2</td>
<td>Slightly</td>
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<tr>
<td>3</td>
<td>Moderately</td>
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<tr>
<td>4</td>
<td>Seriously</td>
</tr>
<tr>
<td>5</td>
<td>Very seriously</td>
</tr>
</tbody>
</table>

**Body image and feelings about how you look:** please let us know how we can help you. Please circle as many of the choices below as apply, then continue.

<table>
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<th>Choice</th>
<th>Description</th>
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<tbody>
<tr>
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<td>Have a staff person talk with you</td>
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<td>2</td>
<td>Provide me additional information</td>
</tr>
<tr>
<td>3</td>
<td>No action needed</td>
</tr>
</tbody>
</table>

Today, how CONCERNED are you about…..

**Feeling nervous or afraid?** Please select one of the choices below, then continue.

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<thead>
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<th>Number</th>
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<tr>
<td>1</td>
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<td>Moderately</td>
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<td>4</td>
<td>Seriously</td>
</tr>
<tr>
<td>5</td>
<td>Very seriously</td>
</tr>
</tbody>
</table>

**Feeling nervous or afraid:** please let us know how we can help you. Please circle as many of the choices below as apply, then continue.

<table>
<thead>
<tr>
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<tr>
<td>1</td>
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<td>Provide me additional information</td>
</tr>
<tr>
<td>3</td>
<td>No action needed</td>
</tr>
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</table>

Today, how CONCERNED are you about…..

**Worrying about the future and what lies ahead?** Please select one of the choices below, then continue.

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
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<tbody>
<tr>
<td>1</td>
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<td>3</td>
<td>Moderately</td>
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<tr>
<td>4</td>
<td>Seriously</td>
</tr>
<tr>
<td>5</td>
<td>Very seriously</td>
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</tbody>
</table>

**Worrying about the future and what lies ahead:** please let us know how we can help. Please circle as many of the choices below as apply, then continue.

<table>
<thead>
<tr>
<th>Choice</th>
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<tbody>
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</tr>
<tr>
<td>3</td>
<td>No action needed</td>
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</table>

Today, how CONCERNED are you about…..

**Making a treatment decision?** Please select one of the choices below, then continue.

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<td>Moderately</td>
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<tr>
<td>4</td>
<td>Seriously</td>
</tr>
<tr>
<td>5</td>
<td>Very seriously</td>
</tr>
</tbody>
</table>
Making a treatment decision: please let us know how we can help you. Please circle as many of the choices below as apply, then continue.

Have a staff person talk with you  
Provide me additional information  
No action needed

Today, how CONCERNED are you about…..

**Feeling lonely or isolated?**  Please select one of the choices below, then continue.

<table>
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<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>Slightly</td>
<td>Moderately</td>
<td>Seriously</td>
<td>Very seriously</td>
</tr>
</tbody>
</table>

**Feeling lonely or isolated:** please let us know how we can help you. Please circle as many of the choices below as apply, then continue.

Have a staff person talk with you  
Provide me additional information  
No action needed

Today, how CONCERNED are you about…..

**Health insurance or money worries?**  Please select one of the choices below, then continue.

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<th>5</th>
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</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>Slightly</td>
<td>Moderately</td>
<td>Seriously</td>
<td>Very seriously</td>
</tr>
</tbody>
</table>

**Health insurance or money worries:** please let us know how we can help you. Please circle as many of the choices below as apply, then continue.

Have a staff person talk with you  
Provide me additional information  
No action needed

Today, how CONCERNED are you about…..

**Feeling too tired to do the things you need or want to do?**  Please select one of the choices below, then continue.

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<td>Seriously</td>
<td>Very seriously</td>
</tr>
</tbody>
</table>

**Feeling too tired to do the things you need or want to do:** please let us know how we can help you. Please circle as many of the choices below as apply, then continue.

Have a staff person talk with you  
Provide me additional information  
No action needed
Today, how CONCERNED are you about…..

**Worrying about family, children and/or friends?** Please select one of the choices below, then continue.

1 __________  2 __________  3 __________  4 __________  5 __________

Not at all                Slightly                 Moderately            Seriously        Very seriously

**Worrying about family, children and/or friends:** please let us know how we can help you.
Please circle as many of the choices below as apply, then continue.

Have a staff person talk with you       Provide me additional information       No action needed

Today, how CONCERNED are you about…..

**Changes or disruption in work, school or home life?** Please select one of the choices below, then continue.

1 __________  2 __________  3 __________  4 __________  5 __________

Not at all                Slightly                 Moderately            Seriously        Very seriously

**Changes in work, school or home life:** please let us know how we can help you.
Please circle as many of the choices below as apply, then continue.

Have a staff person talk with you       Provide me additional information       No action needed

Today, how CONCERNED are you about…..

**Exercising and being physically active?** Please select one of the choices below, then continue.

1 __________  2 __________  3 __________  4 __________  5 __________

Not at all                Slightly                 Moderately            Seriously        Very seriously

**Exercising and being physically active:** please let us know how we can help you.
Please circle as many of the choices below as apply, then continue.

Have a staff person talk with you       Provide me additional information       No action needed

Today, how CONCERNED are you about…..

**Finding meaning and purpose in life?** Please select one of the choices below, then continue.

1 __________  2 __________  3 __________  4 __________  5 __________

Not at all                Slightly                 Moderately            Seriously        Very seriously
Finding meaning and purpose in life: please let us know how we can help you. Please circle as many of the choices below as apply, then continue.

Have a staff person talk with you     Provide me additional information     No action needed

Did you find this survey to be helpful? Circle one option:

YES   NO

Is there anything else you would like us to know about your personal concerns at this time? Enter your comments or continue.

What was your most recent diagnosis? Please circle:

Brain cancer     Breast cancer     Bladder cancer
Colon and rectal cancer     Endometrial cancer     Kidney (renal cell)
Leukemia     Lung cancer     Lymphoma
Melanoma     Multiple myeloma     Ovarian cancer
Pancreatic cancer     Prostate cancer     Skin cancer (non-
melanoma)
Thyroid cancer     Other ____________________

Stage is how widespread the cancer is at diagnosis. When you were diagnosed with your most recent cancer, what stage of cancer did you have? Please circle:

Stage 0     Stage I     Stage II     Stage III     Stage IV
Don’t know

When did you first learn you had cancer? If you don’t remember the exact date, select your closest guess:

_____/_____/_______

Are you currently in active treatment (e.g., surgery, chemotherapy, radiation)? (This does NOT include any drugs used for preventing new or returning cancer, e.g., Tamoxifen).

Yes   No

What is your age (years): ___________________

What is your gender? Circle one option:
Male     Female     Other (please specify)____________________ Do not wish to disclose
What is the highest level of formal education you have completed? Circle one option:

Less than high school  High school graduate or GED  Some college or technical or vocational school  College graduate  Some graduate school  Graduate degree  Prefer not to share

To which racial or ethnic group do you most identify? Circle one option:

American Indian or Alaska native  Asian  Black or African American  Latino or Hispanic  Native Hawaiian or Other Pacific Islander  White  Other __________________________  Prefer not to share

What is your current marital status? Circle one option:

Single, not married  Married  Civil union  Living with significant other  Separated  Divorced  Widowed  Prefer not to share

Who lives with you currently, at least some of the time? Circle one or many options:

I live alone  Spouse or significant other  Children under age 18  Children age 18 or older  One or both parents  Other relatives  Friends or roommates  Other __________________________

What is your current employment status? Circle one option:

Employed full time  Employed part time  Not employed but looking for work  Not employed and not looking for work  Full-time homemaker or family caregiver  Retired (not due to ill health)  Student  Disability  Prefer not to share

Which of the following categories best describes your total household income, before taxes, from all sources last year? Circle one option:

Less than 20,000  20,000 to 39,999  40,000 to 59,999  60,000 to 79,000  80,000 to 99,999  100,000 or above  Don’t know  Do not wish to disclose

Do you currently have any form of health insurance? Circle one option:

Yes  No  Do not wish to disclose

Which insurance? Circle one option:

Do not wish to disclose  I don’t know  Aetna  Blue Cross/Blue Shield  Humana  Kaiser Permanente  Medicaid/Medi-Cal  Medicare  UnitedHealthCare  WellPoint/Anthem  Other __________________________
THANK YOU
Thank you for completing your CancerSupportSource® Distress Questionnaire. Please have a staff person print out My Support Care Plan®. A staff person will be happy to assist you in reviewing the plan and finding valuable resources. Thank you for sharing your concerns so that we can help you reduce distress that cancer can bring into your life.
CONSENT FROM CANCER SUPPORT COMMUNITY VVSB

June 10, 2016

Dear California State University Long Beach Institute Review Board,

This letter is written in support of the quality improvement pilot study, Distress Screening in the Patient with Cancer using the CancerSupportSource® (CSC®) by Nancy Jo Bush, RN, MN, MA, AOCN, FAAN, California State University, Long Beach Doctoral of Nursing Practice student. Administration of the CSC® has taken place in numerous Cancer Support Community (CSC) affiliates across the United States and this quality improvement project will help to integrate distress screening at the Cancer Support Community Valley/Ventura/Santa Barbara affiliate. The Cancer Support Community is committed to improving the experiences of all of our patients, especially those who suffer from distress. Thus, the Cancer Support Community unequivocally supports Ms. Bush's project and believes it will introduce and sustain distress screening in our Valley/Ventura/Santa Barbara affiliate. The Cancer Support Community is committed to improving quality care and providing Ms. Bush all of the resources she requires to complete the project.

Along with the Cancer Support Community headquarters in Washington, D.C. we are providing Ms. Bush permission to access the de-identified data obtained from the administration of the CSS®. This permission includes the ability to share pilot study information and findings with the CSC VVSB staff and to publish findings if warranted. All data will be maintained for HIPPA and confidentiality purposes according to the Cancer Support Community IRB standards. We currently support the use of the CSS® in our affiliate.

Announcement will be made one month prior to initiation of the study to inform the staff of the project and to enhance overall staff awareness and support. Hopefully, Ms. Bush's project will promote the administration of the CSS® at the VVSB affiliate so that it becomes a standard of practice.

We look forward to supporting Ms. Bush in her quality improvement study.

Sincerely, Bridget Karl President & CEO
Hope Alive for Another 25

Please remember Cancer Support Community Valley/Ventura/Santa Barbara in your will or trust.

530 Hampshire Road, Westlake Village, CA 91361 (805) 379-4777 Fax (805) 371-6231
www.CancerSupportVvsb.org info@CancerSupportVvsb.org
This is to advise you that the Institutional Review Board for the Protection of Human Subjects (IRB) of California State University, Long Beach, has reviewed your protocol application. Your application is approved as submitted.

Approval is for a period of one year from July 5, 2016 and conditional upon your willingness to carry out your continuing responsibilities under University policy. If you would like to continue this research after this one year period, please submit a renewal application and an annual report to the Office of University Research two months prior to your expiration date of July 4, 2017.

1. You must clearly indicate in the header or footer of each page of your approved Informed Consent Form the approval and expiration dates of the protocol as follows: "Approved from July 5, 2016 to July 4, 2017 by the CSULB IRB".

2. You are required to inform the Director or Senior Associate Director, Office of Research & Sponsored Programs, in writing (email is acceptable) or through IRBNet within twenty-four hours of any adverse event in the conduct of research involving human subjects. The report shall include the nature of the adverse event, the names of the persons affected, the extent of the injury or breach of security, if any, and any other information material to the situation.

3. You may not change any aspect of your research procedure involving human subjects without written permission from the Director, Office of Research & Sponsored Programs or the Chair of the IRB. Please use the Protocol Modification Form on IRBNet to request any changes.
4. Maintain your research records as detailed in the protocol. Should you have any questions about the conduct of your research under this protocol, particularly about providing informed consent and unexpected contingencies, please do not hesitate to call the Office of Research & Sponsored Programs at (562) 985-8147. We wish you the best of success in your research.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within California State University, Long Beach Institutional Review Board’s records.
Using an Innovative Informatics Approach to Improve Distress Screening in a Community Cancer Setting

Nancy Jo Bush, RN, MN, MA, AOCN, FAAN
University of California, Los Angeles

Joy R. Goebel, RN, MN, PhD, FPCN
California State University, Long Beach

Kayo Matsumoto, MS, MFT
Cancer Support Community, Valley Ventura Santa Barbara

Kholoud Hardan-Khalil, PhD, RN
California State University, Long Beach

Submitted to:
Clinical Journal of Oncology Nursing
June 2017

The authors have no competing interests to report.
**Background:** Quality cancer care includes routine screening for psychosocial distress. However, at a community based cancer support center screening for distress was not a routine practice. The center asked assistance to integrate distress screening at their location. To meet this request, implementation of an innovative informatics tool to screen for psychosocial distress, identify potential resources, and improve community referrals took place.

**Objectives:** The purpose of this article is to present the implementation of an innovative informatics tool, the CancerSupportSource®, for distress screening in a community cancer setting. The Cancer Support Community developed this valid and reliable computer tablet program for distress screening across community cancer settings.

**Methods:** The authors used a Plan, Do, Study, Act quality improvement approach for this project. The CancerSupportSource® offers an evidence-based approach to understand the physical, practical, and psychosocial needs of patients, improve the referral process, and identify community resources for cancer survivors.

**Findings:** Twenty-one patient participants were screened using the CancerSupportSource®. This simple distress screening tool identified thirteen persons at risk for depression, two persons with serious depression, and improved referral to supportive services. Participants and providers stated the distress screening allowed for discussion of intimate questions that may not otherwise have occurred in the intake interview.
Key Words: distress, quality improvement, PDSA Model, community cancer setting, informatics

Implications for Practice:

- Apply the PDSA Model of Improvement for distress screening
- Implement an informatics tool to improve screening for distress
- Identify psychosocial and practical needs to mitigate patient distress

The journey across the cancer trajectory usually brings distress for patients and families due to the threat of mortality and the unforeseen treatments that ensue. Distress in the context of cancer is defined as an "unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment" (National Comprehensive Cancer Network [NCCN], 2017, DIS-2). The causes of distress are multifactorial and can occur anywhere along the cancer continuum (diagnosis, treatment, end-of-treatment, recurrence, and end-of-life care) and may change over time (Gao, Bennett, Stark, Murray, & Higginson, 2010). Distress can range from normal feelings of fear, vulnerability, and sadness, to more serious symptoms of "depression and anxiety, panic, social isolation, and existential and spiritual crisis" (NCCN, 2017, DIS-2). Research has found that patient distress is associated with reduced quality of life, poor response and adherence to treatment, poor self-management, higher healthcare costs, and higher mortality (Estes & Karten, 2014; Fann, Ell, & Sharpe, 2012; Gao et al, 2010). Estimations state that one third to one half of patients receiving
outpatient cancer care have symptoms of distress due to pain, fatigue, insomnia, and depression (Fann et al., 2012).

The Institute of Medicine (IOM) report *Cancer Care for the Whole Patient* (2008) outlines the deleterious effects of unmet psychosocial needs and identifies the beneficial effects of providing psychosocial services to patients (Adler & Page, 2008; Jacobsen & Wagner, 2012). The IOM report, *Delivering High-Quality Cancer Care* (2013), stresses that patient-centered care include emotional support to relieve fear and anxiety and address mental health issues (Levit, Balogh, Nass, & Ganz, 2013). Distress is identified as the 6th vital sign (Mitchell, 2015). However, the literature suggests that routine screening for distress is not universal across settings (Jacobsen & Wagner, 2012). Without adequate screening, many will suffer silently when effective interventions are available to prevent the negative sequelae of distress. The American College of Surgeons Commission on Cancer (2016), an accrediting body of hospitals, set standards for patient-centered care that requires distress screening and appropriate referral for services. Even so, Jacobsen & Wagner (2012) stress that the wider community of oncology professionals are not yet cognizant of these initiatives for care.

Research has suggested that the use of informatics tools may improve the ability to screen for symptoms including distress (Miller, Mullins, Onukwugha, Golant, & Buzaglo, 2014; Wagner et al., 2015). Although the use of informatics to detect symptoms is growing across settings (Baer et al., 2013; McNeely et al, 2015) there are limited descriptions of self-administered tablets for this purpose in the oncology setting. Ahead of its time, the Cancer Support Community (CSC) created, implemented, and evaluated an innovative tablet based informatics tool for use across the country (Miller et
The Cancer Support Community (CSC) introduced the Cancer Support Source® (CSS) in 2014 as a touch screen tablet designed to screen for psychosocial, physical, and practical distress in the person experiencing cancer. Tested for validity and reliability by the CSC, it is widely implemented across the United States (Miller et al., 2012; Buzaglo, Miller, Gayer, Morris, & Gallant, 2013; Miller et al., 2013; Miller et al., 2014). The 15-item tool screens for multiple types of distress (see Table 1) and a sample of the question format is depicted in Figure 1. The CSS also records demographic and clinical information including disease state, stage, and treatments. The CSC estimates that it takes an average 5-7 minutes to complete the distress screening.

The CSS tool generates a "My Support Care Plan" with an overall distress score along with internet resources and a list of local services related to components of distress identified by the participant (see Figure 2). In addition, the care plan serves as an educational resource that the staff can review with the patient. Ideally, administration of the same tool for follow-up or rescreening could determine changes in distress scores after the participant attended a support group, individual therapy, or other CSC activity. If the participant answers moderate to very seriously (three or above) on any one of the depression items, there is the possibility that the person may be at risk for depression. A red flag will appear on the "Distress Screening Report" and trigger an email to the Program Director (see Figure 3). The screener will discuss the issue with the participant, suggest sharing this information with their healthcare team, and refer the patient for six-free individual sessions with a therapist within CSC, or refer the participant outside the
CSC. The participant can also take a copy of the "Distress Screening Report" to his/her provider. The red flag does not prohibit the participant from attending CSC programs.

In summary, the primary purpose of this quality improvement (QI) project was to implement an innovative informatics tool to standardize distress screening. A secondary outcome was to improve referral to resources for a population of participants who screened positive for distress.

**Quality Improvement Framework: PDSA**

To improve the implementation and evaluation of this project the authors chose to employ a Plan-Do-Study-Act (PDSA) framework (see Figure 4). This framework is an effective method of supporting healthcare organizations to initiate change, reach quality goals, and structure improvement work (Crowl, Sharma, Sorge, & Sorensen, 2015). Three essential questions clarify the purpose of the improvement process, suggest measures to ascertain and evaluate the change, and identify the changes involved in the project (Crowl et al., 2015). These three questions are: A) What are we trying to accomplish? B) How will we know if a change is an improvement? and, C) What changes can we make that will result in improvement? (Crowl et al., 2015).

Initially developed for business and industry; this model has been adapted by healthcare for use in quality improvement projects (Crowl et al., 2015; Riblet et al., 2014; Taylor et al., 2014). The Centers for Medicare and Medicaid Services (CMS) have promoted use of this model "...to reduce the gap between what organizations know about quality improvement and what organizations do to improve quality" (Crowl et al., 2015, p. 366). The PDSA is iterative—it allows for planning the change, implementing the change, observing and studying the results, then acting on what is learned.
Distress Screening in Cancer Patients Using the PDSA Model

The authors provide a roadmap for employing the PDSA model for implementing distress screening in a community cancer setting.

**PLAN:**  The QI project took place at a Cancer Support Community (CSC) affiliate. The CSC is the largest nonprofit network of cancer supportive services worldwide. Participants hear about the CSC through brochures in physician offices, advertisements in local newspapers, and from healthcare professionals. Patients coming to a CSC can participate in support groups, education, and interventions (e.g., yoga, journaling). Licensed marriage and family therapists (MFTs) or licensed social workers (LSWs) lead all support groups. The philosophy of this CSC affiliate is "dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community" (CSC, 2017, p. 1). A CSC team identified the stakeholders to coordinate the training of staff, the piloting of the informatics tool, and the evaluating of the process. One month before initiation of the project, staff received an email to enhance overall support. Appropriate institute review boards provided approval for the project.

**DO:**  All participants interested in joining the CSC, attend an orientation program and an intake interview. Distress screening occurred at the beginning of the interview. Ninety-minutes were allotted for the entire process, and on average, a minimum of one hour was needed. Frequently participants expressed emotions with questions on the tool, and the screener provided support and made appropriate referrals.

Since one goal of this project was to ensure sustainability, staff members (e.g., marriage and family therapy interns and social worker interns) were educated to employ
the screening process. Staff training consisted of observing two screenings and
debriefing sessions. The debriefing sessions provided an opportunity for the author
(NJB) to answer questions, review documentation, and ensure confidentiality. In
addition, the CSC has an internet program for all staff to complete prior to implementing
the screening.

**STUDY:** The "Study" phase of the project analyzed descriptive data including:
1) demographics of the population, 2) distress scores, 3) depression risk scores, and 4)
referrals of high-risk participants. The study phase also included the identification of
revisions related to the screening processes (e.g., time allotment). Most participants were
Caucasian, English speaking, employed full-time, married, or partnered, and college
educated. Although breast cancer was the predominant diagnosis, other diagnoses
included ovarian, endometrial, CNS/brain, lung, prostate, colorectal, and non-melanoma
skin cancer.

Distress scores ranged from 3-51 out of 60; and depression scores ranged from
none at all to 16 out of 16 (see Table 2). Referral for appropriate psychotherapy took
place for two participants identified as severely depressed. Thirteen participants (62%)
answered moderate to very seriously (3 or above) on ONE of the following four
concerns: feeling sad or depressed, feeling nervous or afraid, feeling lonely or isolated,
and feeling too tired to do the things you need or want to do. Identified as ‘at risk for
depression’ these participants received appropriate referrals.

**ACT:** The final "Act" phase identifies future modifications to improve distress
screening. One challenge identified was the lack of ability to ascertain whether
participants actually accessed the appropriate referrals. However, this project represents
an improvement over existing processes for psychosocial care. Future projects may want to consider optimizing communication and collaboration with outside psychosocial agencies. Another challenge recognized was staff buy-in for the screening process. New staff was more receptive to integrating innovative processes than seasoned staff. Clinicians interested in implementing similar quality improvement projects may consider incentivizing senior staff to facilitate innovation implementation.

**DISCUSSION**

The National CSC introduced the CSS program in 2014 as an evidence-based, standardized approach to identify and mitigate psychosocial distress among cancer survivors. This project identified the effectiveness of using the informatics tablet screening tool and the perceived value of the screening process for both participants and interviewers (e.g., the CSS allowed discussion of sensitive topics with participants). Ensuring that supportive services are in place is key for program success. In addition, allocating time for the training of the staff in the screening process may be challenging but vital for program success. Finally, this project demonstrates that meeting psychosocial needs improves patient reported outcomes.

For many participants the screening process allowed an opportunity to discuss sensitive topics. During the screening process, it was essential to tailor the mode of delivery to match the degree of the participant's distress. Similar to Biddle et al. (2016), the authors found that allowing adequate time for the interview process supported distress screening. Although the focus of the screening was to identify distress, all the participants expressed the value of sharing their "cancer journey" in a safe and unhurried manner. The time allotted for the intake interview and distress screening also allowed for
intimate questions to be addressed that may not otherwise be discussed in the customary intake interview or consultation (Brandes, Linn, Smit, & van Weert, 2015).

Sufficient support services and referral guidelines also influence the success of any distress screening program (Biddle et al., 2016). The CSC offers support groups for all participants and individual counseling for participants at risk for depression. In addition, the CSS provides the "My Support Care Plan" which lists vital resources found on the internet and in the community. A referral list of resources ranging from physical, practical, to therapeutic support services was developed prior to initiating the screening program so that all professionals felt confident to refer patients appropriately.

Adequate training of the professionals implementing distress screening is vital to positively influence this endeavor (Brandes et al, 2015). Training clinicians to be comfortable with the intimacy of the questions is imperative. If the clinician feels "out of depth" with certain questions (e.g., “worrying about the future and what lies ahead"), the responses of the participants may be limited (Biddle et al., 2016: p. 64). In addition, training in distress screening should include the importance of allowing sufficient time for this sensitive task.

It is important to consider patient-reported outcomes when evaluating the effectiveness of psychosocial distress screening (Chiang, Amport, Corjulo, Harvey, & McCorkle, 2015; Faller et al., 2016; Fromme et al., 2016). In this project the CSS tool asks, "Did you find this survey to be helpful?" The majority of respondents answered yes to this question (18= yes; 3=no [2 males; 1 female]). Each participant received a minimum of one email or phone call to assess if they had attended a support group or other activities offered by the CSC and/or if those referred for healthcare had accessed
care. In addition, there was the opportunity for participants to be re-screened for distress one month after baseline. Unfortunately, only three participants responded to the email invitations to repeat the screening. This low response rate may suggest patient preferences for face-to-face interactions. Future projects may wish to increase the time between initial screening and follow-up to improve the evaluation of patient reported outcomes.

Limitations of this project include the small number of participants screened and the lack of participants completing a follow-up online screening. However, this project demonstrates the feasibility of implementing a standardized screening process in a community cancer setting. Another limitation relates to the homogenous attributes of the sample. Most were female, educated, and employed outside the home. This clearly does not represent the diversity of cancer survivors across the country. However, this project reveals the extent of depression and psychosocial distress experienced in a community sample of cancer survivors accessing support.

**Conclusion**

Screening for psychosocial distress is a standard for quality care across oncology settings. Nurses are called to implement this important evidence based practice into community settings. Mitigation of psychosocial factors contributing to distress is crucial to improve patient experiences. The PDSA framework proved to be a straightforward approach to guide the implementation and evaluation of CSS distress screening. The project demonstrated that the integration of the CSS screening tool in a community cancer center is both feasible and effective in identifying distress and improving referral to supportive services. The project overcame barriers identified in the literature (e.g.,
lack of time and training (Biddle et al., 2016), and identified the specific needs and concerns of the participants coming to the CSC. The oncology nurse in this project provided leadership and role modeling for the team implementing the distress screening. Oncology nurses serve a pivotal role in improving the life experiences of survivors facing the cancer journey.
References


patients. *Addiction Science and Clinical Practice, 10*(Suppl 1), A38.

http://www.ascpjournal.org/content/10/S1/A38


Table 1.
THE CANCERSUPPORTSOURCE® CONCERNS

<table>
<thead>
<tr>
<th>15 Item Tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling irritable</td>
</tr>
<tr>
<td>Sleep problems</td>
</tr>
<tr>
<td>Changes or disruptions in work, school or home life</td>
</tr>
<tr>
<td>Feeling sad or depressed*</td>
</tr>
<tr>
<td>Pain and/or physical discomfort</td>
</tr>
<tr>
<td>Body image and feelings about how you look</td>
</tr>
<tr>
<td>Feeling nervous or afraid*</td>
</tr>
<tr>
<td>Worrying about the future and what lies ahead</td>
</tr>
<tr>
<td>Making a treatment decision</td>
</tr>
<tr>
<td>Feeling lonely or isolated*</td>
</tr>
<tr>
<td>Health insurance or money worries</td>
</tr>
<tr>
<td>Feeling too tired to do the things you need or want to do*</td>
</tr>
<tr>
<td>Worrying about family, children and/or friends</td>
</tr>
<tr>
<td>Exercising and being physically active</td>
</tr>
<tr>
<td>Finding meaning and purpose in life</td>
</tr>
<tr>
<td>*Risk for depression subscale</td>
</tr>
</tbody>
</table>
FIGURE 1.
SAMPLE QUESTION FORMAT FROM CANCERSUPPORTSOURCE®
FIGURE 2.
MY SUPPORT CARE PLAN

My Support Care Plan

Name: Jane Doe
Date of Birth: 01/01/1990
Date of Survey: 06/19/2014
Your distress score: 28/60

Thank you for completing your CancerSupportSource® Distress Questionnaire. This report has been created for you based on how you answered the questions. It is a guide to finding the information and supportive services that could be most useful to you at this time. The distress items listed are ones that you requested additional information. Please review the helpful tips, print and online materials provided in this report. A staff person will be happy to review this report and assist you in finding supportive resources.

Distress Score History

The following chart shows your distress level grouped by categories.

Psychosocial

Emotions like sadness or depression, anxiety, fear and worry about the future can be a distressing part of living with cancer. While some problems may be mild, others may become more serious and keep you from feeling hopeful or in control of your life. Depression, left untreated, can affect your quality of life and your overall health and well-being. It is important to get the support you need so that you can take better care of yourself. You have reported concerns with the following emotional or social concerns.

Feeling irritable

People with cancer and their family members are often under a great deal of pressure to cope with treatments, side effects, and anxieties that can accompany a diagnosis of cancer. Being irritable is a normal human emotion when we are under stress or not feeling well. Yet, we worry that irritability may push away those we love the most. There are specific things you can do to reduce the irritability of everyday life with cancer.
FIGURE 3.
DISTRESS SCREENING REPORT

Survey Results

<table>
<thead>
<tr>
<th>Concern</th>
<th>Screening 06/19/14</th>
<th>Screening 05/22/14</th>
<th>Action Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep problems</td>
<td>1. Slightly</td>
<td>4. Very Seriously</td>
<td>Information</td>
</tr>
<tr>
<td>Changes or disruptions in work, school or home life</td>
<td>0. Not at all</td>
<td>3. Seriously</td>
<td>No action</td>
</tr>
<tr>
<td>Feeling sad or depressed</td>
<td>4. Very Seriously</td>
<td>4. Very Seriously</td>
<td>Talk</td>
</tr>
<tr>
<td>Pain and/or physical discomfort</td>
<td>1. Slightly</td>
<td>2. Moderately</td>
<td>Information</td>
</tr>
<tr>
<td>Body image and feelings about how you look</td>
<td>0. Not at all</td>
<td>1. Slightly</td>
<td>No action</td>
</tr>
<tr>
<td>Feeling nervous or afraid</td>
<td>3. Seriously</td>
<td>3. Seriously</td>
<td>Information</td>
</tr>
<tr>
<td>Making a treatment decision</td>
<td>2. Moderately</td>
<td>2. Moderately</td>
<td>Information</td>
</tr>
<tr>
<td>Feeling lonely or isolated</td>
<td>4. Very Seriously</td>
<td>3. Seriously</td>
<td>Information, Talk</td>
</tr>
<tr>
<td>Health insurance or money worries</td>
<td>0. Not at all</td>
<td>1. Slightly</td>
<td>No action</td>
</tr>
<tr>
<td>Feeling too tired to do the things you need or want to do</td>
<td>3. Seriously</td>
<td>3. Seriously</td>
<td>Information</td>
</tr>
<tr>
<td>Worrying about family, children and/or friends</td>
<td>2. Moderately</td>
<td>3. Seriously</td>
<td>Information</td>
</tr>
<tr>
<td>Exercising and being physically active</td>
<td>1. Slightly</td>
<td>1. Slightly</td>
<td>Information</td>
</tr>
</tbody>
</table>

Risk for Depression 14/16

- Feeling sad or depressed: 4
- Feeling lonely or isolated: 4
- Feeling too tired to do the things you need or want to do: 3
- Feeling nervous or afraid: 3

Top 5 Concerns

- Feeling sad or depressed: 4
- Feeling lonely or isolated: 4
- Finding meaning and purpose in life: 3
- Feeling too tired to do the things you need or want to do: 3
- Feeling nervous or afraid: 3

Staff Requests

<table>
<thead>
<tr>
<th>Feeling lonely or isolated</th>
<th>Feeling sad or depressed</th>
<th>Worrying about the future and what lies ahead</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling lonely or isolated</td>
<td>Feeling sad or depressed</td>
<td>Worrying about the future and what lies ahead</td>
</tr>
</tbody>
</table>

Graph showing trends from 05/22/2014 to 06/19/2014.
FIGURE 4.
MODEL FOR IMPROVEMENT

Retrieved from: http://www.ihi.org/resources/Pages/HowtoImprove/default.aspx
## TABLE 2.
DISTRESS AND DEPRESSION SCORES

<table>
<thead>
<tr>
<th>Distress Scores/ 60 total points= distress</th>
<th>N= 21</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-15=</td>
<td>7</td>
</tr>
<tr>
<td>16-30=</td>
<td>8</td>
</tr>
<tr>
<td>31-45=</td>
<td>4</td>
</tr>
<tr>
<td>46-60=</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Depression Scores/ 16 total points= depression</th>
<th>N= 21</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-4=</td>
<td>7</td>
</tr>
<tr>
<td>5-8=</td>
<td>9</td>
</tr>
<tr>
<td>9-12=</td>
<td>2</td>
</tr>
<tr>
<td>13-16=</td>
<td>2</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
</tr>
</tbody>
</table>
AUTHOR GUIDELINES FOR CJON

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The mission of the Clinical Journal of Oncology Nursing (CJON) is to (a) provide practical information necessary to care for patients and their families across the cancer continuum and (b) to develop the publication skills of oncology nurses. Articles are to be clear, concise yet comprehensive, and well referenced; they should provide practical information, implications for practice, and identify patient education resources, if appropriate. Articles focused on treatments that have not yet received U.S. Food and Drug Administration (FDA) approval will not be accepted unless under review by the FDA; if accepted, articles will be held and published at the time of approval.

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- Background
- Objectives
- Methods
- Findings

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**Implications for Practice:** Provide three concise implications for nursing practice and patient education as reported in the article.

**Case Studies:** Authors are encouraged to include case studies as appropriate to better showcase real-world application of the article's content to readers.

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- **Figures:** Figures should be professionally drawn or computer generated and included on separate pages at the end of the manuscript.
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**References:** The reference list (not a bibliography) must be typed and double spaced and follow APA format (in text and reference list). Use APA's recommended formats for electronic references. Authors are responsible for the accuracy of all reference citations and are expected to have read and verified all of the listed references.

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