

The University of San Francisco

USF Scholarship: a digital repository @ Gleeson Library | Geschke Center

DNP Qualifying Manuscripts

School of Nursing and Health Professions

Summer 8-9-2021

Distress Evaluation during Chemotherapy: The Real-time Assessment Strategies for Oncology Nurses among Asian Population in Outpatient Clinics

Ying Huang

University of San Francisco, yingpsu@gmail.com

Follow this and additional works at: https://repository.usfca.edu/dnp_qualifying



Part of the [Palliative Nursing Commons](#), and the [Psychiatric and Mental Health Nursing Commons](#)

Recommended Citation

Huang, Ying, "Distress Evaluation during Chemotherapy: The Real-time Assessment Strategies for Oncology Nurses among Asian Population in Outpatient Clinics" (2021). *DNP Qualifying Manuscripts*. 54. https://repository.usfca.edu/dnp_qualifying/54

This Manuscript is brought to you for free and open access by the School of Nursing and Health Professions at USF Scholarship: a digital repository @ Gleeson Library | Geschke Center. It has been accepted for inclusion in DNP Qualifying Manuscripts by an authorized administrator of USF Scholarship: a digital repository @ Gleeson Library | Geschke Center. For more information, please contact repository@usfca.edu.

**Distress Evaluation during Chemotherapy: The Real-time Assessment Strategies
for Oncology Nurses among Asian Population in Outpatient Clinics**

Ying Huang, MSN, RN

Nancy Selix, DNP, FNP-C, CNM

Cynthia Huff, DNP, MSN, RN, OCN, CRNI, CNL

Ying Huang, MSN, is a doctoral candidate in the School of Nursing and Health Professions at University of San Francisco; Nancy Selix, DNP, FNP, CNM is an associate professor in the School of Nursing and Health Professions at University of San Francisco; Cynthia Huff is an assistant professor in the School of Nursing and Health Professions at University of San Francisco. Huang can be reached at ying.x.huang@kp.org, with a copy to CJONEditor@ons.org (Submitted August 9th, 2021.) The authors take full responsibility for this content. This work was supported by a quality improvement project grant from the Kaiser Permanente Medical Group. The article has been reviewed by independent peer reviewers to ensure that it is objective and free from bias.

Abstract

Background: Routine oncology visits failed to identify 50-94% of patient's distress, which creates a considerable burden, impairs emotional well-being, and reduces patients' quality of life. Limited in-person visits during the COVID-19 pandemic have reduced access to care for many patients, further adding to their emotional distress. Untreated distress also leads to elevated stress levels, systemic inflammation, non-compliance with treatment, and higher mortality rates. Early distress screening and multidisciplinary care are recommended to reduce the impacts of distress.

Objectives: To identify the best outpatient practices to address newly diagnosed cancer patients' unique needs due to distress.

Methods: Databases searched including CINAHL® Complete, Joanna Briggs Institute EBP Database, APA PsycINFO®, PubMed, and Cochrane Database of Systematic Reviews. Studies had to be written in English or Chinese, published in a peer-reviewed journal, and included individuals aged 18 years or older. The initial search yielded 371 articles.

Findings: Research highlighted the need to assess patients' pre-existing life events, culture, beliefs, and other personal characteristics for optimal distress management. The screening should identify high-risk patients and provide early intervention. Investing in telehealth practice and psycho-oncology education is more cost-effective compared to face-to-face interventions.

Keywords: distress, anxiety or depression, telehealth, screening, management, Asian, psycho-oncology

Implications for Practice:

1. Distress screening protocol should consider the workflow and environment barriers of the oncology clinics.
2. Training in psychological counseling and brief intervention is needed to identify distress in patients and their families.
3. Investing in telehealth best practice and cultural differences guidelines may be helpful for oncology providers.

Distress Evaluation during Chemotherapy: The Real-time Assessment Strategies for Oncology Nurses among Asian Population in Outpatient Clinics

Cancer is a major public health problem and is the second leading cause of death in the United States (National Center for Chronic Disease Prevention and Health Promotion, 2020). In 2021, there will be approximately 1.9 million cancer patients diagnosed, which is equivalent to 5200 new patients each day (Siegel et al., 2021). By 2040, the number of Asian cancer patients will increase by 59.2% with a total number of 15.1 million (International Agency for Research on Cancer, n.d.). Being diagnosed with cancer and treated with chemotherapy is emotionally demanding, and it often imposes significant distress such as anxiety and depression. Previous data showed that 23-46% of cancer patients experience distress (Bártolo et al., 2017; Shin et al., 2020). Studies showed a higher rate of cancer distress in the Asian population than the other ethnicities (Chan et al., 2018). For patients and their families, distress happens not only at the early stage of cancer but also at advanced stages. Even individuals who survive cancer experience distress because of facing uncertainty, fear of recurrences or death, considerations of family, and return-to-work issues. Higher distress levels were reported in patients who were female, 30 to 69 years of age, recently diagnosed, and diagnosed with pancreatic or lung cancer (Carlson et al., 2018).

Distress has a significant impact on the health of cancer patients and their treatments. It is defined as a psychological, social, spiritual, and physically unpleasant experience that may interfere with a cancer patient's physical symptoms, coping ability, and treatment outcomes (National Comprehensive Cancer Network [NCCN], 2021). Distress creates a considerable burden, impairs emotional well-being, and reduces a patient's quality of life. Untreated distress also leads to elevated stress levels, systemic inflammation, non-compliance with treatment, and

higher mortality rates (Bártolo et al., 2017; Granek et al., 2018). To improve distress management, the NCCN (2021) recommends multidisciplinary care in oncology settings, including routine screening, patient education, medication, treating related cancer symptoms, referral to mental health professionals, social work counseling services, and chaplaincy if necessary.

The emotional effect and psychological response during the COVID-19 pandemic have drawn increasing attention from oncology providers. The need for the identification of institutional practices that may facilitate the quality treatment of cancer patients has been highlighted (Helm et al., 2020). However, there are limited guidelines on best practices for treating cancer patients during a pandemic. For example, how do providers help patients understand their health conditions without in-person visits and chemotherapy treatments available; how do providers encourage patients to share their worries, values, and priorities; how to address the needs of patients from different cultural and ethnicity background; and how do providers facilitate patients in palliative/survivorship decision making? Due to limited in-person encounters, investing in telehealth best practice guidelines and psycho-oncology education may be helpful for oncology providers and patients during these unprecedented times. This review aims to identify evidence-based practice strategies that address the unique emotional needs of Asian patients experiencing cancer-related distress.

Search Strategy

A comprehensive literature review was performed to evaluate current distress screening, telehealth practices, and their effects on distress in oncology patients. Relevant articles were searched in electronic databases including CINAHL® Complete, Joanna Briggs Institute EBP Database, APA PsycINFO®, PubMed, and Cochrane Database of Systematic Reviews. The

search was limited to articles published from 2015 through 2021. The following keywords and their combinations were used: *distress, anxiety or depression, telehealth, screening, management, Asian, and psycho-oncology*. To be included in the review, studies had to be written in English or Chinese, published in a peer-reviewed journal, conducted in outpatient settings, and included individuals aged 18 years or older. Specific journals including *Clinical Journal of Oncology Nursing, Oncology Nursing Forum*, and ancestry searches were also conducted. There were 371 articles obtained from the initial search. Ten articles selected in this review include quantitative and qualitative research studies, clinical practice guidelines, systematic review, meta-analysis, and meta-synthesis.

Theoretical Framework

The concept of psychological distress (Ridner, 2004) and The Supportive Care Framework for Cancer Care (Fitch, 2008) are utilized to guide the current review of evidence. Based on these frameworks, a single conceptual framework: Indicators of distress in cancer patients, was developed to guide the distress screening and management for cancer patients (see Appendix A).

Psychological distress is often seen in nursing, medical, psychological, and social sciences. Ridner (2001) conducted a concept analysis to define the five antecedents, five attributes, and consequences of psychological distress. The antecedents of distress are: a living, conscious, biopsychosocial being; stress or unmet needs; personal threat; loss of control; and ineffective coping. The attributes of distress are: perceived inability to cope effectively, change in emotional status, discomfort, communication of discomfort, and harm. Psychological distress may be viewed as a continuum of consequences from negative to positive. The results of psychological distress may be permanent damage, temporary harm, or personal growth.

Permanent damage may be suicide, the release of catecholamines, hypertension, myocardial infarction, poor response to treatments provided, and so on. If the distress is removed in time, patients may return to baseline functioning. As for personal growth, an individual can find meaning in life, realize personal values, and accomplish personal goals.

The Supportive Care Framework for Cancer Care was first introduced by Fitch in 1994. This conceptual framework was designed for cancer care professionals and program managers to understand cancer patients' needs and plan for comprehensive cancer care. This framework has been utilized in program and policy planning. The concepts within the framework have been validated in numerous studies from patients' and cancer providers' perspectives (Fitch, 2008). The Supportive Care Framework for Cancer Care builds on the constructs of human needs, cognitive appraisal, coping, and adaptation as a basis for understanding how human beings experience and deal with cancer. The framework describes the changing needs of individuals in physical, emotional, psychological, social, spiritual, informational, and practical dimensions. The needs vary from person to person. As the disease or treatment changes over time, the needs or their impacts, also change within the same person throughout the illness. Supportive care is provided at all stages in the cancer journey which includes cancer screening, pre-diagnosis, diagnosis, treatments to palliative care and terminal care (Fitch, 2008).

This review combines and utilizes the core concepts of the two frameworks to help understand cancer-related distress in newly diagnosed patients in the Asian population. The measurement variables are the changes in the physical, emotional, spiritual, cognitive, behavioral, environmental, and practical status of patients. The consequences of distress are used to guide the development of management strategies.

Literature Review

The literature included in this review were evaluated using the Johns Hopkins Nursing Evidence-Based Practice (JHNEBP) appraisal tools from the JHNEBP model and guidelines (Dang & Dearholt, 2018). These tools grade the research and non-research evidence into five levels and three quality standards that include high, good, low, or major flaws. Level I is the highest level (e.g., RCTs, systematic review of RCTs), which represents unbiased procedures and has less risk of systematic errors. The author systematically went through checklists of the appraisal tools for each piece of evidence and rated the level of evidence for the studies. The JHNEBP appraisal tools provide a trustworthy guide for the interpretation and application of study results. This review included quantitative, qualitative, longitudinal, clinical guidelines, and systematic review studies with high/good quality. Screening distress for new cancer patients, training staff on cultural and psychosocial management skills, and facilitate distress management among the oncology teams are well supported by the current evidence.

Understanding Distress in Cancer Patients

Distress is a multi-dimensional experience. Qualitative investigators revealed that patients and families use several words to describe distress. In a review by Carolan et al. (2015), distress caused by disbelief during diagnosis was interpreted as “acute anxiety” in patients. Caregivers described patients who are distress as a “bit depressed”. Delirium is perceived as a cause of distress in both patients and families. Among patients with advanced cancer, distress complicates the communication within the families and with health providers. Both patients and families have difficulty in telling others about their distress, and they also experience distress in any communication interaction. Withholding such discussions with an individual’s support group

may add to the distress and reduce emotional well-being and ultimately adversely affect outcomes.

In addition to the NCCN's definition as an individual experience, Carolan et al. (2015) suggest that distress is also a two-way interaction shared experience within the family. Such distress within the family is influenced by relational functioning, common negative dyadic coping, dyadic adjustment, family support, family hardiness, and communication practice. Unstable relationships resulted in greater distress among the families. If the distress is present within a family, assessing both patients and family members, using the same tools, to ensure that a consistent and corresponding investigation of the phenomenon is recommended (Carolan et al., 2015)

The selected studies showed a higher rate of cancer distress in the Asian population than the other ethnicities. Chan et al. (2018) used a longitudinal design to evaluate distress in Asian adolescent and young adult (AYA) patients living in Singapore at the time of cancer diagnosis, again at one and six months after the initial diagnosis. The results showed that 43.1 % of patients experienced distress (Distress Thermometer score >4) at the time of cancer diagnosis. That is, approximately one in two Asian patients experience clinically significant distress. The percentage of distressed patients went up to 47.7% one month after the diagnosis and the number reduced to 27.7% six months later.

For patients with untreated distress, the distress scores were associated with physical and psychological symptom burden. For example, patients experienced dizziness and loss of hair at the time of diagnosis; and symptoms of nausea, sore muscles, dry mouth, low back pain, headache, sore mouth, and fatigue at 1 month after diagnosis. The psychological symptom burden was worry and depressed mood at the time of diagnosis, including nervousness, and

despair about the future at one month later; and the depressed mood and worry six months after the diagnosis (Chan et al., 2018; McMullen et al., 2018). These findings suggest the need for early recognition of distress among cancer patients to address their needs.

Many problems were associated with a higher level of distress among Asian patients. Work and school, financial and insurance issues, fears, nervousness, and worry contributed largely to patients' distress (Chan et al., 2018). While these problems are usually considered normal emotions and common cancer-related issues among clinicians, the problems may lead to severe psychological disorders such as anxiety and depression if left untreated. To avoid the unrecognized and untreated distress, more staff training is needed to distinguish the normal emotions and persistent distress that cause anxiety and depression in cancer patients.

Understanding individual characteristics of patients who suffered from persistent distress may be helpful for clinicians to engage sooner in those exhibiting higher-risk behaviors. Lam et al. (2016) used grounded theory to interview 42 Cantonese- and Mandarin-speaking women with locally advanced or metastatic breast cancer. The researchers found different underpinnings of persistent and transient distress. Women with persistent distress had been living through an ongoing life crisis. They tended to misinterpret some physical symptoms as a sign of cancer recurrence or progression. They forced themselves not to think about cancer and avoid situations that reminded them about their illness. Maladaptive rumination and thought suppression were common responses to cancer in these women. The patients' or families' fears of stigmatization and discrimination are common, and this demoralization further isolates these women from valuable social and other supportive resources. Furthermore, women with persistent distress avoided peer support to minimize activating the anxiety. Peer social support in these patients should be introduced and evaluated early to facilitate adaptation.

Other factors such as treatment experience, duration of chemotherapy, and household income are key predictors of distress (McMullen et al., 2018). Different from common perception, the disease and treatment factors, such as the type of cancer, treatment intent, emetogenicity of the treatment regimen, and combined chemo-radiotherapy had no significant impact on distress. Additionally, socio-economic and demographic characteristics such as employment status, receipt of government benefits, and relocation from a rural to an urban locality during treatment were not associated with levels of distress (McMullen et al., 2018).

Distress Screening and Referrals

Multiple distress screening and measurement tools were identified in this review. Generally, telephone-based distress screening services were available in outpatients and community clinics. Eight screening tools were reported in the studies. The National Comprehensive Cancer Network Distress Thermometer (DT) was the most used tool, followed by the Hospital Anxiety and Depression Scale (HADS). Other tools are the Impact of Event Scale (IES), Distress Impact Thermometer (DIT), Edmonton Symptom Assessment Scale (ESAS), Decision Conflict Scale (DCS), and Problem list (PL) (Chan et al., 2018; Taylor et al., 2020; Urech et al., 2018). These measurements capture different attributes of distress (see Appendix B). Although the validity and reliability of these tools were reported in the face-to-face encounters, the validity or acceptability of the screening tools in telephone administration was unclear.

The characteristics of distress measurement timepoints were discussed in Taylor et al.'s study (2020). The frequency of screening varied from not specified, one time only, weekly then monthly, quarterly, within certain days of diagnosis or treatment, pre-treatment, one-month post-diagnosis, 90 days post-discharge, or repeated twice as the follow-up. The distress screening and

supportive care referral protocols varied from different studies. In the review by Taylor et al. (2020), two studies provided supportive care referrals after the one-time screening. Seven studies completed a second assessment before referrals. Four studies repeated screening over time for unremitting or escalating distress. Patients with ovarian cancer, prostate cancer, or at palliative and advanced stages were able to access additional screening and referral support.

Distress referral procedures are based on DT scores. Services typically used a cut-point of four or more to trigger referrals. The NCCN guidelines (Riba et al., 2019) emphasize stepped and tiered models of care to refer patients based on their distress severity. This ensures patients can receive low-intensity care and progress to higher intensity care as needed. Taylor et al. (2020) also pointed out that for higher intensity distress, additional rescreening or ongoing screening is needed.

Indicators of Patients with Distress

During each chemotherapy session, nurses may observe some emotional, behavioral, and verbal indicators as signs of distress (see Table 1). The study of Granek et al. (2019) suggested that the most obvious indicators are the emotional symptoms of depression. These symptoms include the inability to experience pleasure, apathy and withdrawal, feeling or showing extreme discouragement, sadness, hopelessness and helplessness, or sometimes patients are not showing any facial expressions of emotion. Patients may also show irritability, anger, or even aggression toward the health providers. Fear and anxiety were also considered as potential signs of distress. Patients usually experience increasing anxiety at the time of diagnosis, disease prognosis, no response to treatments, and when facing uncertainty, death and dying. Nurses may notice some patients become “silent” with intrusive thoughts, uncooperative, and have trouble sleeping.

When patients appeared to avoid conversation about their condition, it could be a form of avoidance and depersonalization.

Granek et al. (2019) also gave examples of behavioral indicators include crying while talking with nurses or receiving chemotherapy. If a patient looked neglecting personal hygiene, not involving activities of daily living, eating less, appeared to be lonely without any social support, they are at high risk of distress. Patients may verbalize their distress explicitly. They will have statements such as: “I am tired of this.”, “I don’t want to live anymore.”, “I don’t want to suffer and live-in pain.” etc. Patients’ family members or caregivers often report to nurses that the patient looks depressed, asking about antidepressants or how to help with patient’s distress (Granek et al., 2019). Real-time reporting and direct communication with patients could lead to improved distress management that would allow patients to return to their daily lives more quickly after experiencing distress.

Table 1***Signs of Distress in Cancer Patients during Chemotherapy***

Change Status	Signs and Symptoms
Physical, Emotional and Spiritual	Change in physical appearance, fear, guilt, grief, less cooperative, depression, anger and irritation, hopelessness, anxiety, emotional incongruity with the situation, spiritual crisis, difficulty sleeping, feeling sad, worrying, nervous
Cognitive and Behavioral	Perceived inability to cope, social isolation, silence, self-blame, burst out, attack providers, avoidance or disengagement coping, depersonalization, cry, change in daily routine, desire to act against medical advice, suicide, dependence on others to make decisions
Verbal	Scream, communication of discomfort, ask for help, family inquiry about mental health issues
Environmental and Practical	Transfer to the hospital or emergency department from clinic, family crisis, work-related issues, financial burden, legal issues

Cancer-related Distress in Asian Culture

Understanding the different cultural implications can help nurses interpret the distress more accurately. Chinese Confucianism favors emotional suppression and control, Taoist ethics forbear problems while maintaining inner harmony (Spencer et al., 2010). Asians are relatively shy and non-expressive with regards to their psychological feelings (Sun et al., 2021). Also, mental health issues are usually taboo among Asian decedents. Asian Americans understand psychological disorders as signs of weakness or craziness. They feel shame and embarrass even when struggling with mental health issues. Most of them keep silent and never seek for help (Spencer et al., 2010).

Asian culture typically highlights the community and forbearance. Because of stigmas, many Asian individuals are reluctant to mention their cancer, depression, anxiety and distress because there are many stigmas. They are afraid of being alienated in their community because of their diseases. Instead of contacting mental health professionals, most Asians reached out to friends, relatives, and church members for support. If an Asian individual is constantly asking a medical doctor to address a racing heartbeat, insomnia, or headaches, the psychiatric disorder might be the cause since these symptoms carry no shame of admitting to anxiety, depression, or addiction (Spencer et al., 2010). The assumption of mainstream psychotherapy like “Talk or speak out with mental health professionals” may not be applicable in the Asian community.

Understand a patient’s cultural background and remove any assumptions can reduce barriers and facilitate distress management. Asian individuals may prefer to deal with emotions by doing things, such as sports or academics. The study of Hoang et al. (2020) stated that Chinese breast cancer patients are more likely to adopt avoidance coping when facing distress. Hoang’s study showed that immigrant Chinese American cancer survivors are more reluctant to

express their concerns to family and friends due to a concern of burdening them or shame and stigma. Distancing coping may be a helpful way of reducing psychological distress in patients with high levels of concern regarding their disease and prognosis. It is thus important to provide appropriate resources and care for survivors both in pre- and post-treatment phases, such as encouraging this population to seek social support to attend to their mental health needs (Hoang et al., 2020).

Effective Distress Communications with Asian Patients

The increasing cultural, racial, and ethnic diversity of the patient population in the United States encourage nurses to identify ways to promote effective cross-cultural communication. When communicating with someone whose cultural background differs from one's own, nurses might have difficulties in understanding and correctly interpreting the patient's information. Nurses may also use social categorization and bias in their decision-making processes without proper training (Granek et al., 2020). Understanding cancer patients' communication-related experiences, preferences, and perspectives can lead to improved reporting of symptoms and improved care. Quality culturally sensitive communication between patients and nurses reduces the patient burden and enhances patient satisfaction. This is of greater relevance during the COVID-19 pandemic with the increased use of telehealth (Carrasco, 2021).

Clinical Implications

The evidence of this review suggests that current distress screening and management protocols have limited alignment with the evidence-based guidelines. Telehealth psycho-oncology education is more cost-effective compared to face-to-face interventions. The development of a distress screening protocol should consider the workflow and environment barriers of oncology clinics. The NCCN Distress Thermometer is a feasible unidimensional

screening tool for quick screening in outpatient settings. There is a need to provide low-intensity psychological counseling training for clinicians so they can better serve as brief intervention counselors or therapists to resolve patients' immediate issues.

To identify those receiving chemotherapy potentially at-risk of chronic distress, the clinician should further assess pre-existing/competing life stress, personal characteristics (e.g., culture, beliefs, and endurance) of cancer patients and their families, as well as other factors that could potentially affect distress levels. It is important to provide psychological counseling training for clinicians for brief interventions so they can meet patient needs for counseling and distress management.

Understanding cultural beliefs about cancer and culture-specific ways of coping that influence racial/ethnic communities can help address the disparity in health services, as well as increase patients' accessibility to cancer screenings and treatments. Public information efforts to increase awareness of the mental illness and fight stigma are encouraging people of all backgrounds to speak up and ask for help.

Conclusions

Identifying emotional distress among patients with cancer is only the first step to providing holistic psychosocial care and diminishing the mental health treatment gap. Attention can be given to implementing training models that help nurses improve their communication skills in general and their recognition of potentially treatable anxiety and depression. Referral to specialized mental health care should be offered to patients for whom an increased risk is identified. This stepped care can ensure the delivery of evidence-based psychotherapy and psychopharmacology treatment to cancer patients with emotional distress.

References

- Bártolo, A., Pacheco, E., Rodrigues, F., Pereira, A., Monteiro, S., & Santos, I.M. (2017). Effectiveness of psycho-educational interventions with telecommunication technologies on emotional distress and quality of life of adult cancer patients: A systematic review. *Disability and Rehabilitation*. <http://doi.org/10.1080/09638288.2017.1411534>
- Carlson, L.E., Zelinski, E.L., Toivonen, K.I., Sundstrom, L., Jobin, C.T., Damaskos, P., & Zebrack, B. (2018). Prevalence of psychosocial distress in cancer patients across 55 North American cancer centers. *Journal of Psychosocial Oncology*, 37(1), 5-21. <http://doi.org/10.1080/07347332.2018.1521490>
- Carolan, C.M., Smith, A., & Forbat, L. (2015). Conceptualising psychological distress in families in palliative care: Findings from a systematic review. *Palliative Medicine*, 29(7), 605-632. <http://doi.org/10.1177/0269216315575680>
- Chan, A., Poon, E., Goh, W.L., Gan, Y., Tan, C.J., Yeo, K., Chua, A., Chee, M., Law, Y.C., Somasundaram, N., Kanesvaran, R., Ng, Q.S., Tham, C.K., Toh, C.K., Lim, S.T., Tao, M., Tang, T., Quek, R., & Farid, M. (2018). Assessment of psychological distress among Asian adolescents and young adults (AYA) cancer patients using the distress thermometer: A prospective, longitudinal study. *Supportive Cancer in Cancer*, 26(9), 3257-3266. <http://doi.org/10.1007/s00520-018-4189-y>
- Carrasco, S. (2021). Patients' communication preferences around cancer symptom reporting during cancer treatment: A phenomenological study. *Journal of the Advanced Practitioner in Oncology*, 12(4), 364-372. <https://doi.org/10.6004/jadpro.2021.12.4.2>
- Dang, D., & Dearholt, S.L. (2018). *Johns Hopkins nursing evidence-based practice: Model and guidelines*. (3rd ed.) Sigma Theta Tau International.

Fitch, M. (2008). Supportive care framework. *Canadian Oncology Nursing Journal*, 18(1), 6-14.

<http://doi.org/10.5737/1181912x181614>

Granek, L., Nakash, O., Ariad, S., & Shapira, S. Ben-David, M. (2019). Mental health distress:

Oncology nurses' strategies and barriers in identifying distress in patients with cancer.

Clinical Journal of Oncology Nursing, 23(1), 43-51. [http://doi.org/10.1188/19.CJON.43-](http://doi.org/10.1188/19.CJON.43-51)

[51](http://doi.org/10.1188/19.CJON.43-51)

Granek, L., Nakash, O., Ariad, S., Shapira, S., & Ben-David, M. A. (2020). The role of

culture/ethnicity in communicating with cancer patients about mental health distress and

suicidality. *Culture, Medicine & Psychiatry*, 44(2), 214-229. Retrieved from

<https://doi.org/10.1007/s11013-019-09650-9>

Granek, L., Nakash, O., Ben-David, M., Shapira, S., & Ariad, S. (2018). Oncologists' treatment

responses to mental health distress in their cancer patients. *Qualitative Health Research*,

28(11), 1735-1745. <http://doi.org/10.1177/1049732318786479>

Helm, E.E, Kempinski, K.A., & Galantino, M.L.A. (2020). Effect of disrupted rehabilitation

services on distress and quality of life in breast cancer survivors during the COVID-19

pandemic. *Rehabilitation Oncology*, 38(4), 153-158.

<https://doi.org/10.1097/01.REO.00000000000000233>

Hoang, T. M., Shin, L. J., Xu, S., & Lu, Q. (2020). Coping with breast cancer among immigrant

Chinese Americans. *Asian American Journal of Psychology*, 11(2), 108-116.

<http://dx.doi.org/10.1037/aap0000175>

International Agency for Research on Cancer. (n.d.). *Cancer Tomorrow*. World Health

Organization. <https://gco.iarc.fr/tomorrow/en/dataviz/bars?mode=population>

Lam, W.W.T., Yoon, S.W., Sze, W.K., Ng, W.Y., Soong, I., Kwong, A., Suen, D., Tsang, J., Yeo, W., Wong, K.Y., & Fielding, R. (2016). Comparing the meaning of living with advanced breast cancer between women resilient to distress and women with persistent distress: A qualitative study. *Psycho-Oncology*, 26(2), 255-261.

<http://doi.org/10.1002/pon.4116>

McMullen, M., Lau, P.K.H., Taylor, S., McTigue, J., Cook, A., Bamblett, M., Hasani, A., & Johnson, C.E. (2018). Factors associated with psychological distress amongst outpatient chemotherapy patients: An analysis of depression, anxiety and stress using the DASS-21. *Applied Nursing Research*, 40, 45-50. <https://doi.org/10.1016/j.apnr.2017.12.002>

National Center for Chronic Disease Prevention and Health Promotion. (2020, December 16). *Cancer*. Centers for Disease Control and Prevention.

<https://www.cdc.gov/chronicdisease/resources/publications/factsheets/cancer.htm>

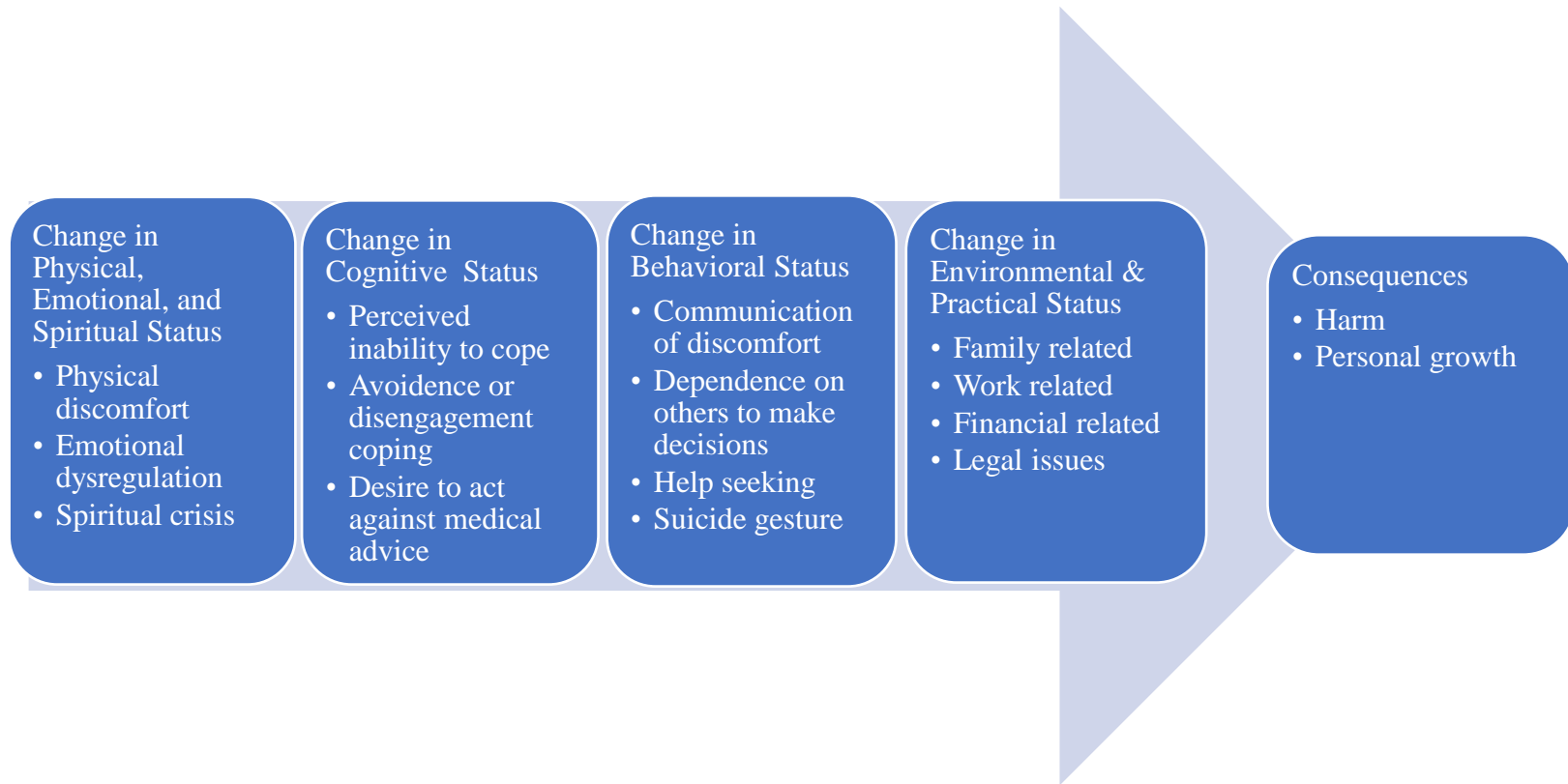
National Comprehensive Cancer Network. (2021, January 5). *NCCN clinical practice guidelines in oncology (NCCN Guidelines): Distress management Version 2.2021*. National Comprehensive Cancer Network.

https://www.nccn.org/professionals/physician_gls/pdf/distress.pdf

Riba, M. B., Donovan, K. A., Andersen, B., Braun, I., Breitbart, W. S., Brewer, B. W., Buchmann, L. O., Clark, M.M., Collins, M., Corbett, C., Fleishman, S., Garcia, S., Greenberg, D.B., Handzo, R.F., Hoofring, L., Huang, C., Lally, R., Martin, S., McGuffey, L., ... & Darlow, S.D. (2019). Distress management, version 3.2019. NCCN clinical practice guidelines in oncology. *Journal of the National Comprehensive Cancer Network*, 17(10), 1229-1249. <https://doi.org/10.6004/jnccn.2019.0048>

- Ridner, S.H. (2001). Psychological distress: Concept analysis. *Journal of Advanced Nursing*, 45(5), 536-545. <http://doi.org/10.1046/j.1365-2648.2003.02938.x>
- Shin, H., Bartlett, R., & De Gagne, J.C. (2020). Integrative literature review on psychological distress and coping strategies among survivors of adolescent cancer. *Oncology Nursing Forum*, 47(5), E131-E148. <http://doi.org/10.1188/20.ONF.E131-E148>
- Siegel, R.L., Miller, K.D., Fuchs, H.E., & Jernal, A. (2021). Cancer statistics, 2021. *CA: A Cancer Journal for Clinicians*. <https://doi.org/10.3322/caac.21654>
- Spencer, M. S., Chen, J., Gee, G. C., Faboam, C. G., & Takeuchi, D. (2010). Discrimination and mental health-related service use in a national study of Asian Americans. *American Journal of Public Health*, 100, 2410-2417. <http://doi.org/10.2105/AJPH.2009.176321>
- Sun, H., Thapa, S., Wang, B., Fu, X., & Yu, S. (2021). A systematic review and meta-analysis of the distress thermometer for screening distress in Asian patients with cancer. *Journal of Clinical Psychology in Medical Settings*, 28, 212-220. <https://doi.org/10.1007/s10880-020-09705-9>
- Taylor, J., Fradgley, E. A., Clinton-McHarg, T., Roach, D., & Paul, C. L. (2020). Distress screening and supportive care referrals used by telephone-based health services: A systematic review. *Supportive Care in Cancer*, 28(5), 2059-2069. <http://doi.org/10.1007/s00520-019-05252-8>
- Urech, C., Grossert, A., Alder, J., Scherer, S., Handschin, B., Kasenda, B., Borislavova, B., Degen, S., Erb, J., Faessler, A., Gattlen, L., Schibli, S., Werndli, C., Gaab, J., Berger, T., Zumbrunn, T., & Hess, V. (2018). Web-based stress management for newly diagnosed patients with cancer (STREAM): A randomized, wait-list controlled intervention study. *Journal of Clinical Oncology*, 36(8), 780-788. <http://doi.org/10.1200/JCO.2017.74.8491>

Appendix A Conceptual Framework: Indicators of Distress in Cancer Patients



Appendix B Comparison of Different Distress Screening Tools

Table 1

Distress Screening Tools

Measurement	Feature	Advantages	Limitations
Distress Thermometer (DT) ^a	Originally invented to screen for distress among cancer patients. A thermometer-shaped scale ranging from 0 (no distress) to 10 (extreme distress), and patients were asked to pick a score based on their distress over the past 7 days. It is recommended that the appropriate cut-of value for the DT was 3, 4 or 5.	A self-report questionnaire that can be completed in 10 min by patients, is a simple and practical screening tool for all health care institutions. It is a brevity, ease, and less stigmatizing format. This instrument is the National Comprehensive Cancer Network (NCCN) recommended screening tool.	DT is poor at identifying individuals without psychological morbidity, it has a high degree of false positives.
Hospital Anxiety and Depression Scale (HADS) ^b	The HADS is the criterion measure for defining anxiety, depression, and comorbid anxiety–depression, including the 7-item HADS-A and 7-item HADS-D. For each item, participants are asked to choose one of four options that best reflects how they felt in the past week. Scoring 15 or higher should be referred for further psychiatric assessment and treatment by mental health professionals	Has been validated against standardized psychiatric interviews, cancer patients and their caregivers.	Not able to identify patients and partners with a psychiatric disorder
Impact of Event Scale (IES) ^c	The most widely used measures of event-specific distress, was developed to assess the impact of traumatic life events. The IES is composed of 15 items and has two subscales that assess the frequency of intrusive and avoidant cognitions	Measures both frequency and severity of distress	Being diagnosed or treated for cancer without experiencing concurrent adverse events is not sufficient to merit a diagnosis of PTSD.

Measurement	Feature	Advantages	Limitations
	associated with a specific stressor. Subjects respond using a four-point scale, ranging from ‘not at all’ to ‘often’, regarding how often they experienced specific symptoms during the past week.		
Distress Impact Thermometer (DIT) ^d	The DIT is a 1-item questionnaire with an 11-point Likert scale that has the same thermometer-like format as the Distress Thermometer. Scores range from 0 to 10, and higher scores indicate less favorable status. Screening for adjustment disorders and major depression (with suicidal ideation) in cancer patients.	Includes questions about the “distress” and the “impact” of distress on daily life activity. The combination of the IT with the DT showed higher specificity with preserved sensitivity in the screening of clinically significant psychological distress than using the DT alone.	
Edmonton Symptom Assessment Scale (EASA) ^e	ESAS was initially developed as a clinical tool to document the symptom burden in patients with advanced cancer admitted to a palliative care unit. Most versions of ESAS include 7 physical symptoms (pain, fatigue, nausea, drowsiness, appetite, shortness of breath, appetite, sleep), 2 emotional symptoms (depression, anxiety) and one global item (well-being). ESAS scores of 0, 1–3, 4–6 and 7–10 is generally considered as none, mild, moderate, and severe in clinical practice	A simple and useful method for the regular assessment of symptom distress. The assessment of multiple symptoms at the same time has allowed researchers to gain insights into symptom clusters. The American College of Surgeons Commission on Cancer mandates distress screening as a criterion for accreditation. ESAS has been proposed as tool for such purpose. Has been validated by multiple groups, translated into over 20 languages, and adopted in both clinical practice and research to support symptom assessment in many centers worldwide.	Needs standardization of multiple versions and explores its full potential to support symptom management.

Measurement	Feature	Advantages	Limitations
Decision Conflict Scale (DCS) ^f	<p>The DCS measures a person’s perception of the difficulty involved in making a decision about medical treatments. It has 16 items measuring 5 dimensions of decision making (feeling: uncertain, uninformed, unclear about values, unsupported; ineffective decision making). The items assessing perceptions of effective decision making are administered after the treatment decision has been made. Participants are asked to indicate their extent of agreement with each item on a 5-point response scale (1 strongly agree, 5 strongly disagree). Negatively worded items are reverse scored with higher scores indicating greater decision-related distress. Examples of items include “My decision shows what is most important for me” and “The decision about my treatment is hard to make.”</p>	<p>The DCS has been validated in a range of population groups. It is sensitive to people making different health decisions and to the effect of decision aids. The internal consistency for the total scale ranging from .78 to .89. DCS is brief, is easy to administer, and has low-literacy pictorial and other language versions available.</p>	<p>Only to identify patients who has decision-related distress and who needs decision support. When planning evaluations of decision support interventions using the DCS, it is important to consider the appropriate measurement timing as well as other factors that may influence efficacy such as decisional stage, information-seeking style, decision type, and contents of the decision support interventions</p>
Problem List (PL) ^g	<p>PL is a list of associated problems for the patient to identify specific problem areas. Each item is directly related to one of five domains: practical, relationship, emotional, spiritual, or physical. A total of 36 items comprises the problem list: seven practical, three relationship, five emotional, two spiritual, and 19 physical items.</p>	<p>Use in the combination of DT to identify specific areas of concern which lead to distress.</p>	<p>There is limited research investigating the relationship between number of items endorsed and overall distress ratings. Additional research is needed to better understand how the quantity of distressing factors influences risk for distress</p>

Note. Information from the resources below

^a Graham-Wisener, L., Dempster, M., Sadler, A., McCann, L., & McCorry, N. K. (2021). Validation of the distress thermometer in patients with advanced cancer receiving specialist palliative care in a hospice setting. *Palliative Medicine*, 35(1), 120–129. <https://doi.org/10.1177/0269216320954339>

^c Salsman, J. M., Schalet, B. D., Andrykowski, M. A., & Cella, D. (2015). The impact of events scale: A comparison of frequency versus severity approaches to measuring cancer-specific distress. *Psycho-oncology*, 24(12), 1738–1745. <https://doi.org/10.1002/pon.3784>

^d Akizuki, N., Yamawaki, S., Akechi, T., Nakano, T., & Uchitomi, Y. (2005). Development of an impact thermometer for use in combination with the Distress Thermometer as a brief screening tool for adjustment disorders and/or major depression in cancer patients. *Journal of Pain and Symptom Management*, 29(1), 91–99. <https://doi.org/10.1016/j.jpainsymman.2004.04.016>

^e Hui, D., & Bruera, E. (2017). The Edmonton Symptom Assessment System 25 years later: Past, present, and future developments. *Journal of Pain and Symptom Management*, 53(3), 630–643. <https://doi.org/10.1016/j.jpainsymman.2016.10.370>

^f Garvelink, M. M., Boland, L., Klein, K., Nguyen, D. V., Menear, M., Bekker, H. L., Eden, K. B., LeBlanc, A., O'Connor, A. M., Stacey, D., & Légaré, F. (2019). Decisional Conflict Scale use over 20 years: The anniversary review. *Medical Decision Making*, 39(4), 301–314. <https://doi.org/10.1177/0272989X19851345>

^g VanHoose, L., Black, L. L., Doty, K., Sabata, D., Twumasi-Ankrah, P., Taylor, S., & Johnson, R. (2015). An analysis of the distress thermometer problem list and distress in patients with cancer. *Supportive Care in Cancer*, 23(5), 1225–1232. <https://doi.org/10.1007/s00520-014-2471-1>