Implementation of Distress Screening and Referrals Among Oncology Outpatients Initiating Palliative Care

Jessica Psonak

Under Supervision of

Carolyn Greely

Second Reviewer

Claire Bode

A DNP Project Manuscript
Submitted in Partial Fulfillment of the Requirements for the
Doctor of Nursing Practice Degree

School of Nursing, University of Maryland at Baltimore
May 2023

Abstract

Problem: 33 out of 105 (31%) oncology outpatients at an academic cancer center were documented to have symptoms of psychological distress (PD) during initiation to palliative care services, which can lead to decreased quality of life, nonadherence to treatment, and increased burden on healthcare staff if untreated. **Purpose**: To implement a distress screening and referral protocol for oncology outpatients through utilization of the *Distress Thermometer and Problem List* (DT) screening tool to identify individuals with significant distress (scores of four or greater) and guide healthcare providers in referral interventions. **Methods**: DT screenings for cancer outpatients initiating palliative care services were completed by a medical assistant via telephone within seven days of new referral appointments over a 16-week period; the palliative care provider was electronically notified of individuals with significant distress scores, including documentation of a problem list. The provider incorporated the distress scores into new patient evaluations and initiated additional referrals to interdisciplinary care teams, as indicated. **Results**: 53 patients were eligible for the intervention, 21 patients (40%) had distress screenings completed, 15 screened patients (71%) demonstrated scores for significant distress and referral documentation was completed for 44 (83% of total patients), including 87% of target patients with DT scores four and greater. 17 % of patients were not able to be reached via telephone and 2% of patients refused screening when called. **Conclusions**: Identifying patients with significant distress can guide healthcare workers in providing necessary interventions and resources for those suffering from PD. In this QI project, patient needs were primarily addressed by the palliative care provider for symptom management and advanced care planning. This project supports the need for palliative care resources in the outpatient cancer care setting.

Keywords: distress screening, oncology, palliative care

Implementation of Distress Screening and Referrals Among Oncology Outpatients Initiating Palliative Care

Psychological Distress (PD) is a significant phenomenon observed in clinical practice among patients diagnosed and treated for cancer. PD can be defined as an unpleasant emotional or psychological experience, including feelings of worry, sadness, anger, helplessness, feeling out of control, social isolation, insomnia, and frequent thoughts about illness or death (McCarter et al., 2018 & Riba et al., 2019). External evidence supports that about 33 percent of cancer patients suffer from significant distress, which can lead to decreased quality of life, nonadherence to medical care, poorer health outcomes, and increased treatment burden to healthcare teams (Compen et al., 2018 & McCarter et al., 2018). Patients in need of palliative care services are particularly vulnerable to poor outcomes of distress due to large symptom burden, disease severity and progression, and uncertainty of health (Bergerot et al., 2020).

At a large ambulatory academic cancer center, internal evidence from chart reviews supported that 33 out of 105 oncology patients reported distress during initial palliative care consult. Data collected during chart review of initial palliative care provider notes, included reviewing narrative notes for history of present illness, review of systems, and assessment and plan documentation. Main sources of distress included anxiety about illness (nine of 33), anxiety about treatment, such as transplant, radiation, fear of needles, fear of surgery, or use of foley catheter (eight of 33), depression related to illness or requiring prolonged hospitalization (10 of 33), exacerbated previously diagnosed anxiety or depression conditions related to cancer diagnosis or treatment (three of 33), distress regarding physical symptoms of illness or treatment side effects, such as pain, fatigue, neuropathy, altered taste, weight loss, urinary frequency, diarrhea, insomnia, and inability to maintain self-care or complete ADLs independently (15 of

33), and spiritual distress, such as regret related to lack of life experiences and fear of dying (two of 33). Two main root causes were identified of PD during palliative care transition, including physical symptoms related to illness and treatment, and mental/emotional burden of living with cancer (Appendix A). Currently, no formal screening exists at this large academic cancer center to address the root causes of PD.

This quality improvement project aimed to address the practice problem of PD in cancer patients transitioning to palliative care. A literature review to support the practice change was completed, including an appraisal of six articles, and a synthesis of key findings (Appendices B and C). Bergerot et al (2020)'s descriptive "mini review" concluded that validated distress screening tools, such as the Distress Thermometer (DT) screening tool, are recommended to guide healthcare workers in managing the care of oncology patients with advanced stages of cancer. Yeh et al (2014)'s level one systematic review of 19 Randomized Control Trials (RCTs) found that the DT was a reliable, valid, and easy to use screening tool for both clinicians and patients and recommends routine use of DT tool among oncology patients in various stages of treatment. Graham-Wisener et al (2020) conducted a level four cohort study to validate the use of DT for patients with advanced cancer and hospice needs and found the DT to be a reliable and valid tool for measuring distress and found cutoff scores greater than or equal to four indicated significant distress requiring clinician intervention. Lewis et al (2021) conducted a cohort study for head and neck cancer patients and found that 56 percent of this population had significant distress and concluded further intervention is recommended to promote positive health outcomes. Riba et al (2019) article supported the National Comprehensive Cancer Center (NCCN) clinical practice guidelines for managing PD in oncology patients, including the use of the DT and problem list for oncology patients to guide clinician referrals to improve patient outcomes.

Furthermore, Vogt et al (2021)'s cohort study concluded that structured assessment and screening using the DT helped decrease symptom burden for patients receiving palliative care and improve quality of life.

Collectively, the articles were graded as B, good quality evidence, which supported a practice change (Newhouse 2005). The evidence recommended screening all oncology patients for distress during critical timepoints in their cancer journey, including the transition to palliative care services, and recommended DT as a reliable and valid screening tool (Bergerot et al., 2020; Graham-Wisener et al., 2020; Lewis et al., 2020; Riba et al., 2019; Vogt et al., 2021; Yeh et al., 2014). Evidence supported NCCN guidelines that distress scores greater than or equal to four indicate significant distress that require further evaluation and intervention (Bergerot., et al., 2020; Graham-Wisener et al., 2020; Riba et al., 2019; Yeh et al., 2014). Following screening and obtaining a distress score and problem list using DT tool (Appendix D), the clinician is encouraged to make necessary referrals unique to individual patient needs to help manage distress (Bergerot et al., 2020; Riba et al., 2019;Vogt et al., 2021); Referrals to interdisciplinary care teams, may include the oncology team to manage physical symptoms, social work to help provide practical resources, mental healthcare providers to support emotional distress, chaplain to support spiritual needs, and dietician to support nutrition needs (Bergerot et al., 2020 & Riba et al., 2019).

The purpose of this quality improvement project was to implement the routine use of DT screening for 100 percent of patients in an academic ambulatory cancer center during initiation of palliative care services, to identify individuals suffering from significant PD (distress scores greater than or equal to four) and to provide appropriate healthcare interventions or referrals to address patient specific needs.

The Knowledge to Action (KTA) framework was used to support the problem and screening intervention (Appendix E). The framework begins with knowledge creation and synthesis, which was done in the planning phase of the project and included reviewing and appraising the available literature (Field et al., 2014). The highest quality evidence available in the literature was obtained to support screening with Distress Thermometer Tool. The framework concepts of adapting knowledge and assessing barriers to implementation guided the assessment of this project. Tailoring knowledge and the intervention to the site helped to gain stakeholder buy in and promoted facilitation of the screening implementation. Furthermore, KTA framework concepts of monitoring use of knowledge (screening and referrals) and evaluating intervention effectiveness, were completed during the implementation and weekly tracking phase of the project (Field et al., 2014).

Methods

The project site was a busy academic cancer center that promotes evidence-based practice, including quality improvement. The cancer center has a diverse workforce that practices a positive workplace culture and fosters teamwork. Staffing shortages that existed in the cancer center during implementation, as found in other fields of healthcare, posed a challenge to everyday care of patients in this facility. The PC team included three staff members, a nurse practitioner provider (NP), a registered nurse (RN), and a medical assistant (MA), all of whom worked part time in the PC clinic and had other cancer center duties or other clinics to manage. Prior to project implementation, the PC clinic lacked a formal structure to screen for distress when patients were referred for palliative care (Appendix F); This differs from the screening recommendations in the literature (Riba et al., 2019; Yeh et al., 2014). Prior to project implementation, a patient was referred to PC via staff messages in the electronic health record

(EHR) with documented reason for referral (example: pain management). The process did not include a comprehensive screening of the patients' needs and possible distress related to illness or other sources. Once the PC NP evaluated the patient, the NP then collaborated with PC RN to develop a treatment plan for the patient. The former process did not include a formal referral documentation process if the patients' needs could not be managed by the PC NP alone.

At this academic outpatient cancer center, PD screening with the DT tool was incorporated into the PC workflows to address the current gap in clinical practice (Appendix G). During project implementation, new PC patients were identified by the RN in the EHR and listed as "new referral," ensuring all patients who were eligible for intervention were easily identified. After a cancer patient was referred to PC services and identified by the RN as a new referral in the EHR, the PC MA called the patient to complete the DT screening over the telephone within one week of the patient's PC consultation. Distress screenings were documented for eligible patients in flowsheets (via telephone encounter) in the EHR, including documentation of the problem list. All patients with distress scores greater than or equal to four had corresponding telephone encounters, including distress flowsheets, electronically routed by the MA to the PC NP. Prior to each new patient consult, the PC NP, viewed the distress screening telephone encounter, and reviewed the distress screening score and problem list. This information guided the PC NP in planning for the needs of the patient. All referrals were made by the NP and documented in a checklist format at the bottom of the PC consult electronic note, including the options to check referrals made to various departments such as social work/patient navigator, registered dietician, mental health counselor, psychiatry, pain management, and substance use resources. Checkboxes also included an option for the provider to select "referral not indicated,"

documenting the reason (s), such as “patient being managed by palliative care team” or “patient currently being followed by psychiatry,” etcetera.

Implementation strategies and tactics used to achieve the project aim and enhance project sustainability included gathering buy in from PC staff members, including consideration of staff preferences and desired workflows, as well as simplifying process requirements to decrease additional work burden on the staff. The project lead (PL) also educated staff members on screening and documentation procedures prior to implementing the intervention and throughout tracking. Weekly individual staff “check ins” provided staff with support and allowed the PL to receive staff feedback on processes, provide education, assess barriers, and make any process changes as appropriate. Interventions were implemented over a 16-week period beginning September 5, 2022, and ending December 22,2022.

Two process goals were used as measures for the project. The first goal included 100% of patients will be screened for PD using the DT screening tool within seven days of scheduled palliative care consult. The second process goal was identified as 100% of patients with DT scores of four or greater will have referral documentation completed by the provider. Referrals made to various care teams, such as dietician, social work, patient navigator, mental health counseling, psychiatry, substance use, pain management and primary oncology team were included (Riba et al., 2019).

The process of collecting data on screening and referrals was done weekly by the PL. Screening data, including screening documentation and distress scores, was extracted from electronic flowsheets through manual chart review by the PL. Referrals were measured through manual chart review of PC consult notes, specifically assessing referral checkboxes to measure number and types of referrals made. In addition to weekly screening and referral data collection,

the PL completed weekly assessments of contextual elements related to the project to promote intervention compliance and success. Contextual elements promoting project success, included weekly check ins with the PC staff to assess for any problems with workflow processes, issues with compliance, including documentation of distress screening with problem list in the flowsheets by the MA and documented referrals by the NP. Barriers were identified and addressed by the team lead, including high work demands of staff members, staff adherence, and staff members schedules (vacation, personal days, calling out sick). Additionally, the ability to contact the patients via telephone was another barrier, as some patients did not answer the telephone during the project intervention. Because of the size of the department, weekly communication with the team lead was feasible. The DT screening tool was already incorporated into the MA and RN electronic flowsheets, making this intervention cost effective and feasible. Simplified workflow processes, with consideration of staff members' preferences also promoted facilitation of the project.

Project data was collected weekly, every Monday by the PL, and a retrospective chart review (for the previous week) was completed in the EHR to assess whether interventions were completed for eligible patients. This included the PL logging into the EHR at the hospital site and reviewing each patient identified as "new referral" on the provider's list of patients. Upon chart review, the PL observed the notes section of the chart to view the provider's encounter, review the referral documentation and confirm whether the patient was seen by the provider. Some patients were scheduled, but not seen due to rescheduling or no-show appointments. Once the PL confirmed the patient was seen, the PL reviewed the MA documentation within seven days, to assess for the telephone encounter and distress flowsheet documentation. From the telephone encounter, the PL assessed whether the distress screening was completed (yes/no), the numerical

distress score (zero through ten), and the routing information (whether provider was electronically notified) if the patient was determined to have scores for significant distress (four or greater). If the patient was called for screening, but the patient did not answer and a message was left requesting a return call, that was noted by the PL. There were no processes in place during implementation to confirm with the provider whether the distress flowsheets were viewed prior to patient visits. Therefore, a conclusion cannot be made to confirm that the provider utilized the distress scores when making referral decisions and completing referral documentation. The provider was, however, responsible for checking staff messages daily, which included the routed distress screening telephone encounters.

Quantitative methods to draw inferences about the project results were based on data from distress scores and referrals, including number and type of referrals. Descriptive statistics, such as frequencies and percentages of distress scores were tracked. Run charts were used to measure the completion of project goals during weekly implementation to illustrate change over time, including staff compliance of distress screenings and referrals made for qualifying patients. A run chart with zero data for any given weeks suggested that there were no eligible patients. One factor found to decrease patient eligibility was the provider's availability to assess patients, including days or weeks when the provider was sick or on vacation, which required rescheduling of consults. Methods for understanding variations in data included weekly check-ins with staff to troubleshoot any barriers for compliance and address any staff concerns.

The project proposal was submitted to the University of Maryland Human Research Protection Office (HRPO) and received determination as non-human research; Institutional Review Board (IRB) approval was not required prior to project implementation. Patient data collected during project implementation was completed in a quiet office space, which facilitated

protection of patient privacy and confidentiality. Data was stored in REDCap, a secure system approved by the UMSON, and only accessed by the project team lead and supervising faculty. Secure logins were used to ensure proper identity of permitted users. All patients eligible for intervention had the opportunity for inclusion. No conflicts of interests were identified by those approving and/or participating in the project.

Results

Results from 16 weeks of implementation found that 53 patients were eligible for the screening intervention. Of those eligible, 21 (40%) had screening intervention documented (Figure 1 and Table 1). 15 screened patients (71%) had DT scores of four or greater, indicating significant distress (Figure 3). 87% of patients with significant distress, and 83% of total eligible patients had referral documentation completed (Figure 2). A special cause cannot be determined, as no shift, trends, or runs were identified in data analysis (Figures 1 and 2). Common causes for variation in the data included time limitations, staff availability to complete interventions, high work demands, and prioritization of other patient care tasks over project intervention. 90.5 % of screened patients reported some levels of distress. 29% of patients reported the maximum distress score of 10, which represented the most frequently reported score (Figure 3). Types of referrals that were made during the implementation period included referrals to patient navigator, dietician, substance use, and hospice (Figure 4). Most patients (60%) had zero referrals made to interdisciplinary care teams due to patient symptoms being managed by the palliative care team. Other patients were not referred due to already being managed by primary oncology team (10%) or other interdisciplinary care teams, such as psychiatry or dietician (9%). During project implementation, there were no social workers or mental health counselors employed at the

project site, and thus no referrals were made to these departments. Additionally, 17% of patients were not screened due to telephone barrier and 2% of patients refused screening.

Discussion

This quality improvement (QI) project found a significantly higher occurrence of psychological distress (PD) in the target population when utilizing a self-reported Distress Thermometer screening tool (71%), compared to internal data, which was based on staff perception of patient distress levels (31%). This QI project also found that oncology patients initiating palliative care (PC) reported significantly higher levels of distress, when compared to external literature based on the general oncology population, 71% and 33% respectively (Compen et al., 2018 & McCarter et al., 2018). During the project implementation, the PC provider played a key role in addressing and treating physical symptoms contributing to distress sources, such as uncontrolled nausea or pain. This project highlights the great need for allocation of resources in the PC clinic to help address PD. Barriers and limitations identified during the project evaluation included limitations in human resources allocated to the PC clinic, including limited staffing, and lack of availability of hospital resources, such as lack of social workers or mental health counselors to receive referrals. Additional limitations included high burden on staff members to prioritize other tasks over screening intervention, availability of clinic staff to complete interventions due to small clinic size, and a telephone barrier.

Conclusions

Although the screening intervention was not completed for all eligible patients in this initiative, the project provided valuable data for hospital workers at the site. This project served to bring great awareness to the needs of cancer patients initiating palliative care and further validates the Distress Thermometer and problem list screening tool as a valid and reliable to

identify distress and guide healthcare interventions for this population. Factors to promote sustainability at the project site include allocation of human resources to the PC team and other hospital departments where referrals may be initiated. Hiring staff members to complete screenings and assessments for patients to address PD is crucial in sustaining the project. Additional factors to promote sustainability include having support from leadership to promote staff accountability and developing unit policies to standardize routine screenings into practice at the critical timepoint of palliative care referral. Furthermore, in-person or electronic screenings may be helpful to mitigate the telephone barrier. Following project evaluation, several implications for practice were identified. The site found that utilizing distress thermometer screenings in the electronic health record (EHR) was found to be helpful and feasible, and allowed for easy communication of distress screenings among staff members. Additionally, incorporating distress screenings as a standardized assessment during the initial palliative care visit may be helpful in treating distress and collaborating treatment goals with patients. Lastly, to reduce the burden on staff to complete screenings, a future project could aim to send automated distress thermometers directly to patients via electronic portals such as My Chart.

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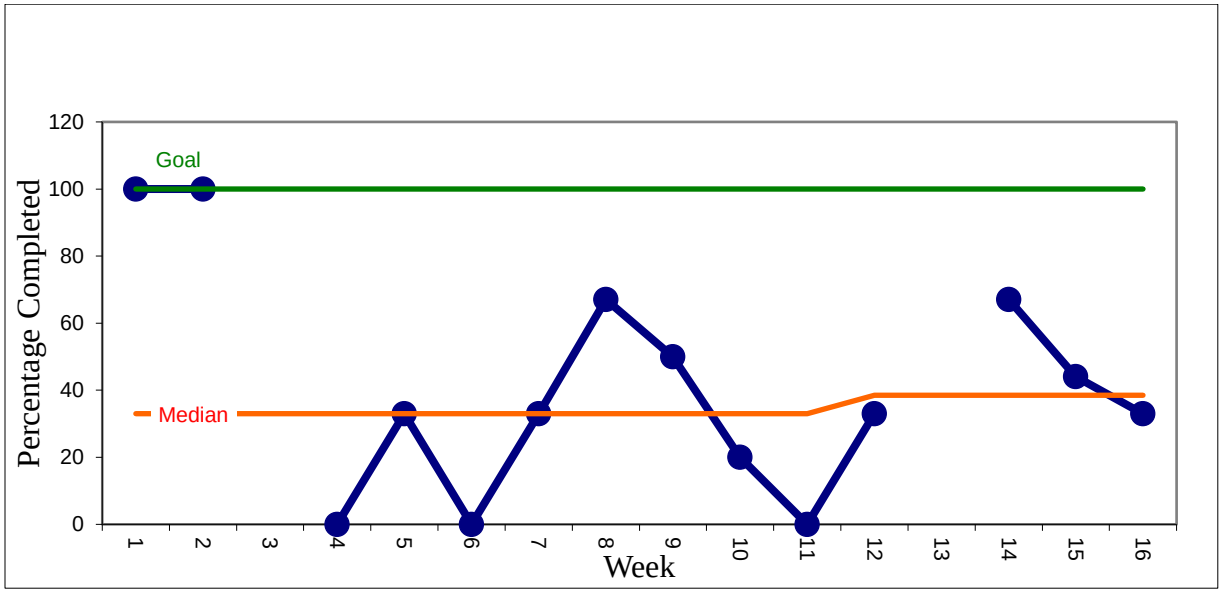
Figure 1

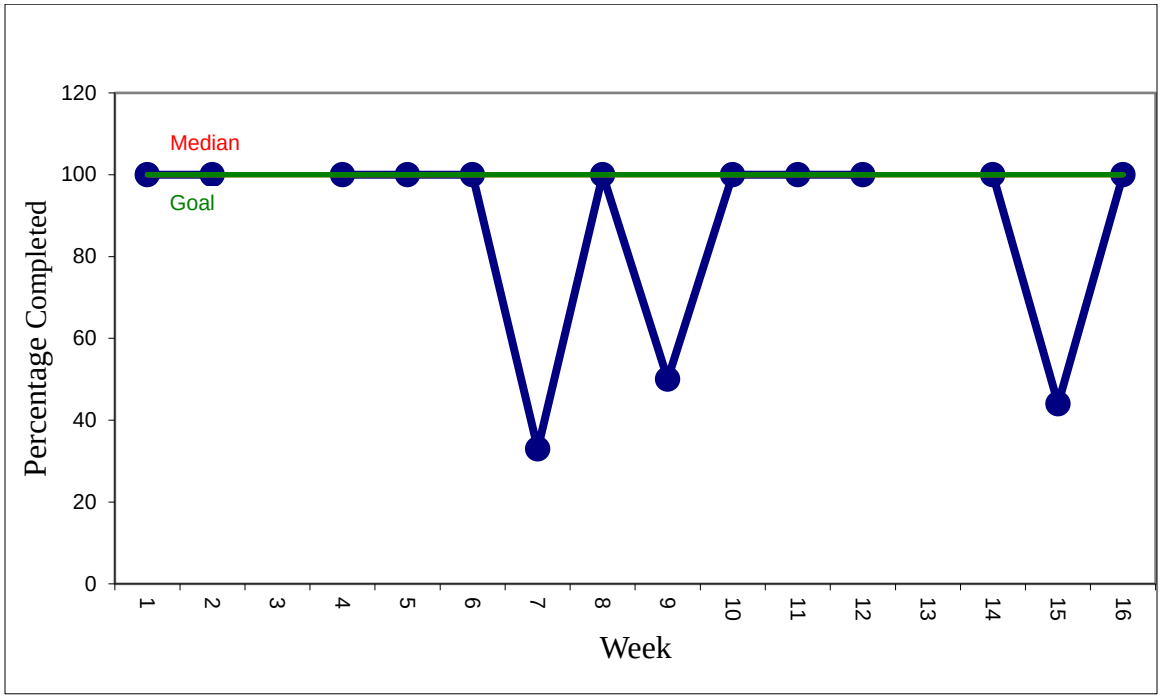
Completion of Distress Screenings Run Chart



Note. There were zero eligible patients for weeks three and thirteen.

Figure 2

Completion of Referral Documentation Run Chart



Note. There were zero eligible patients for weeks three and thirteen.

Table 1

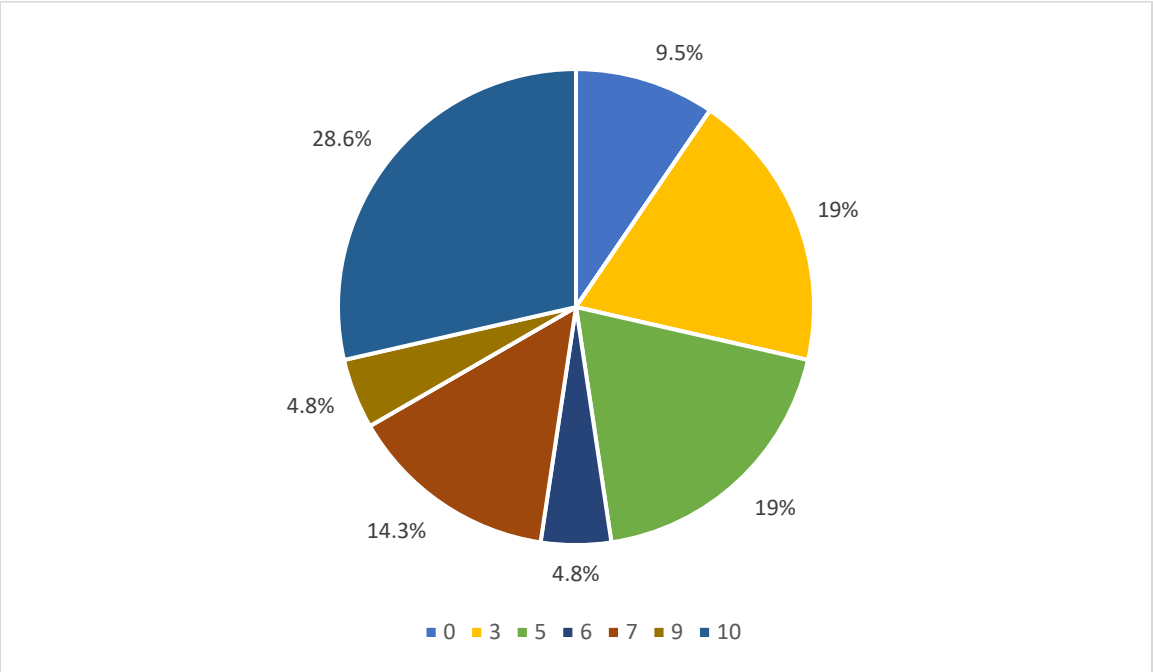
Categorical Data for Screenings and Referrals of Eligible Participants

Week	Number Eligible	Number Screened	Number with Distress Score four or greater	Number of patients with Referrals Documented
1	4	4 (100%)	1	4 (100%)
2	2	2 (100%)	2	2 (100%)
3	0	n/a	n/a	n/a
4	1	0 (0%)	n/a	1 (100%)
5	6	2 (33%)	2	6 (100%)
6	3	0 (0%)	0	3 (100%)
7	3	1 (33%)	1	1 (33%)
8	3	2 (67%)	1	3 (100%)
9	2	1 (50%)	1	1 (50%)
10	5	1 (20%)	1	5 (100%)
11	5	0 (0%)	n/a	5 (100%)
12	3	1 (33%)	1	3 (100%)
13	0	n/a	n/a	n/a
14	3	2 (67%)	0	3 (100%)
15	9	4 (44%)	4	4 (44%)
16	3	1 (33%)	1	3 (100%)

Note. No data available for weeks three and thirteen due to zero patients eligible for intervention.

Figure 3

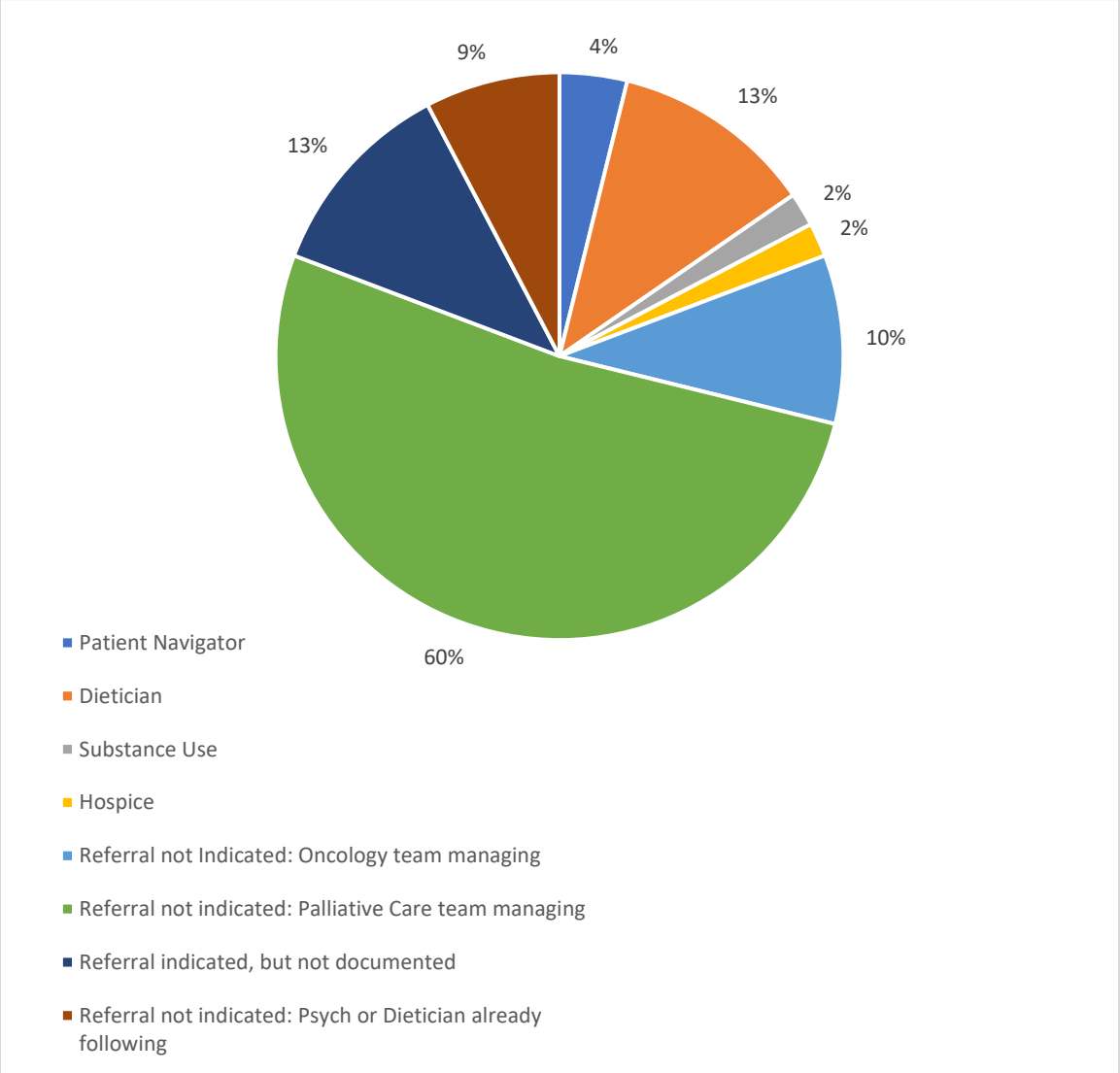
Frequency of Distress Scores by Percent (N=21 screened patients)



Note. Zero percent of patients had scores of one, two, four, or eight.

Figure 4

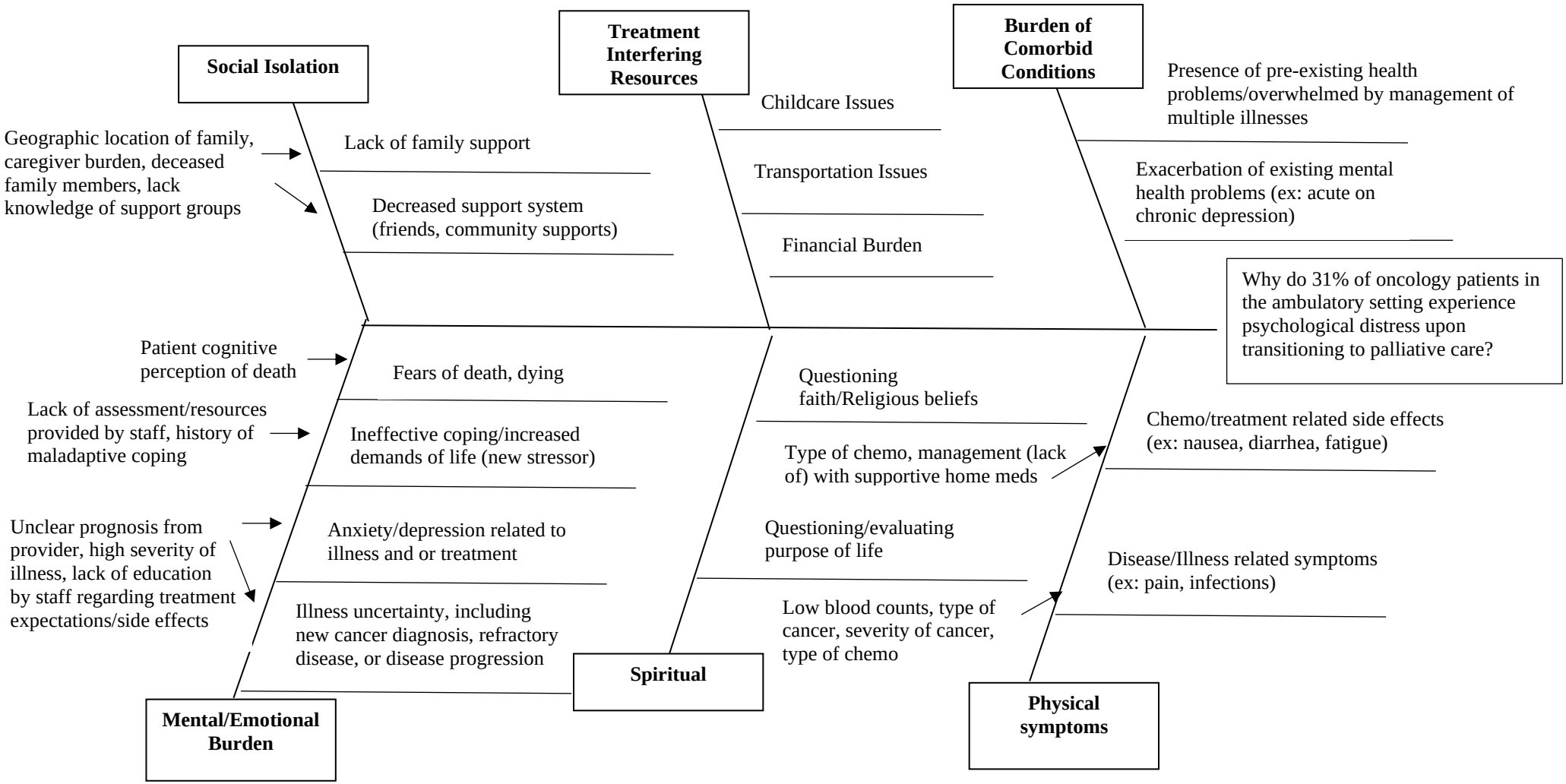
Frequency of Referral Types by Percent (N=44 patients with referral documentation)



Note. No referrals were made to interdisciplinary teams including mental health counselor, psychiatry, or pain management. At the time of implementation, no social workers or mental health counselors were employed in the project setting and thus no referrals were made to these departments. Symptom management and end of life planning/goal setting were primary needs addressed by the palliative care provider during visits.

Appendix A

Root Cause Analysis



Appendix B

Evidence Appraisal

Source 1 Citation: Bergerot, C. D., Philip, E. J., Bergerot, P. G., & Pal, S. K. (2020). Distress and quality of life among patients with Advanced Genitourinary Cancers. *European Urology Focus*, *6*(6), 1150–1154. https://doi.org/10.1016/j.euf.2019.10.014

Purpose	The purpose of the review is to define psychosocial distress, explore impacts on quality of life and identify current strategies for psychosocial screening and supportive care delivery in oncology patients with advanced genitourinary cancer.
Design	"Mini review" literature review; descriptive
Sample	Studies were reviewed with primary sample including individuals with various advanced genitourinary cancer, such as prostate, kidney, and bladder cancers.
Intervention	Not applicable; Non-experimental review
Outcome measures	Levels of distress and quality of life and described in the literature; however, there were no interventions in this study, therefore no outcomes measures were further discussed.
Results	The study identifies several tools that have been standardized and validated instrumental screening tools to assess for distress, including Distress Thermometer, Hospital Anxiety and Depression Scale, Brief Symptom Inventory-18, and Patient-Reported Outcomes Measurement Information System Distress. The review supports that distress screening can identify unmet needs, reduce symptom burden, increase communication between patient and provider, and help guide the development and implementation of interventions. The review supports screening during periods of increased vulnerability such as time of diagnosis, beginning and ending treatments, and during times of disease recurrence or progression. Studies support patients with poor prognosis experience higher levels of distress. **Conclusion:** Validated distress screening tools are recommended as part of comprehensive treatment in this population and can be useful in assisting healthcare providers to identify patients in need of support and help guide referral pathways. Interventions should be tailored to individual needs of patient. The review recommends further research is needed to examine the efficacy of distress screening programs in this population, including ability to address symptom burden, improve quality of life, and influence clinical outcomes.
Evidence Level	Level 5 (Melnyk)- systematic review of descriptive and qualitative studies
JHNEBP quality grade	C- flaws that exist in the review include that the article did not describe the selection or quality of articles included in this "mini review." Strengths and limitations of included studies were not discussed. Additionally limited information is available from sample participants. However, the findings and recommendations discussed in the article seemed to be feasible to implement, with no proposed harm to patients. Additionally, consistent findings were present among various articles used in the literature review (Newhouse 2005).

Source 2 Citation: Graham-Wisener, L., Dempster, M., Sadler, A., McCann, L., & McCorry, N. K. (2020). 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

Purpose	To provide the first validation of Distress Thermometer in an advanced cancer population receiving palliative care in a hospice setting. The study aims to evaluate the sensitivity and specificity of the Distress Thermometer in screening for distress, anxiety, and depression, identify optimal cut-off points for Distress Thermometer to determine when to make referrals for further psychological assessment, and to identify clinical socio-demographic factors associated with increased psychological morbidity among this population.
Design	Correlation design/analysis; longitudinal design
Sample	Sampling type: Convenience. Data was collected from 202 patients between September 2014 and August 2016 with advanced cancer from inpatient or day hospice care in the UK. Complete data was collected from 139 patients. Power analysis was done, using alpha value of 0.05 and was determined 138 patients needed for power analysis, which this study met. Eligible patients that did not participate in study included those who were too "unwell" to participate and others that declined. Participants were considered heterogeneous in terms of type of cancer and other demographics, including gender and marital status.
Intervention	The distress Thermometer and the Hospital Anxiety and Depression Scale were administered upon patient admission and were completed independently by patient or with clinician support if needed. Both screenings were administered consecutively, first Hospital Anxiety and Depression Scale was administered, followed by Distress Thermometer. All patients were considered for inclusion in the study, except for patients with non-malignant disease. All participating patients had same intervention. Screening measures: Distress Thermometer Version 2 was used as index test and was defined as a single-item, 11-point visual scale with respondents indicating how distressed they have felt over the past week from "no distress" to "Extreme Distress." The Hospital Anxiety and Depression Scale was used as the reference measure and consisted of a 14-item questionnaire with two subscales for anxiety and depression with Scale that ranged from zero to 42. The Hospital Anxiety and Depression Scale was used a reference due to its supported validity demonstrated in previous studies.
Outcome measures	Two Screening tools were used to measure distress. Distress Thermometer was measured on subjective scale of zero to ten, with zero being "no distress" and ten being "extremely distressed." Hospital Anxiety and Depression Scale was used as a reference and ranged from zero to 42, with higher numbers, indicating greater distress. Means scores and standard deviations were used to compare distress thermometer scores with Hospital Anxiety and Depression Scale scores. A receiver operating characteristic analysis was done to compare cut off scores from Distress Thermometer to Hospital Anxiety and Depression Scale scores to measure scores appropriate for referral for further assessment of distress.
Results	Scores on Distress Thermometer ranged from 0 to 10, with mean score of 5.40 (SD 2.91). The total Hospital Anxiety and Depression Scale ranged score ranged from 2 to 34, with mean score of 17.35 (SD 8.31). The optimal distress cutoff according to area under the curve to screen for distress and anxiety was ≥ 6 and ≥ 4 for depression in this study. **Conclusion**: This study contributes to previous studies to support the Distress Thermometer to be a valid method for screening psychological morbidity in oncologic palliative care population. Based on the study analysis, Distress Thermometer cutoff of ≥ 5 may be optimal in screening for distress and initiating further intervention to manage distress. Strengths disclosed included power of sample size, specific population identified of palliative care/hospice, and consistent findings with other studies. Limitations may include culture variations outside the UK may impact generalizability for screening used in other cultures/countries. In addition, Anxiety and Depression Scale that was used as a reference may indicate different subtypes of distress, specific to that specific scale, therefore two different scales are not 100 percent comparable, although literature supports the reference scale used as a best comparing scale to study Distress Thermometer Cutoffs scores.
Evidence Level	Level 4 (Melnyk)- cohort study, no control group, assessed one cohort of patients during a specific period.
JHNEBP quality grade	B- good quality for sufficient sample size, defined conclusive results, and strengths and limitations discussed. Study design could be stronger if it was a randomized experimental designed study with control group (Newhouse 2005).

Source 3 Citation: Lewis, S., Pandey, S., Salins, N., Deodhar, J., Patil, V., Gupta, T., Laskar, S. G., Budrukkar, A., Murthy, V., Joshi, A., Prabhash, K., Nair, S., Chaturvedi, P., Noronha, V., & Agarwal, J. P. (2021). Distress screening in head and neck cancer patients planned for cancer-directed radiotherapy. *The Laryngoscope, 131*(9), 2023–2029. https://doi.org/10.1002/lary.29491

Purpose	The study aimed to estimate the prevalence of baseline clinically significant distress (distress score ≥4) in head and neck cancer patients treated with radiotherapy using the NCCN Distress Thermometer and assess predictive factors of distress.
Design	Cross-sectional study; cohort study
Sample	Sampling type: convenience. Sample included 600 patients, which met 80% power analysis criteria. (620 patients screened) Excluded patients were either not eligible or refused. Eligibility criteria included patients with diagnosis of head and neck cancer, aged 18 and older, with Eastern Cooperative Oncology Group 2 or less, and planned to undergo curative radiation therapy (definitive and adjuvant). Patients who were previously treated with chemotherapy or radiation therapy were excluded.
Intervention	Patients were screened using Distress Thermometer (DT) prior to receiving radiation. DT screening used was a self-reporting tool where patients rated their overall distress on a scale of zero to 10, where zero is "no distress" and 10 is "extreme distress." A score of 4 or more indicated clinically significant distress. Patients who screened ≥ 4 were screened for an additional study (study not reported). If patient refused to participate in further study, counseling and appropriate referrals were done by primary physician.
Outcome measures	Distress scores from 600 patients were statistically analyzed on a univariate and multivariate analysis. Distress scores and causal factors were analyzed including demographic factors (gender, marital status, education, employment) and disease related factors (stage of cancer, comorbidities, proliferative growth, site of cancer) to assess for causes of distress.
Results	Median distress score of cohort was four. Mean distress score was 4.24. 56.7% of patients had clinically significant distress. A univariate analysis determined causal factors of distress included low economic status (P=0.04), presence of proliferative growth at presentation (P=0.008), site of tumor (oral cavity P=0.04), presence of a tracheostomy tube or Ryle's tube (P=0.01). Low economic status was significant for a multivariate analysis for high levels of distress (P=.0.04). Additionally, the main physical symptom reported was pain (45.2%). **Conclusion**:56% of head and neck cancer patients had clinically significant baseline distress, including high levels of distress in patients with low socioeconomic status. The study recommends intervention to mitigate distress in this population. Strengths of the study that were disclosed included large sample size, and generalizability to high prevalence of head and neck cancer patients. Potential weaknesses include study was completed at a single-center, and the study did not address feasibility factors to implement screening, such as facilities with limited resources/staff. Screening did not use "problem list" portion of tool that is used to assess specific patient reported sources of distress, such as practical problems, social/family stressors. Study did not address further interventions following use of screening tool when significant distress is encountered.
Evidence Level	Level 4 (Melnyk)- cohort study, no control group, assessed one cohort of patients during a specific period.
JHNEBP quality grade	B- good quality for sufficient sample size, defined conclusive results, and strengths and limitations discussed. Study design could be stronger if it was a randomized experimental designed study with control group (Newhouse 2005).

Source 4 Citation: Riba, M. B., Donovan, K. A., Andersen, B., Braun, I. 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. G., Hoofring, L., Huang, C.-H., 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

Purpose	To provide clinical practice guidelines for healthcare clinicians to appropriately manage psychological distress among oncology patients in various settings and stages of illness.
Design	Clinical practice guidelines based on literature review
Sample	Guidelines are based on a magnitude of studies involving screening and interventions of oncology patients, including patients in various stages of disease, treatment, end of life transitions, high symptom burden and more.
Intervention	While the authors of the clinical practice guidelines did not perform interventions, a literature review reflects guidelines for recommended interventions to be used in practice to manage distress in this population. Distress Thermometer and Problem list continues to be recommended for use to screen oncology patients and identify specific sources of distress. A score of ≥4 indicates significant clinical distress that is recommended to be further managed by oncology team, which can include various interventions such as symptom management and referral to other interdisciplinary care teams such as social work, chaplain, mental health counselors, psychiatrists, for evaluation. The screening is recommended to be performed at every visit by a clinician when feasible, but always at critical vulnerable points patients' cancer journey, such as at initial visit, disease progression, new treatments, transition in care, end of life treatments. The guidelines also recommend re-evaluation of distress during follow up visits post initiation of interventions but does not specify time frame.
Outcomes Measures	Distress scores using Distress Thermometer screening tool and problem list are used to measure distress screening. Clinically significant distress is identified as scores ≥4. The Distress Thermometer tool has been studied to have high sensitivity and specificity for measurement of distress among various high-quality studies. Outcome measures aside from distress that could be measured include quality of life, symptom severity, and patient satisfaction with healthcare services.
Results	**Conclusion**: All oncology patients are recommended to be screened for distress, using distress Thermometer and problem list tool beginning at initial diagnosis, and at critical times of vulnerability throughout care such as with new treatments, disease progression, and end of life. Problem lists are recommended to individualize treatment and guide necessary referrals to various hospital resources. Hospitals can use Distress screening and referrals as a quality metric to improve the quality of cancer care. Staff and leadership should be trained and involved in distress management of cancer patients to improve outcomes for this population.
Evidence Level	Level 5 (Melnyk)-While there are few references to higher quality studies used in the literature review to recommend clinical practice guidelines, the authors disclose that majority of guidelines are based on lower quality evidence studies. This is likely due to the limitations of available high-quality studies on this topic. The topic is multifactorial, subjective in nature, and has an ethical component that may limit use of future experimental trials.
JHNEBP quality grade	A- high quality. Expertise from NCCN guidelines are clearly evident. Guidelines have continued to be revised for two decades (most recent 2019) to include robust research available to support guidelines (Newhouse 2005).

Source 5 Citation: Vogt, J., Beyer, F., Sistermanns, J., Kuon, J., Kahl, C., Alt-Epping, B., Stevens, S., Ahlborn, M., George, C., Heider, A., Tienken, M., Loquai, C., Stahlhut, K., Ruellan, A., Kubin, T., Dietz, A., Oechsle, K., Mehnert-Theuerkauf, A., Oorschot, B., … Lordick, F. (2021). Symptom burden and palliative care needs of patients with incurable cancer at diagnosis and during the disease course. *The Oncologist*, *26*(6). https://doi.org/10.1002/onco.13751

Purpose	To assess distress, symptom burden, quality of life, and supportive care needs in patients with newly diagnosed incurable cancer
Design	Prospective longitudinal observational multicenter study
Sample	Convenience sampling was used to screen 1050 individuals at 20 different cancer centers in Germany. Of the total screened patients, 500 individuals were chosen to participate in study, based on consent and eligible inclusion criteria. Inclusion criteria included: confirmed diagnosis of incurable

	cancer, adults 18 years and older, those not affected by life threatening complications of cancer, and those who could read and speak German language. Exclusion criteria included severe physical, cognitive, and/or verbal impairments that affected consent process or ability to comply with study requirements. Although there is no mention of a power analysis completed, the sample size section of the article mentions that 500 participants were "intended" for the study. Also mentioned is that statistical analysis was performed by SPSS Version 24.0, without confirming whether this included power analysis. Unclear if sample size was sufficient, although article illudes to sufficient sample size.
Intervention	Participants were screened with multiple validated self-reported screening tools at four timepoints including: baseline (newly diagnosed), three months, six months, and 12 months follow up to screen for distress, symptom burden, and quality of life. The NCCN Distress Thermometer (DT) screening tool was used to measure distress at described timepoints. Other screening tools that were used at timepoints included Functional Assessment of Cancer Therapy (FACT), Schedule for the Evaluation of Individual Quality of Life (SEIQoL), Patients Health Questionnaire-4 (PHQ-4) and modified Support Care Needs Survey. Interventions were done from October 2014 to October 2016. Participants had an option to complete screening tools online or by paper and pencil. Data was pseudonymously stored in a central study database, which was audited for accuracy and analyzed using SPSS v. 24.0 software. Professional support was offered to patients who scores were clinically significant.
Outcomes Measures	Psychological Distress levels were measured, through DT screening tool (scale from 0-10 with 10 being highest level of subjective distress), noting ≥ 5 scores determined clinically significant distress. Anxiety and depression levels were measured through the PHQ-4 screening (subjective scale from 0-12, with 12 being highest levels of anxiety and depression), noting scores ≥ 6 as clinically significant anxiety and depression. Symptom burden and quality of life were measured using the FACT screening tool (consisting of 27 questions) and the SEIQoL tool (Quality of life ranges from scores of 0-108, with 108 noted as highest perceived QOL.
Results	Key findings: 67% of patients reported distress at baseline, there was a slight decrease over time in this study, but even after 12 months follow up, about 50% of patients remained with significant distress. Higher levels of distress were noted in cancers of stomach, esophagus, hepatobiliary, and head and neck. 41% of patients with moderate to severe distress wished to receive professional support after baseline screening, and the desire for professional support, including palliative care services, increased to 57% after 12 month follow up. Patients with head and neck cancer demonstrated the lowest scores of QOL, compared to other cancer locations. The average QOL score was 59. For anxiety and depression, the mean score of PHQ-4 was 4.6 at baseline, which was higher than other measured timepoints. About 33% of patients reported moderate to severe psychological distress at baseline according to PHQ-4 screening. **Conclusion**: The study results confirm the need for early individualized support for cancer patients with incurable disease, starting at the time of diagnosis. Structured assessment and regular screening are recommended for clinical use in this population to evaluate individualized care burden and needs. Strengths of study included were the large population of patients with various types of cancers from various cancer centers. The study also measured several factors that impact cancer patients, such as distress, QOL, and anxiety/depression. Discussed limitations in the study include that the study did not include all types of tumors, specifically urologic and neurologic cancers were not included in the study due to limited access to this population during study period. Additionally, selection bias was possible.
Evidence Level	Level 4 (Melnyk)- cohort study, no control group, assessed one cohort of patients during a specific period.
JHNEBP quality grade	B- good quality due to large sample size, defined conclusive results, and strengths and limitations discussed. Study recommendations are also feasible and consistent with other study findings. Study design could be stronger if it was a randomized experimental designed study with control group. Also, the article should have been clear on whether power analysis was met to make findings generalizable (Newhouse 2005).

Source 6 Citation: Yeh, M.-L., Chung, Y.-C., Hsu, M.-Y. F., & Hsu, C.-C. (2014). Quantifying psychological distress among cancer patients in interventions and scales: A systematic review. *Current Pain and Headache Reports*, *18*(3). https://doi.org/10.1007/s11916-013-0399-7

Purpose	The purpose is to examine results from Randomized Control Trials on the relative effectiveness of interventions in reducing cancer-related psychological distress and the scales employed to measure distress.
Design	Systematic Review of Randomized Control Trials (RCTs)
Sample	234 studies were identified in search as potentially relevant to purpose. Following complete appraisal, 19 RCTs that were included in the review, evidence was gathered from 2543 participants. Inclusion criteria for review included studies that measured interventions for psychologic or emotional distress and related outcomes. Exclusion criteria included case-control studies, trials comparing different cancer drug treatments, surgical interventions, review papers, or child or animal model studies. From the sample of participants, the most common types of diagnosed cancers in the 19 studies, included female breast cancer, colorectal, lung, and prostate cancers. This sample is consistent with statistical reports in the United States for the most prevalent cancers. Time frames of participants illness was not noted (ex: newly diagnosed, progressive disease, etc..). Three studies included participants with various cancer sites, while other studies focused specifically on a singe type of cancer. No additional information was provided about sample/participants.
Intervention	An electronic database search was conducted for RCTs from October 2008 to July 2013 using three different databases: PubMed, MEDLINE, and CINAHL. Keywords used in search were "cancer," "cancer patients" "psychological distress," "emotional distress," and "Randomized Control Trial." Data was independently extracted and assessed by two researchers. **Interventions** to manage distress varied among RCTs. The most frequently employed interventions included exercise training (yoga and walking programs), cognitive behavioral therapy, and complementary therapy. Other interventions significant in the review included meeting with a psychologist and a combination of using a written journal and peer counseling, expressive writing, educational videos, self-administered stress management, psychosocial rehabilitation, partner-assisted emotional disclosure meaning-making intervention, intimacy enhancing therapy, beaty treatments, internet based cognitive behavioral therapy. All interventions varied in timeframe, including interventions lasting from 30 minutes to 12 weeks.
Outcomes Measures	**Screening for distress** was used to measure distress levels at various timepoints across studies. Measurement timepoints varied among studies. Majority of the studies measured at least baseline distress levels (pre-intervention) and post intervention stress levels. Up to six month follow up was done in select studies. A total of seven main instruments were used among various studies. Screening instruments included Profile of Mood States-Short Form (four studies), Distress Thermometer (three studies), Hospital Anxiety and Depression (three studies), Brief Symptom Inventory-18 (three studies), Mental Health Inventory (three studies), State-Trait Anxiety Inventory (two studies), and Center for Epidemiological Studies-Depression Short Form (one study). Each instrument tool was described in terms of scales and questions used for scoring. **Distress Thermometer**, is described as a single self-reported assessment (developed in 1998) using an "11-point visual analogue scale (0=zero distress, 10-extreme distress)." Scores of ≥4 indicated moderate or severe distress and trigger further evaluation, recognized as per NCCN guidelines
Results	Out of 19 included studies, eight studies reported that interventions had positive effects, improving the symptoms of psychological distress. Specific effects were not discussed; however, the article mentions previous research associated lower distress levels with increased quality of life, positive effects on cancer recovery, and positive effects on long term survival. The interventions that were significant included exercise training, cognitive behavior therapy, complementary therapy, meeting with a psychologist, and peer counseling combined with keeping a written journal. Interventions noted to have no evidence of effective reduction in cancer-related psychological distress, which included interventions from 11 studies, included expressive writing, educational videos, self-administered stress management, psychosocial rehabilitation, partner-assisted emotional disclosure meaning-making intervention, intimacy enhancing therapy, beauty treatments, internet based cognitive behavioral therapy. The three most employed screening tools were identified as "Profile of Mood States-Short Form (POMS-FS)," "Distress Thermometer (DT)," and "Hospital Anxiety and Depression (HADS)." The Review notes that the psychometric properties of these instruments have been tested among cancer patients and demonstrate internal consistency, test-retest reliability, and construct validity. Specifically, The Distress Thermometer is a highly useful tool for both patients and providers, mainly due to its simplicity to score and easy interpretability. **Conclusion**: Numerous studies have demonstrated the long-term benefits of interventions in reducing psychological distress among cancer patients. The review recommends future studies focus on practical interventions to manage distress, such as exercise training, or cognitive behavioral Therapy. Previous research has identified distress as a

	"sixth vital" sign for cancer patients. The review supports the routine screening for distress to identify and measure unmet needs, which can address patients in need of interventions. Strengths of the study include high level evidence of included studies. Disclosed limitations of the study include that a meta-analysis could not be conducted due to due to the heterogeneity of the RCTs. Significant differences among interventions and the types of cancers make it impossible to compare the results of the trials using uniform criteria.
Evidence Level	Level 1 (Melnyk)- Systematic review of RCTs.
JHNEBP quality grade	B-good quality was given to this source because the review did include high quality studies with fairly consistent results, as well as included strengths and limitations. The conclusion was graded as fairly definitive, congruent with B grading because the review listed three different screening instruments and two different interventions as effective but left the reader wanting more guidance on recommendations (Newhouse 2005). It would have also been helpful to define what "routine screening" would encompass, and during what time points in a patient's cancer journey.

Appendix C

Evidence Synthesis

Category (Level Type) Melnyk Rating System	Total Number of Sources/Level	Overall Quality Rating JHNEBP	Synthesis of Findings
Level 1 – Evidence from a systematic review or meta-analysis of all relevant randomized control trials (RCTs)	1	B	This systematic review of 19 RCTs provides good quality evidence supporting the importance of distress screening using "Distress Thermometer" instrument as a valid and reliable tool to measure psychological distress in cancer patients. Types of cancer among the reviewed studies was variable, which show this intervention is relevant to individuals with many different types of cancer. The review supports the need to screen and manage distress to facilitate positive health outcomes for patients, including increased quality of life, and mitigate negative impacts on life expectancy and cancer recovery. The review supports National Comprehensive Cancer Network (NCCN) guidelines that distress scores greater than or equal to four indicate significant distress that yield further evaluation and intervention. This review highlights the use of Distress thermometer as a feasible screening tool for distress due to its simplicity to use for patients and healthcare providers and its easily interpreted scores by providers (Yeh et al., 2014).
Level II · Evidence obtained from well-designed RCTs.	No Level II evidence found in literature search within 10 year timeframe that address identified population, intervention and outcome of project.		
Level III -Evidence obtained from well-designed controlled trials without randomization	No Level III evidence found in literature search within 10 years that address		

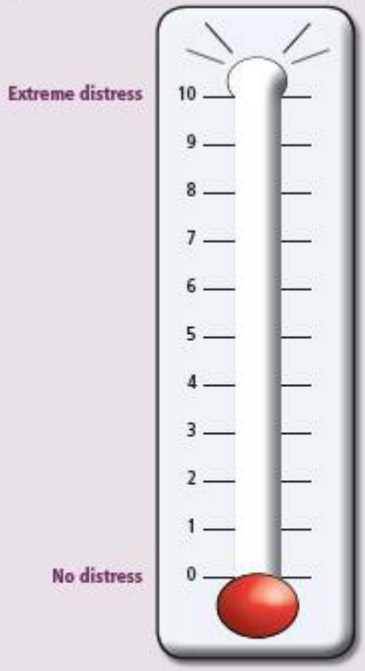
	identified population, intervention, and outcome of project.		
Level IV -Evidence from well-designed case-control and cohort studies	3	B	Graham-Wisener et al (2020) cohort study's key findings support the use of Distress Thermometer (DT) as a valid tool to measure distress in oncology patients, specifically in the palliative care and hospice setting. A cut off score of greater than or equal to five was identified as representing clinically significant distress scores yielding further evaluation and intervention (Graham-Wisener et al.,2020). While Lewis et al (2021) study did not observe patients during palliative care, the article focused on individuals with head and neck cancer, identifying 56% of patients reporting significant distress (Lewis et al., 2021). Lewis et al (2021) used a cut off score of greater than or equal to four, which was another difference between the first two studies. Both Lewis et al (2021) and Graham-Wisner et al (2020) recommended further intervention to manage significant distress but not include specific recommendations. Like the first two studies, the third Level IV study was also defined as a cohort study. Key findings included that 67% with incurable metastatic cancer reported significant distress using the DT (Vogt et al., 2021). Cancers of stomach, esophagus, hepatobiliary, and head and neck were among the highest levels of distress. All three studies recommend routine distress screening for cancer patients to help guide individualized interventions to address specific sources of distress (Graham-Wisener et al.,2020; Lewis et al., 2021; Vogt et al., 2021).
Level V- Evidence from systematic reviews of descriptive and qualitative studies	2	B	Bergerot et al (2020) descriptive review highlights recommendations for distress screening as part of comprehensive treatment in the oncology population. Screening can be useful in assisting healthcare providers to identify patients in need of support and help guide referral pathways. Distress Thermometer (DT) is recognized as a valid tool to measure distress in this population and guide individualized interventions (Bergerot et al., 2020). Additionally, Bergerot et al (2020) article supports screening during periods of increased vulnerability such as time of diagnosis, beginning and ending treatments, and during times of disease recurrence or progression. Riba et al (2019) article on the NCCN clinical guidelines on distress management in cancer patients has consistent key findings with Bergerot et al (2020) article. Key findings include using DT during routine clinical visits and at pivotal timepoints in patient's cancer journey. Such pivotal timepoints may be related to new diagnosis, changes in treatment, changes in disease state (disease progression), and end of life. Additional, NCCN defines "clinically significant distress" as distress scores greater than or equal to four on DT screening. NCCN recommends using the "problem list" that is often included

			in the DT screening, to help clinicians recognize individual problems that may be contributing to patients' distress levels and recommends using problem list to guide support care referrals to various interdisciplinary teams, such as social work, chaplain, primary oncologist, counseling, and other mental health resources (Riba et al., 2019). Unlike Bergerot et al (2020) article, Riba et al (2019) recommends that all healthcare professionals in oncology setting be trained on distress screening and management. The NCCN identifies positive outcomes measures linked to distress screening and managements, such as improved quality of life, symptom severity, and patient satisfaction with healthcare services (Riba et al., 2019).
Recommendations Based on Evidence Synthesis This collective body of literature represents good quality and consistency to recommend a practice change. The literature supports and recommends the use of distress screening though use of Distress Thermometer (DT) tool during time of diagnosis and critical timepoints throughout patients' journeys, such as during the palliative care transition. During the palliative care transition, disease progression, end of life needs, and high symptom burden may all negatively contribute to individuals' distress levels, making this an extremely vulnerable time for patients, as they often fear the unknown and face challenging symptoms/side effects of treatment. Additionally, the above literature supports the intervention of DT screening and problem list to help identify individuals' unique needs and help guide supportive care referrals and interventions.			

Appendix D

Distress Thermometer Screening Tool and Problem List

Instructions: First, please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.



Second, please indicate if any of the following has been a problem for you in the past week, including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems
❒	❒	Child care
❒	❒	Housing
❒	❒	Insurance/financial
❒	❒	Transportation
❒	❒	Work/school
❒	❒	Treatment decisions
		Family Problems
❒	❒	Dealing with children
❒	❒	Dealing with partner
❒	❒	Ability to have children
❒	❒	Family health issues
		Emotional Problems
❒	❒	Depression
❒	❒	Fears
❒	❒	Nervousness
❒	❒	Sadness
❒	❒	Worry
❒	❒	Loss of interest in usual activities
❒	❒	**Spiritual/Religious Concerns**

YES	NO	Physical Problems
❒	❒	Appearance
❒	❒	Bathing/dressing
❒	❒	Breathing
❒	❒	Changes in urination
❒	❒	Constipation
❒	❒	Diarrhea
❒	❒	Eating
❒	❒	Fatigue
❒	❒	Feeling swollen
❒	❒	Fevers
❒	❒	Getting around
❒	❒	Indigestion
❒	❒	Memory/concentration
❒	❒	Mouth sores
❒	❒	Nausea
❒	❒	Nose dry/congested
❒	❒	Pain
❒	❒	Sexual
❒	❒	Skin dry/itchy
❒	❒	Sleep
❒	❒	Substance abuse
❒	❒	Tingling in hands/feet

Other Problems: _____

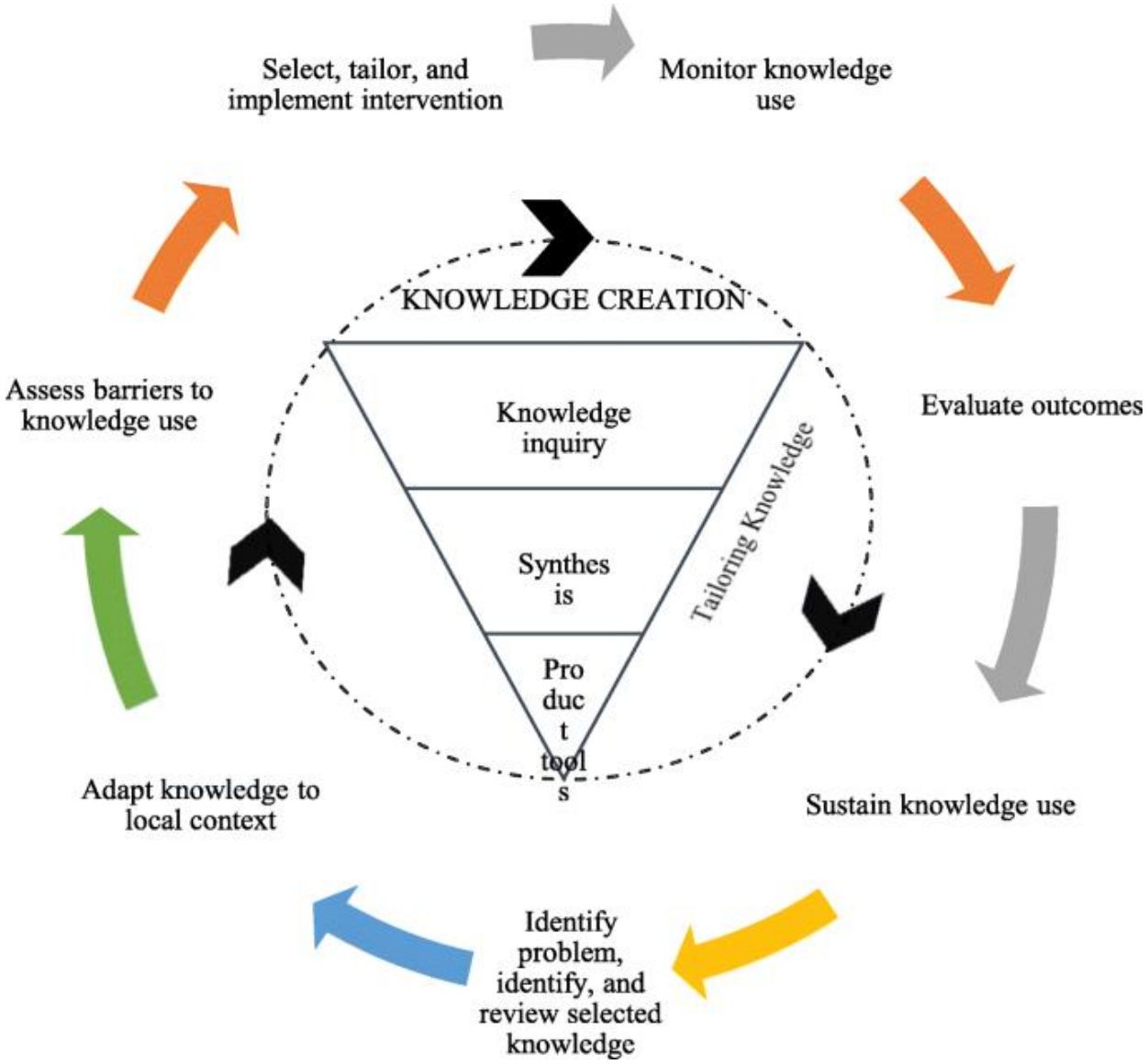
FIGURE 1. Distress Thermometer Screening Tool

Note. Adapted with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management V.2.2013. © 2013 National Comprehensive Cancer Network, Inc. All rights reserved. The NCCN Guidelines® and illustrations herein may not be reproduced in any form for any purpose without the express written permission of the NCCN. To view the most recent and complete version of the NCCN Guidelines, go online to NCCN.org. NATIONAL COMPREHENSIVE CANCER NETWORK®, NCCN®, NCCN GUIDELINES®, and all other NCCN Content are trademarks owned by the National Comprehensive Cancer Network, Inc.

Note. Adopted from NCCN (Riba et al., 2019)

Appendix E

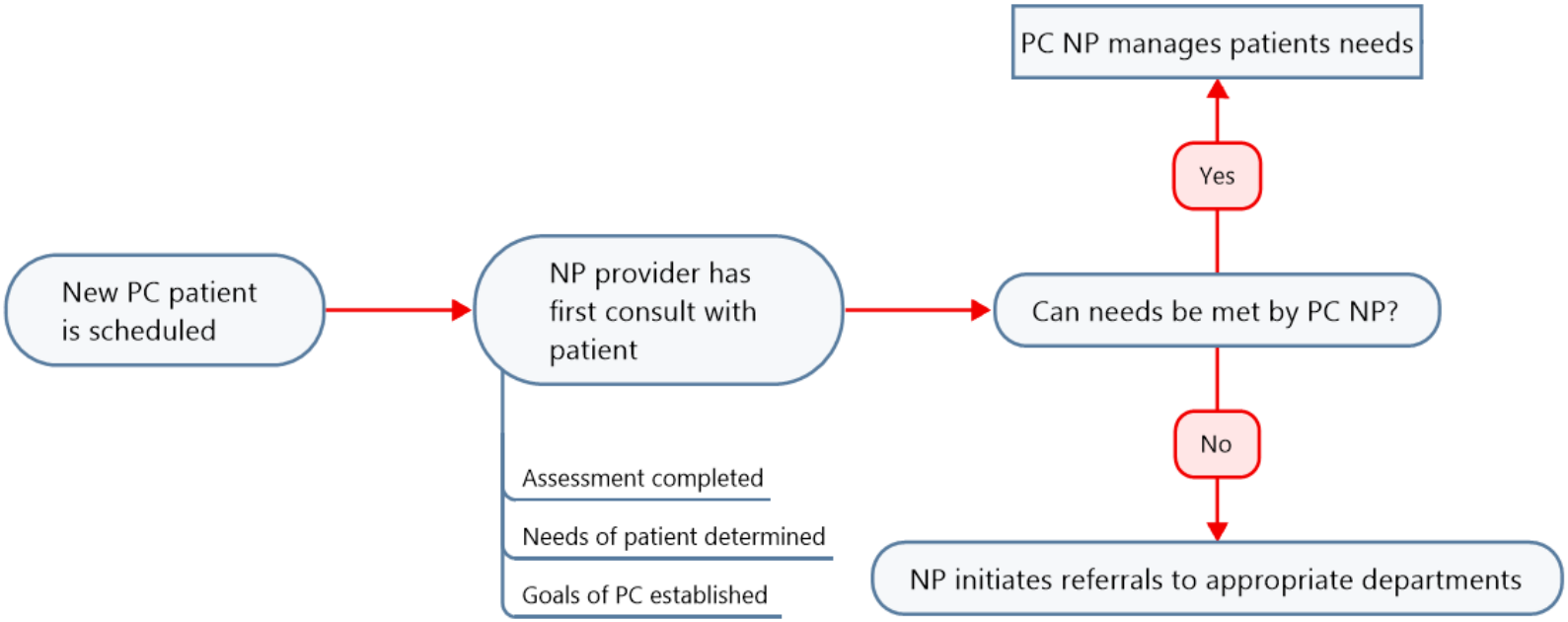
Knowledge to Action Framework



Note. Adopted from Field et al (2014)

Appendix F

Process Map Prior to Project Implementation



Appendix G

Process Map During Project Implementation