

Service Utilization in Oncology after Distress Screening



The interdisciplinary approach to treating patients with cancer has become an increasingly important model of care, especially when providing psychosocial support. Patients experiencing distress, anxiety, and other psychological problems are more likely to have adverse effects in several areas of their care including compliance with treatment, disease burden, and overall quality of life.¹ Distress, as defined by the National Comprehensive Cancer Network (NCCN), is “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer.”² Up to 50% of patients with cancer will experience a clinically significant level of distress.³ There is also evidence that close to 40% of patients with cancer who have psychosocial issues are not identified or addressed during the course of their care.⁴ These findings highlight the need for a screening process that identifies patients in need of additional interventions and potential unmet needs.

After identifying distress and the situational factors that exacerbate it, health care professionals can refer patients to the appropriate support services to facilitate relief of these additional burdens. Potential barriers to detecting distress include patient hesitancy to discuss psychosocial issues, somatization of feelings, and variability in clinician communication skills. Implementation of standardized screening allows clinicians and patients to effectively navigate these barriers.⁵ Screening followed by interventions for emotional distress is effective in improving disease burden and quality of life.^{5,6} Standardized screening not only increases identification of distress but also decreases health care provider variation in initiating and accurately detecting distress.⁵ The rate of referrals to support services has increased due to improved detection of patient needs, yet the effectiveness of implementing these referral processes remains questionable. Funk et al demonstrated that many patients with cancer experience barriers that affect their engagement with support services following initial screening.⁷ Evaluation of the screening and referrals process related to the use of services can promote current understanding of variables that may influence patient engagement with referred services and identify potential areas within the referral process that need improvement.

For instance, there is emerging research on the impact of the COVID-19 pandemic on patient access to care and psychosocial

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functioning. The prevalence of emotional distress and psychosocial issues has increased in the general population; further, relatively higher distress has been observed in patients with preexisting health conditions.⁸ Ng et al indicated that patients with cancer are more likely to exhibit anxiety related to COVID-19 and health but are less likely to exhibit psychological distress when compared with the general population.⁹ Cohen et al showed similar reported levels of distress among patients with cancer except in those with higher intolerance for uncertainty.¹⁰ There are, however, insufficient data examining potential associations between screened levels of distress and the use of patient support services during COVID-19. These issues affecting patient care should be further examined within the context of a global pandemic.

The study discussed in this paper has 2 aims: to evaluate distress and unmet needs in patients with cancer at a National Comprehensive Cancer Center (NCCN)-accredited cancer center in the Midwestern United States during the COVID-19 pandemic and to assess the relationship between distress, unmet needs, and rates of related support service use. Outcomes of research on distress and unmet needs in patients with cancer during COVID-19 are mixed, and continued research on our understanding of the need for triage and intervention within this population is critical.

Methods

Sample

Participants were adult patients attending an appointment at an NCCN-accredited cancer center in the Midwest. Data were collected from March 17, 2020, to September 17, 2021, as part of standard

clinical care. Incomplete cases (defined as missing distress thermometer scores or having 1 of the 15 unmet needs responses left incomplete) were removed, and the final study sample included 3256 patient encounters. The data that support the findings of this study are available from the corresponding author upon reasonable request. The National Cancer Institute (NCI)-accredited cancer center quality assurance team aided in data abstraction. Institutional review board approval was obtained (STUDY0D002040) with waived consent due to deidentified retrospective data abstraction.

Measure

The study used a needs assessment with 3 components: a distress score (scale, 0-10), 15 unmet needs (eg, practical, emotional, nutritional, substance, and physical), and self-selecting supportive care services.¹¹

Procedure

Following the Commission on Cancer Mandate 5.2, the staff at the cancer center identified education appointments in the Department of Medical Oncology, appointments during the first and third weeks in the Department of Radiation Oncology, and postoperative appointments in the Department of Surgical Oncology as pivotal encounters based on modality. During these appointments, a trained medical assistant provided scripted instructions. Patients were then given a paper copy of the needs assessment to complete independently. Once completed, the assessments were gathered by a medical assistant, and the data were entered directly into the patients' electronic health record (EHR). Care teams were notified; they addressed distress or unmet needs as identified in the screening results by conversing with patients about supportive care service options. The triage metric was a score of 6 or higher on the distress thermometer, 2 or more unmet needs in any specific domain, or a self-selected referral. Trained research personnel extracted all study variables from the EHR.

Data Collection

Approval for data analysis by the institutional review board of the University of Kansas Medical Center was achieved under a quality improvement review process. Demographic variables were age, gender, race, and marital status. Gender was coded as male or female. Race also included several categories. Age, a continuous variable, was set at the time of the distress measurement. Marital status was coded dichotomously as married or single. Distress and unmet needs were extracted from the needs assessment; they included distress score from the previous 24 hours (scale, 0-10) and unmet needs (scale, 0-15). The number of unmet needs by domain was also coded (scale, 0-3).

Use of services was abstracted from the EHR by the quality assurance team. It was defined as access to and assistance by any social worker, psychologist, dietitian, palliative care specialist, rehabilitation oncologist, or financial navigator in the 12 months following the needs assessment. Service use included encounters in ambulatory and inpatient settings. Data were assessed both dichotomously and by frequency.

Results

Participant Characteristics

All participants were aged 39 to 97 years (mean [SD], 63.26 [13.865] years; range, 39-97 years). The majority of participants were female (63.4%). For race, 85.3% of participants identified as White, 6.4% as Black, 5.3% as Hispanic, and 1.2% as Asian, which was consistent with area demographics. Participants' average (SD) distress score was 1.46 (2.315). For this NCI-accredited cancer center, the defined criterion for distress is a score of 6 or above; it was identified in 268 individuals (8.23%). According to the NCCN, a distress thermometer score of 4 or more indicates significant distress; 13.6% of the participants met that criterion. In step 2 of the evaluation, patients on average (SD) reported a score of 1.80 (0.25) for psychological issues in terms of unmet needs.

Having a higher distress score was associated with greater use of services. Extrapolation from the findings suggests that as participants' ages rise, so does their use of services.

Service Utilization

The overall number of psychological services varied from 0 to 5 different kinds of support services. Patients used an average (SD) of 2.68 (3.01) services. An evaluation of services provided at this institution showed that social workers were the most often used service providers (41.1%) with an average of 0 to 53 appointments per person. The mean (SD) frequency of social work visits was 2.68 (3.69) for individuals who used social work services 1 or more times. Dietitians were the second most popular service (19.4%) with 1 to 26 appointments recorded. The average (SD) frequency of visits for individuals who used dietitians at least once was 3.62 (4.13). Psychologists were used 3.28% of the time (range, 0%-7%), with those who used it at least once having an average (SD) visit frequency of 1.64 (1.19). Rehabilitation was used 6% of the time (range, 0%-8%), and the mean (SD) number of visits for those who used the service at least once was 1.68 (1.22).

Service Utilization and Distress

The first step was to look at descriptive statistics (Table 1). The analyses did not exclude outliers. The utilization statistics were skewed, but they were not altered to guarantee that conclusions were interpretable. In addition, the data were reevaluated to verify that outliers were not caused by inaccurate data input, and the data's legitimacy was validated. Data were retained in their original form, since the skewness of the data reflects real patterns in service consumption (ie, patients seldom use psychological treatments). The outliers included 10 participants who used services more often than others, but studies looked at variables categorically (using services vs not using services) and

Table 1. Descriptive Statistics and Frequencies of Unmet Needs, Total and By Category

DOMAINS	NO (%)	YES (%)	MISSING	MEAN	SD
Practical					
Advanced directive and living will	94.1	5.1	0.8	0.05	0.220
Travel and lodging	96.3	2.9	0.8	0.03	0.167
Social Security and work issues	96.7	2.5	0.8	0.02	0.156
Emotional					
Anxious, worried, or irritable	90.9	6.6	2.5	0.07	0.251
Crying more, feeling sad, or feeling depressed	84.3	14.9	2.5	0.15	0.357
Relationship concerns	91.9	7.2	0.8	0.07	0.260
Nutritional					
Lost at least 5 pounds w/o trying	95.8	3.4	0.8	0.03	0.182
Eating less	81.9	10.8	7.4	0.12	0.320
Pain that prevents eating	89.1	10.1	0.8	0.10	0.302
Substance					
Smoking	97.4	1.7	0.8	0.02	0.131
Alcohol	98.8	0.4	0.8	<0.001	0.065
Drug use	99.0	0.2	0.8	<0.001	0.460
Physical					
Pain/Fatigue	76.3	22.6	0.8	0.23	0.42
New physical symptoms	89.4	9.7	0.8	0.1	0.298
Worsening physical symptoms	92.7	6.5	0.8	0.07	0.247

continuously (number of visits) to make sure the results were not skewed by the outliers. Control factors were determined by looking at the relationships between predictors and demographic variables.

Distress was associated with age, although distress did not differ substantially by gender. Race had no significant effect on distress. As a result, the ensuing logistic regression analyses only included age as a covariate. The correlation between distress and patient likelihood

to use services across domains (eg, psychology, social work, dietary, chaplaincy) was also examined. The total number of domains used at least once (range, 0-4 domains) was the outcome variable. Coefficients that were not standardized are reported. When correcting for age, distress predicted service usage.

Distress had a substantial role in the whole model, accounting for 4.8% of the variance. How distress affects the categorization of

service consumption was evaluated by recoding the target variable to 1 if the participant had visited any of the services at least once and 0 if otherwise. Using logistic regression, the effects of distress on service usage were studied. The logistic regression model was statistically significant. The model correctly identified 51.4% of patients and explained 4.5% of service usage variance (Nagelkerke R^2). Both the participants' level of distress and ages were statistically significant in influencing the access of at least 1 treatment. Having a higher distress score was associated with greater use of services. Extrapolation from the findings suggests that as participants' ages rise, so does their use of services.

Unmet Needs and Service Utilization

To examine whether unmet needs can be used to predict use of health care services by patients with cancer, a regression model was estimated with the 5 domains of unmet needs used as the independent variables and service utilization score used as the dependent variable. Regarding the overall significance of the model, the linear regression model is statistically significant. This indicates a significant relationship between the unmet needs of and the use of health care services by patients with cancer. However, only 29% of the variation in the use of health care services by patients with cancer can be predicted by at least 1 of the 5 domains of unmet needs.

These findings are encouraging and suggest that when distress is identified, patients are connected to psychosocial services to aid in symptom management.

Examining the individual contribution of each of the domains, nutritional and emotional needs were statistically significant and contributed significantly to health care service utilization. The other domains of unmet needs, such as practical, substance, and physical, did not play substantial roles in the whole model. Results of the analysis suggest that there is a statistically significant relationship between unmet needs and use of health care services. Therefore, unmet needs can significantly predict the use of services by cancer patients.

Practical Unmet Needs and Use of Social Worker Services

To examine whether the practical domain of unmet needs can be used to predict use of social worker services by patients with cancer, a regression model was estimated with the practical domains of unmet needs used as the independent variable and social worker utilization score used as the dependent variable. Regarding the overall significance of the model, the linear regression model is statistically significant, indicating a significant relationship exists between practical unmet needs and the social health care service utilization of patients with cancer. However, only 13% of the variation in social health care service use of patients with cancer can be predicted by the practical domains of unmet needs.

The contribution of the practical domain of unmet needs is significant and contributes significantly to social worker service utilization. Analysis suggests that there is a statistically significant relationship between practical unmet needs and use of social worker services. Therefore, practical unmet needs can significantly predict the use of social workers by cancer patients.

Emotional Unmet Needs and Psychological Service Utilization

To examine whether the emotional domain of unmet needs can be used to predict the psychological health care service utilization of patients with cancer, a regression model was estimated with the emotional domains of unmet needs used as the independent variable and psychological service utilization scores considered the dependent variable. Regarding the overall significance of the model, the linear regression model is statistically significant. This finding indicates that a significant relationship exists between emotional unmet needs and use of psychological health care services by patients with cancer; however, only 10% of the variation in psychological health care service utilization by patients with cancer can be predicted by the emotional domain of unmet needs.

The contribution of the emotional domain of unmet needs is significant, and it contributes significantly to health care service utilization. There is a significant relationship between emotional unmet needs and psychological services utilization. Thus, emotional unmet needs can significantly predict use of psychological services by cancer patients.

Dietary Concerns and Dietitian Service Utilization

To examine whether dietary concerns can be used to predict nutritional health care service utilization in patients with cancer, a regression model was estimated; dietary concern was the independent variable, and nutritional service utilization scores was the dependent variable. Regarding the overall significance of the model, the linear regression model is significant. This indicates that a significant relationship between the dietary concerns and nutritional health care service use of patients with cancer exists; however, only 30% of the variation in the use of nutritional health care services by patients with cancer can be predicted by dietary concerns.

The contribution of dietary concerns is significant, and it contributes significantly to nutritional health care service utilization. This result suggests that there is a significant relationship between dietary concerns and use of nutritional health care services. Thus, it can be concluded that dietary concerns can significantly predict the use of nutritionist services by cancer patients.

Unmet Substance Needs and Service Utilization

To examine whether unmet substance needs can be used to predict the different categories of health care service use by patients with cancer, several regression models were estimated; the different categories of service utilization used were the dependent variables and the substance domain of unmet needs was the independent variable. Regarding the overall significance of the models, none of the linear regression models were significant. Moreover, none of the models predicted up to 1% of the variation in the health care service use by patients with cancer from unmet substance needs. Analysis suggests

that there is no significant relationship between unmet substance needs and health care service use when estimated individually.

Discussion

As stated previously, the study's first aim was to evaluate distress and unmet needs in patients with cancer; the second aim was to assess the predictive value between distress and unmet needs with service utilization rates of related support services. Distress and unmet needs were measured using the needs assessment, and use of support services was measured over the following 12 months in a longitudinal fashion. These results have significant implications related to our understanding of distress and unmet needs in patients with cancer during the COVID-19 pandemic, which has continued to impact the immunocompromised population. In addition, it provides critical data on the implementation of referrals and use of services to assist patients with their reported distress and unmet needs.

Regarding the first aim of the study, participants' average (SD) distress score was 1.46 (2.315), with the average distress score falling in the normal range. In fact, 13.6% of patients reported a score of 4 or more, which suggests that clinical intervention is needed to address distress. Whereas the results of prepandemic research showed that up to 50% of patients reported meaningful distress, these study results suggest that patients may have had decreased distress with a lower rate of clinical intervention required during the pandemic. The results are important to consider in the context of COVID-19 and the continued impact it may have on the oncology patient population.

Patients with cancer have been considered a high-risk population throughout the pandemic due to their immunocompromised state. This finding may be related to high rates of anxiety, social isolation, and increased symptoms of depression.¹² However, in this study, the lower rates of distress may be related to the normalization of isolation due to quarantine mandates.¹² Further research related to distress and the impact of COVID-19 on patients with cancer is critical with the pandemic still being managed.¹³

The second aim of the current study was to evaluate the predictive value of the needs assessment in connecting patients to psychosocial services. A component of the Commission on Cancer mandate for distress screening—referral to the appropriate psychosocial support service—is recommended, and documentation of those referral rates now is required.¹⁴ Regarding the distress scores' predictive value, when controlling for age, distress predicted high rates of psychosocial service use. Of note, the use of support services primarily fell to social workers and dietitians, with a minority of patients using psychology services or rehabilitation oncology.


These results are important to consider due to several factors. First, the data were collected from the initial days of quarantine mandates due to COVID-19 and for the following 18 months. During this time, as with many health care systems, accessibility to support services was altered. In this setting, social workers began working remotely, and they could complete most patient contacts via telephone. Similarly, dietitians were permitted to work remotely using the telephone. Eventually, dietitians and social workers developed a rotation for remote work with 1 in-person representative available for emergency situations. Additionally, social workers and dietitians do not bill for services at this institution. On the other hand, as telehealth

connectivity and a process to bill for services were established, there was a delay in accessing psychology and rehabilitation oncology services immediately following the quarantine orders. Other barriers (competing treatment demands, depression, stigma) have also been cited for lower service utilization of psychology services.^{7,15} These services are also billable, which may serve as a barrier for patients. Lastly, there is only 1 rehabilitation oncologist and 5 psychologists available to provide care for more than 7000 patients.

Despite the lower utilization rates of some of the support services, the relationship between distress and use of psychosocial services was significant. These findings are encouraging and suggest that when distress is identified, patients are connected to psychosocial services to aid in symptom management. This correlation was also found when examining the relationship between unmet needs and use of social services such that having more unmet needs was related to higher rates of support service use. Furthermore, when examining specific types of unmet needs, patients were connected to the corresponding support service providers (eg, practical unmet needs to social workers, emotional unmet needs to psychologists, and nutritional unmet needs to dietitians). This is further evidence in support of the utility of the Commission on Cancer mandate for distress screening and its effectiveness for connecting patients in need to appropriate comprehensive care.

Study Limitations

Study results should be assessed within the context of several limitations. First, the sample was largely homogeneous and primarily made up of White people. While this is representative of the Midwest population, findings may be limited in their generalizability. In addition, support service utilization was quantified via EHR data, which may limit capture rates of encounters and underrepresent use of services. Patient satisfaction with support services was not measured, nor was the impact of the use of services on distress, unmet needs, quality of life, or other important outcomes. Future research may benefit from examining outcome measures associated with support service utilization. Other factors not assessed in this study included time from distress screening to social service encounter, impact of disease stage and type, and other psychosocial supports that may have direct or indirect effects on distress.

This study also had several methodological strengths, including its longitudinal nature and the clinically driven data collection in a naturalistic environment. The study examined distress, unmet needs during a critical event, and the possible impact on patients with cancer. In addition, investigators affiliated with this study assessed the effectiveness of distress screening and referrals to appropriate comprehensive supportive care services. Future research may examine additional variables that mediate the association between distress/its possible outcomes and the use of services. 

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