# **Diffusion of Distress Management Guideline into Practice.**

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# Abstract:

# Objective

The purpose of this study was to explore system and clinician-related barriers, and predictors for the adoption of the National Comprehensive Cancer Network Distress Management Guideline (DMG) into oncology outpatient practice.

# Methods

This descriptive, correlational study surveyed a national sample of oncology nurses working in an outpatient setting who completed the survey electronically or by mail.

# Results

Study respondents (n = 409) were predominantly certified nurses (84%) yet largely unfamiliar with the DMG; 17% of respondents were using the DMG. Time, staff uncertainties and ambiguous accountability were the largest barriers to not assessing distress. Compared with those not using any assessment tool, those using the DMG were more comfortable discussing distress, worked as an oncology nurse longer, scored colleagues higher on valuing distress screening and had more organizational processes in place to support evidence-based practices. Significant predictors of DMG use included higher familiarity with the DMG (OR 3.81, p < .001), lower perceived barriers (OR 0.41, p = .001), non-profit status (OR 3.93, p = .05) and urban or rural (versus suburban) work settings (OR 04.59, p = .04; overall model chi-square 133.25, df 12, p < .001, Nagelkerke R2 .67).

# Conclusions

This study identified barriers and predictors to using the DMG, which are amenable to interventions. DMG adoption may be augmented by interventions, which increase familiarity with the guideline. Additionally, adoption of the DMG may improve through explicit articulation of the responsibilities oncology team members have in cancer-related distress screening and

management. Further studies are needed to evaluate the efficacy of such interventions and their impact on patient care outcomes.

**Keywords:** cancer | oncology | distress | translational | research | clinical practice guideline | nursing

# Article:

# Introduction

The reported incidence of cancer-related distress is between 5% and 70%, dependent upon the cancer site and stage [1-4]. Patient outcomes associated with cancer-related distress include increased depression, lower quality of life and reduced adherence to treatment plan [5-10]. The assessment and management of cancer-related distress thus has the potential to improve patient outcomes throughout the cancer trajectory.

Implementation of evidence-based practice guidelines helps ensure high-quality and costeffective oncology care [11]. The National Comprehensive Cancer Network (NCCN) developed the Distress Management Guideline [DMG; [12]] to address the psychosocial needs of cancer patients. The guideline recommends routine screening of cancer-related distress using the Distress Thermometer. Despite research evidence and recommendations for practice included in the DMG, distress continues to be under-assessed and under-estimated in people with cancer [13].

Although the implementation of an evidence-based guideline can ensure quality, there are inherent difficulties in implementation because of differences between the controlled environment in which research is conducted and the real-life complexities of clinical practice settings [14]. Despite that the DMG has existed since 1999, investigators [15] found in a 2005 survey of institutional representatives from 18 NCCN sites that only eight of 15 (53%) responding NCCN member institutions routinely screened for distress, three of which used the distress thermometer. Only three institutions screened every patient, and the other five screened certain groups of cancer patients. Reasons provided for not routinely screening for distress included a lack of valuing the assessment and insufficient resources despite all 15 NCCN institutions reporting the availability of mental health services in their setting.

Oncology physicians increasingly use evidence-based guidelines for quality performance measurement [16, 17]. In a survey of medical oncologists (n = 448) in 2007, over half reported routinely assessing for distress. However, only 14% reported screening using a validated

instrument with the majority asking direct questions or observing the patient. Additionally, only 33% were at least somewhat familiar with the NCCN DMG [18]. The study reported the largest barriers to screening for distress as perceived by physicians were lack of time, limited referral resources and unwillingness of patients to discuss distress. Familiarity with the NCCN DMG was the strongest predictor of screening. Other significant predictors included clinician gender (females more likely to screen), longer time in practice, availability of mental health resources and clinician uncertainty about identifying distress. Interestingly, only the barrier of limited referral resources coincided with the predictors for routine screening.

Distress management must be an interdisciplinary effort [12]. Interventions are based upon the nature of the distress source and may include chaplains, social workers, mental health professionals, family or physicians. The screening and decision to refer is completed by the oncology team, often by a nurse. Fitch's [19] review described the nursing roles of assessment, patient education and symptom management being facilitated by the use of Distress Thermometer. Fitch also noted that nurses report higher levels of clinical uptake of distress screening results than other clinicians. Loscalzo, Clark and Holland [20] identified nurses as 'natural allies' (p. 20) to patient psychosocial needs and emphasized the nursing role of screening and referral to the psychosocial team. The critical role was also expressed by Vitek et al. [21] as they describe nurses to have frequent and often prolonged contact with the patient providing the opportunity for screening, in-depth assessment as the sixth vital sign emphasize the change in values and culture of the clinical setting, often facilitated or championed by positions held by nurses.

However, there are no studies of nursing awareness of the NCCN DMG or research to characterize factors that influence DMG's adoption by nurses. The purpose of this translational study was to explore system and clinician-related barriers, and predictors of adoption of the DMG into routine oncology nursing practice in the outpatient setting. The specific study aims were the following: (i) assess oncology nurse level of awareness and adoption of the DMG; (ii) examine relationships between organizational and clinician characteristics, and adoption practices; and (iii) identify factors that predict adoption of the guideline.

# Theoretical framework

The study was guided by Rogers' Theory of the Diffusion of Innovation [23]. The theory posits that the rate of adoption of findings into routine practice is affected by how individuals and organization perceive the relative advantage, compatibility, complexity, trial-ability and

observability of an innovation. Rogers also describes how the number of people involved in making a decision to adopt an innovation has an effect on the rate of implementation. Other variables influencing the rate of diffusion of an innovation into practice include the type of communication channels used, the social system in which the innovation is to be implemented and the extent of the change agents' promotional efforts.

### Design/methods

This descriptive, correlational study surveyed a randomly selected national sample of Oncology Nursing Society members. An electronic survey followed a tailored design approach [24]. The variables in this study addressed clinician, organizational and guideline issues related to implementing evidence into practice [14, 25].

### Study sample/setting

The study sampling frame consisted of Oncology Nursing Society (ONS) members whose membership profile included an e-mail address and whose primary work setting was identified as 'outpatient hospital based clinic', 'outpatient other', 'outpatient physician office/infusion center', 'outpatient radiation free standing' or 'outpatient hospital based'. Eligible participants had to be practising within the USA. To adequately represent the approximately 37,000 member ONS population, a sample size of 380 was indicated by a priori random sample size estimation using a 95% confidence level and 5% confidence interval.

### Instruments

Participant demographic information was collected to describe the sample. With permission, the survey utilized 17 questions from the survey of medical oncologists used by Pirl et al. [18]. Two questions assessed nurse awareness and use of the DMG. Additional survey questions were developed on the basis of the five variables determining the rate of adoption using Roger's Diffusion of Innovation framework. The survey was reviewed by five advanced practice oncology nurses familiar with translational science or the DMG. The reviewers evaluated survey items for clarity of wording and relevance to Rogers' framework. Questions were retained if they were considered relevant by a minimum of 4 (80%) reviewers. Suggestions for improved clarity were incorporated. The survey was then completed using a web-based platform by six nurses to ensure electronic functionality. The survey required 10–20 min to complete by the six nurses; their responses were not used in the analyses. The final survey consisted of 58 questions

completed by all study participants. Using skip-logic, participants indicating they used the DMG were directed to answer an additional 45 questions.

To reduce data complexity, three scales were formed assessing organizational characteristics of respondent work place. Eight questions using a six-point scale (1 = not at all, 6 = very much a barrier) made up the Barrier scale, assessing the degree to which identified issues were barriers to screening for distress in the respondents' practice setting. Similarly, eight items using a six-point scale comprised the Value scale, indicating the degree to which the nurse perceived his or her co-workers value screening for distress. Higher scores indicated higher levels of collegial valuing of distress screening. After statistical differences between groups on individual items were analyzed, the Barrier and Value scales were analyzed for internal consistency of items using Cronbach's coefficient alpha. A four-item Work Culture scale, with higher scores indicating a more supportive culture, assessed the degree to which the work place had processes in place supporting the use of evidence-based guidelines. Work Culture scale items were individually evaluated for adequate cell size and significance between adopters and non-adopters using chi-square analysis. Reliability for the scale was determined using the Kuder–Richardson 20 formula used for dichotomous scale items.

### Procedure

The study received Institutional Review Board approval by the first author's place of employment at the time of the study. Consent to participate was implied by completion of the survey. A third party contractor managing the membership list for ONS identified eligible participants. The principal investigator was blinded to study participants' identity at the time of accrual. Systematic randomly selected eligible participants were sent an e-mail explaining the study and inviting them to participate. They could respond to the investigator or the contractor if they chose to decline participation at that time. A second e-mail was sent with the internet link to the electronic survey. Two additional reminder emails were sent 2 weeks apart.

Participants were incentivized to complete the survey by entering a random drawing for one of three Apple® iPods. Participants were required to provide an e-mail address for award notification. The survey was administered electronically using Survey Monkey®, a secure system that allows the participant to complete the survey from any computer having internet access [26]. Responses were available only to the study team.

The response rate to the electronic survey was 14%. Because this was less than projected to represent the population and after ethical review, a paper survey was sent to the original sample members who also had a mailing address listed in the ONS membership data base. The demographic responses to the mailed responses were compared with the electronic responses to detect possible duplication.

### Analysis

Summary statistics were used to describe the study sample. Responses were analyzed for missing data. Items were omitted or a missing response rate reported if there was more than 10% missing data points. Depending on the level of measurement, correlations, group comparisons using t-test or crosstab analysis with chi-square tests of association were used to examine relationships between organizational and clinical characteristics, adoption practices and level of awareness of the DMG. Logistical regression was used to determine predictors of DMG adoption. Variables with a chi-square or t score significance value of  $\leq 0.2$  on separate bivariate analyses were entered into the initial regression equation. Alpha was set at .05. Analyses were completed using IBM spss (version 19) [27].

# Findings

Participant flow is illustrated in Figure 1. The total response rate to the survey was 22.8% (n = 420). Of the 420, 11 surveys were eliminated because more than 90% of the data were missing; the final analyses included 409 surveys.

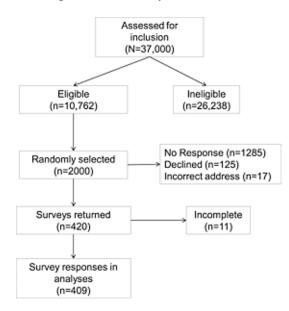


Figure 1. Study enrollment

The study sample (refer to Table 1) was predominantly non-Hispanic (98%) and female (99%) with only five males responding. Nurses worked an average of 23.15 years (SD 9.80), as an oncology nurse for 15.88 years (SD 9.13) and at the current place of employment for 10.59 (SD 8.77) years. All states were represented in the sample with the exception of Alaska and Vermont. There were no statistically significant differences in demographic or study variable responses between those completing the survey via postal mail versus those completing the survey electronically.

Variable	п	%
Female	384	99
Ethnicity		
Hispanic, Latin or Spanish origin	9	2
Non-Hispanic, non-Latina	378	98
Racial background	388	95
Asian	7	2
Black/African American	10	3
Native Hawaiian/Pacific Islander	1	1
American Indian/Alaskan Native	3	1
White	364	94
Other	3	1
Education level		
Diploma/associate degree	133	34
Bachelor degree	159	41
Masters degree or above	96	23

# Table 1. Characteristics of study sample (N = 409)

Variable	n	%
Role		
Staff nurse	179	46
Management	70	18
Educator	10	3
Advanced practice	48	12
Research	32	8
Other	50	13
Work setting		
Area of employment		
Rural	65	16
Urban	171	42
Suburban	152	37
Tax status		
For profit	133	39
Not-for-profit	205	61
Not reported	71	17
Type of care setting		
Hospital based	232	57
Free standing	128	31
Other	49	12
NCCN institution	115	53

Variable	n	%
Did not know	147	36
Not reported	46	11

- 1. Percentages may not add to 100 because of rounding.
- 2. NCCN National Comprehensive Cancer Network.

There were missing data problems related to characterizing the work setting in terms of profit/non-profit, teaching/non-teaching, and public/private with missing data on variables as high as 69%. We included profit/non-profit status, although 17.5% were missing as the remaining sample size (n = 338) was still adequate for the regression analysis. Data regarding affiliation with a college or university and whether the practice was public or private are therefore not reported.

Awareness and adoption levels of the Distress Management Guideline

Few nurses (23%) were 'highly familiar' with the DMG, 38% were not at all familiar with the DMG and the remaining 39% rated themselves in-between on a six-point scale. Only 69 (17%) respondents used the Distress Thermometer and/or other components of the guideline. Fifty (13%) respondents indicated they use a different tool to assess for distress, 41 (11%) did not know which tool was used and 231 (59%) did not use any systematic tool to assess for distress. There was a positive but weak correlation between familiarity with the DMG and comfort levels discussing distress (r = .28, R2 = .08, p < .001). Of those using the DMG who responded to the question (n = 61), 43 (70%) rated their success of using the DMG as 4 or higher on a six-point scale ranging from '1 = not at all' to '6 = very successful'.

Organizational and clinician characteristics and adoption practices

Within the Barrier scale (Cronbach alpha = 0.87), lack of time was rated highest, whereas the belief that interventions are ineffective was not much of a barrier (refer to Table 2). Items in the Value scale (Cronbach alpha = 0.84) indicated that social workers and advanced practice nurses (i.e. clinical nurse specialists and nurse practitioners) were perceived to value distress screening the most. Radiation therapists, and managers or administrators were rated the lowest.

n	Mean	SD	
Barriers	396	3.22	1.09
Lack of time	396	4.1	1.6
Staff uncertainty about how to identify distress	394	3.4	1.6
Staff uncertain about treatment options for distress	392	3.4	1.6
Lack of clarity about who is responsible for screening	395	3.4	1.7
Limited referral resources	395	3.2	1.7
Patients unwilling/reluctant to discuss distress	394	3.2	1.2
Staff uncomfortable discussing distress with patients	394	2.9	1.4
Belief that interventions are ineffective	393	2.1	1.3
Perceived valuing of screening by colleagues	397	4.91	.89
Social workers	313	5.5	1.0
Advanced practice nurses	307	5.4	0.9
Psychologist/counselors	234	5.3	1.3
Staff nurses	390	5.1	1.1
Chaplains	276	5.1	1.4
Physicians	391	4.6	1.3
Radiation therapists	302	4.3	1.5
Managers/administrators	374	4.3	1.6

# Table 2. Average scores of scale items and variables used in regression <sup>a</sup>

n	Mean	SD	
Work Culture scale (range 1–2)	390	1.66	.37
Patient comfort level discussing distress	408	5.06	.97
Nurse comfort level discussing distress	407	4.59	.99
Familiarity with DMG	407	2.85	1.86
Years as oncology nurse	383	15.88	9.13

a All but the Culture scale and Years as oncology nurse are based upon a six-point scale from '1 = not at all' to '6 = very much'.

The Work Culture scale (Kuder–Richardson 20 = 0.81) asked whether or not their work setting routinely conducted quality improvement activities (79% yes), used a structured process for making evidence-based clinical decisions (69% yes), had a routine method for reviewing patient outcomes (61% yes) or had an organized process for obtaining feedback about nursing practice (54% yes). Thus, over half of the respondents' work places had processes in place, which support or promote the use of evidence-based practices.

Distress Management Guideline users versus non-users

When compared with those not using anything, those using the DMG were more comfortable discussing distress (t = -3.58, df 297, p < .001, 95% CI -.72 to .21), were more familiar with the guideline (t = -16.59, df 153, p < .001, 95% CI -3.17 to -2.50) and worked as an oncology nurse longer (t = -2.14, df 283, p = .03, 95% CI -5.48 to .23). Nurses using the DMG had readily available resources when a psychosocial referral was needed. Specifically, those using the DMG reported they had a social worker (chi-square = 16.81, p = .001), psychiatrist (chi-square = 11.34, p = .01), support group leader (chi-square = 14.74, p = .002), navigator (chi-square = 39.53, p < .001) or chaplain (chi-square = 11.0, p = .007) available on the cancer staff or within the hospital rather than available in the community or not available at all when compared with nonusers. When comparing those who use the DMG with those who use nothing (Table 3), DMG users scored lower on the Barrier scale and higher on the Value and Work Culture scales.

Variable	n	Mean	SD	t <sup>*</sup>	df	CI	<i>p</i> *
Barrier scale							
Non-users	231	3.45	1.03	5.03	297	.43 to .99	<.01
Users	68	2.73	1.02				
Value scale							
Non-users	228	4.82	.92	7.97	135	56 to13	.01
Users	68	5.12	.74				
Work Culture scale							
Non-users	228	1.58	.39	19.85	153	31 to14	<.01
Users	69	1.81	.28				

### Table 3. Comparison of Distress Management Guideline users versus non-users

### \* Two-tailed.

Value and Work Culture scales are reported using equal variance not assumed values.

Predictors of using the Distress Management Guideline

Twelve variables met the criteria for being entered into the logistic regression analysis with Use versus Non Use as the binary outcome. The model was estimated in two blocks, the first being those variables that are considered non-modifiable. The second block consists of variables that may be modified. As depicted in Table 4, the likelihood of using the DMG was increased when there was higher familiarity with the guideline, lower perceived barriers, when working at a not-for-profit institution or when working in an urban or rural area. Exploratory analysis using chi-squared automatic interaction detection software did not identify significant interaction effects [28] and thus are not reported. Effect size using Cohen's classification [29], viewed as the Nagelkerke pseudo R2, shows a weak effect (.13) for the non-modifiable variables in Block One. However, a significant improvement is seen in the model when modifiable variables are added in Block Two with the pseudo R2 value increasing to .67 (a medium to large effect).

	Wald	р	Exp(B)
Block One – non-modifiable			
Urban, nor rural or suburban	3.39	.07	3.04
Rural, not urban or suburban	4.12	.04	4.59
Tax status	3.75	.05	3.93
Free standing vs. hospital based	.002	.96	.97
Model chi-square 20.93 df 4, $p < .001$ , Nagelkerke $R^2 = .13$			
Block Two – modifiable			
Years as an oncology RN	.36	.55	1.02
Education level of respondent	.03	.87	.95
Familiarity with the DMG	32.59	<.001	3.81
Patient comfort level with discussing distress	1.07	.30	.69
RN comfort level with discussing distress	.29	.59	.80
Work culture scale	.86	.35	2.25
Value scale	.88	.35	1.40
Barriers scale	10.74	.001	.41

# Table 4. Predictors of using the Distress Management Guideline (DMG)

Model chi-square 133.25 df 12, p < .001, Nagelkerke  $R^2 = .67$ 

### Discussion

### Sample

The response rate to the electronic survey was lower than anticipated. This led to the addition of a mailed survey. There was an over-representation of certified nurses (84%) when compared with ONS membership certification rate of 52% [30]. The sample had more nurses with greater than 10 years of experience in oncology when compared with the ONS membership (67% versus 47%, respectively) [31].

### Nurse awareness and adoption

Nurse awareness and adoption of the NCCN DMG was slightly higher in this study than that of medical oncologists [18] in 2007 yet remains low. Although the increased familiarity may indicate wider dissemination of the guideline, the clinical implications of this finding may be influenced by the possibility of more than one respondent working at the same institution. The lack of familiarity with the guideline, despite a high percentage of certified nurses in this sample as well as ONS member access to multiple articles involving the DMG, calls into question the efficacy of evidence dissemination.

### Organizational and clinician characteristics relationships with guideline adoption

Reducing barriers to screening requires work at the individual and organizational levels. Nurses routinely conduct patient assessments thus in the ideal position to identify and intervene for identified problems. However, interventions to decrease distress may require time or expertise beyond what is available to the nurse. Nurses using the DMG rated time as less of a barrier to distress screening than those who do not use any tool to screen for distress. This may be due to the reduction in clinical care disruptions experienced when distress is routinely assessed and managed [20]. The perception of time as a barrier to using the DMG may be influenced by the non-user groups' reported lack of available referral resources. The lack of resources for referral may shift the responsibility for follow-through with the patient in distress to the nurse, adding to the perceived lack of time. The lack of readily available resources for referral was an identified barrier, particularly for those not using the DMG. This finding is congruent with other studies [22, 32, 33]. As identified in the guideline, collaboration with social workers, mental health professionals, spiritual leaders and integrative therapy professionals should occur and would help alleviate the barrier of time for nurses by providing adequate follow-up and appropriate referral, instrumental in achieving positive patient outcomes for cancer-related distress interventions [22, 32-34]. It may be necessary to expand the psychosocial intervention skill set of nurses if such referral resources are scarce.

Careful documentation of patient distress scores, necessary referral resources and effects on patient satisfaction and financial outcomes [20] may help justify funded positions. For outpatient cancer care settings with fewer resources available on site, awareness and building excellent relationships with community resources may reduce barriers to follow-up. [34]. However, the perception that screening may substantially increase the need for referral services is tempered by a study conducted in the Netherlands in which up to 60% of patients experiencing psychological distress reported they did not need additional support services, preferring to wait or identifying concerns related to their distress as currently being managed by self or family [35]. Perhaps screening approaches should include a perceived need for additional help or information [36-38].

### Predictors of guideline adoption

Regression analysis indicated that screening for distress using the DMG may be improved by increasing awareness of the guideline and reducing perceived barriers in for-profit and suburban outpatient work sites. Increased awareness of the DMG is the first step guideline adoption [23]. As discussed earlier, the rate of adoption may be influenced by several characteristics of an innovation. Thus, the decision to adopt the DMG may require what Rogers [23] identifies as commercialization – marketing the guideline in the practice setting. Internal marketing could accelerate the diffusion of the DMG into practice if efforts focus on the advantage of using the guideline to meet recent American College of Surgeons accreditation requirements for distress screening and management [39]. Engaging key stakeholders such as patient representatives, nurses, physicians and mental health professionals in communication and decision-making has been a key factor in successful implementation of distress practice guidelines, particularly in Canada [22, 33, 40].

The integration of the process of distress screening and management into the electronic medical record with point-of care data capture is recommended. Digitization of the Distress Thermometer and programming automatic referrals when desired by the patient [41] or when levels are above an indentified cut-off score may have a profound effect on DMG adoption [20, 22, 42]. Having the Distress Thermometer integrated into the electronic medical record would also assist a clinic's ability to meet the core objectives of Medicare's incentive to demonstrate meaningful use of an electronic medical record [43].

#### Limitations

The study is limited by the lack of national representation of non-ONS members. Additionally, the study may be limited by the low number of men and minority respondents, and overrepresentation of certified and oncology experienced nurses. The time needed to complete the survey was neither estimated nor measured and may have been too excessive, thereby contributing to the lower than anticipated response rate. It is unknown if a non-response bias occurred or if more than one nurse from the same institution responded to the survey.

# Conclusions

There is substantial room for improvement in the diffusion of the NCCN DMG into practice. Focused efforts on increasing nurse awareness of the DMG and reducing perceived barriers will be critical to the successful adoption of the DMG. However, awareness is a necessary but insufficient approach to practice change. Interventional studies to increase the utilization of the DMG and evaluate impact on patient outcomes are needed.

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