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Preferences for notification of imaging results in patients with metastatic cancer

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Abstract

Objective: This study examines the preferences of patients with metastatic cancer regarding notification of imaging results, as well as distress surrounding the process.

Methods: On imaging day, preferences for notification, expectations of results, health literacy, and social support were measured. After receiving results, patients reported on actual delivery methods. At both times, patients were screened for overall distress, anxiety, and depression.

Results: The majority of patients preferred notification within 2 days and during a face-to-face visit with their oncologist. Although levels of distress, anxiety, and depression were low, patients with higher anxiety, depression, and social isolation had higher distress. There was no correlation between absolute distress levels and agreement between notification preferences and actual delivery methods. Receiving results from a preferred provider was associated with a decrease in distress from imaging day to follow-up. Face-to-face delivery of results was more important to people with lower health literacy.

Conclusions: While distress regarding the receipt of results was low, it was higher for some groups of patients. Attending to the preferences of these subgroups may help to minimize distress.

Practice implications: Receiving results from preferred personnel and diminishing patients' sense of social isolation might provide psychological benefit during the period surrounding imaging.

Keywords

Metastatic cancer; Imaging results; Distress; Health literacy; Social support; Expectations

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1. Introduction

Psychological distress during the cancer experience has been linked to many negative outcomes including lack of adherence to treatment, difficulty coping with symptoms, impairments in overall functioning, and decreased satisfaction with healthcare [1-3]. The National Comprehensive Cancer Network (NCCN) Distress Management Guidelines recognize several time points when patients have increased vulnerability to distress, including but not limited to the diagnostic workup, treatment for advanced disease, and when there is recurrence or disease progression [4]. Common to all of these is the need for patients to undergo and await the results of imaging tests, which can have serious implications for both future treatment and prognosis [5].

Past research indicates that scanning is associated with psychological distress in patients with non-metastatic and metastatic cancer, and that quality of life can be negatively impacted as a result [1,6]. In addition, distress and/or anxiety associated with imaging and notification of results can have a potentially deleterious effects on patients' understanding of their illness and clinical discussions about treatment, both of which are critical to informed decision making [6]. There is currently no literature that specifically examines how patients with metastatic cancer who undergo frequent and arguably high-stakes imaging exams experience the time surrounding imaging examinations and delivery of results. In addition, there are no studies that have examined factors that may exacerbate or alleviate distress for these patients during this period. Given a recent call to examine the challenges associated with living with metastatic cancer, it important to better understand the concerns in this population of patients in order to alleviate distress and improve overall quality of life [7].

There is literature to suggest that patients in other cancer contexts may have preferences for how and when they are notified about results. In a study of women awaiting results of breast biopsy, a preference was shown for receiving either positive or negative results quickly, regardless of whether these results were delivered in person [8]. Likewise, for patients awaiting skin biopsy results, the most important consideration given was the method of communicating results (telephone call, online patient portal, office visit) that would allow delivery in the shortest amount of time [9]. Other studies suggest that the outcome of the test (normal vs. abnormal result) has an influence on preference for delivery. In a study of women waiting for mammogram results, women preferred to receive normal results via a telephone call from the referring physician, but abnormal results in a face-to-face meeting, even though this would likely prolong the wait-time for notification [10]. Similarly, in a study of individuals with cancer who underwent CT for various reasons, 70% stated that they would prefer that their radiologist deliver test results if normal, while 51% stated the same if results were abnormal [1]. Although there is no current literature in either non-metastatic or metastatic cancer patients to suggest how patients might be impacted when they fail to receive test results consistent with their preference, these previous findings suggest that matching a patient's preference for delivery of results might lessen the degree of distress experienced during this period. For example, knowing that they will receive results in a few days or that their oncologist will call them with the results might buffer some of the uncertainty related to test results.

Additional factors that might impact levels of psychological distress are degreeofsocial support, health literacy, and expectations of imaging results. Positive social support is theorized to help people manage uncertainty and enhance perceptions of personal control in stressful situations, whereas, social isolation is thought to increase feelings of loneliness and decrease perceptions of personal control [11,12]. Although extensive research supports the impact of positive and negative social interactions in reducing stress and improving health and medical outcomes, there is no research that has specifically examined the effects of these types of support on distress surrounding any type of test result. Decreased health literacy – defined as the ability to obtain, process and understand medical information – is associated with increased anxiety, depression, and overall distress in cancer patients, but like social support, has not been studied in direct relationship to distress levels during the period when diagnostic testing is completed or results are delivered [13]. However, given the often high-stakes results of imaging tests, it is possible that metastatic cancer patients with low health literacy may experience greater distress if they anticipate difficulty understanding the results. Finally, we were interested in the effect of optimistic expectations related to imaging results on patient distress. Not only has general optimism been found to be inversely related to levels of distress in patients with cancer, but optimistic expectations regarding cancer prognosis has been linked to less distress [14], suggesting that optimism about results may have a similar effect on distress in this population.

In an attempt to better understand the distress that patients with metastatic cancer may experience, this study measures psychological distress surrounding CT and magnetic resonance imaging (MRI) in patients with advanced gastrointestinal or lung cancer, two solid tumor types that necessitate regular imaging to evaluate effects of treatment. In addition, this study will examine metastatic patient preferences for notification of imaging results and the relationship between distress and concordance, which we define as agreement between the preferred method (timeframe, method of delivery, personnel) of receiving results and actual method of delivery. Finally, this study investigates the impact of social support, health literacy, and expectations on distress levels during this period.

2. Methods

The study was approved by the Institutional Review Boards at Wayne State University and Karmanos Cancer Institute. Patients in treatment for metastatic gastrointestinal and lung cancer at the Karmanos Cancer Center in Detroit, MI, who were scheduled for a routine CT or MRI to assess treatment response, were recruited. Eligible patients were currently in treatment for active metastatic disease, over the age of 18, able to speak, read, and write in English, and were without cognitive or perceptual disturbances. There were no specific instructions given to members of the research team on how to engage with patients while information was being collected. Patients were approached about the study during a routine, outpatient visit with their medical oncologist. During this clinic appointment, a member of the research team explained the study procedures to interested patients. Those who agreed completed consent, Health Insurance Portability and Accountability ACT (HIPAA) authorization, and a short questionnaire assessing socio-demographic characteristics and health literacy. On the day of imaging, a member of the research team met with patients in the radiology suite and questionnaires were completed assessing preferences for notification of imaging results (timeframe, method of delivery, personnel), importance of those preferences, distress level, symptoms of anxiety and depression, and degree of social support. In addition, patients were asked about their expectations of the results. One week after notification of results, a research assistant contacted patients via telephone at home to complete a final questionnaire that asked about the results of their imaging tests, their distress level, symptoms of anxiety and depression, and how they were notified (timeframe, method of delivery, personnel). Following collection of the data above, a member of the research team abstracted information from the electronic medical record, including frequency of imaging examination over the past two years, date of notification of CT/MRI results, and actual imaging results.

2.1. Measures

2.1.1. Health literacy—Patients completed a 3-item measure assessing how often they have someone help read them medical forms, how difficult it is to read medical forms, and how confident they feel completing medical forms [15]. Items were rated on a 5-point Likert scale from 0=never to 4=always.

2.1.2. Distress—Patient distress was assessed with the Distress Thermometer, a widely used measure of distress that is part of the National Comprehensive Cancer Network (NCCN) Distress Management Guidelines [16]. This brief screening tool rates overall distress (on a scale of 1–10), with scores ≥4 suggestive of clinically significant distress. Change in distress from pre-imaging to post-imaging was calculated as a difference score (−1=*distress increased*, 0=*no change*, 1=*distress decreased*).

2.1.3. Anxiety and depression—Symptoms of anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS), which was developed for populations with medical illness and has been validated extensively in oncology patients [17]. The HADS has two 7-item subscales: Depression and Anxiety. Scores are interpreted as no (0-7), mild (8-10) moderate (11-14), or high (15-21) levels.

2.2. Social support

Social support was assessed with the Emotional Support, Social Isolation, and Instrumental Support subscales of the PROMIS (*Patient Reported Outcomes Measurement Information System*; www.nihpromis.org). These scales were developed by the National Institutes of Health for use in health-related research. The Emotional Support subscale measures perceptions of being cared for and valued and having close relationships (e.g., “I have someone who will listen to me when I need to talk”), while the Social Isolation subscale assesses perceptions of being avoided, excluded, detached, disconnected, or unknown by others (e.g., “I feel isolated from others”). The Instrumental Support subscale measures perceived ability to get assistance with tasks (e.g., “Do you have someone to help you with your daily chores?”). A score of 50 (SD = 10) on these subscales is the average for the U.S. general population. For Emotional and Instrumental Support, higher values indicate greater levels of support. The reverse is true for Social Isolation, where higher values indicate more social isolation.

2.2.1. Patient expectations for results—

Patients were asked a one-item question about their expectations for the result: “Did you and your doctor talk about or do you have any idea about what you expect the test to show?” (−1=*cancer or tumor is smaller*, 0=*cancer or tumor is not changed*, 1=*cancer has progressed or tumor is larger*). We calculated concordance between anticipated results and actual results by comparing patient response, yielding a dichotomous measure of expectation concordance (1=*yes* and −1=*no*).

2.3. Patient preferences for notification

On the day of CT/MRI, patients completed a questionnaire assessing their preferences for timeframe of notification (<24h, 1–2 days, 3–5 days, one week), method of delivery (telephone, email, letter, face-to-face visit), and notifying personnel (oncologist, radiologist, physician assistant, nurse). In addition, patients were asked to rate the importance of each of their preferences for notification (timeframe, method, and personnel) on a 4-point Likert scale (from 0=*not important at all to* 3=*extremely important*). Concordance for timeframe of notification, method of notification, and notifying personnel were calculated by comparing patient preferences on each item with actual notification method, yielding three dichotomous preference concordance outcomes (1=*yes* and −1=*no*).

2.4. Analysis

Descriptive data were summarized using counts and percentages for categorical variables and mean, standard deviation (SD), and range for continuous variables. We explored the association between primary study variables (preferences, concordance, expectations, and distress) and demographic and psychological variables using Pearson’s product-moment correlation. Chi-square, discriminant analysis, and regression analysis were used to determine if change in distress was associated with concordance in timeframe of notification, method of delivery, and notifying personnel.

3. Results

The study was conducted from January to November 2017 and 100 patients with metastatic gastrointestinal or lung cancer were enrolled. The 87 participants who provided data for all time points are included in the analysis. Characteristics of participants are presented in Table 1.

As shown in Table 1, participant levels of distress, depression, and anxiety were relatively low on both the day of CT/MRI and following the delivery of imaging results. Patients’ emotional and instrumental support were higher than the general population, and social isolation was lower. Almost 80% of participants (n = 68) reported adequate or higher health literacy, the remaining 20% (n = 18) reported marginal to limited health literacy (M = 3.24, SD = 1.21). The frequency of imaging ranged from every month to every year with the majority of the sample (n = 65) receiving scans every two months or less (M = 2.04, SD = 1.55).

Table 2 describes patient preferences for notification and how results were actually delivered to patients. Although the majority of participants preferred notification within 2 days after completion of CT/MRI, most were notified 3–5 days later or one week following the imaging exam. Most participants preferred notification from their treating oncologist and received results from this provider. While approximately two-thirds of patients chose a face-to-face visit for notification, and the majority were in fact notified in this manner, some did prefer the delivery of results via telephone.

Although concordance - or agreement between preferences for timeframe of notification, method of delivery, and notifying personnel and actual delivery of results - was not correlated with imaging day or post-result levels of distress, there was a positive correlation between concordance for notifying personnel and change in patient distress from imaging day to follow-up ($r = .249$, $p < .05$). This suggests that receiving results from preferred personnel may be more important in reducing distress than receiving results in a preferred timeframe or method.

As expected, imaging day distress was positively correlated with imaging day anxiety ($r = .606$, $p < .01$) and imaging day depression ($r = .547$, $p < .01$). Post-result distress was also positively correlated with post-result anxiety ($r = .683$, $p < .01$) and post result depression ($r = .523$, $p < .01$). At both points of assessment, patients who reported higher levels of anxiety and depression also reported higher levels of distress.

Although there was no association found between emotional and instrumental support and distress on imaging day or post-result, social isolation was positively correlated with imaging day distress ($r = .257$, $p < .05$). Additionally, social isolation significantly predicted distress on the day of study enrollment, $\beta = .280$, $t(72) = 2.01$, $p < .05$. Lower levels of health literacy were also associated with a preference for receiving results in a face-to-face visit, $\chi^2(8, 85) = 13.50$, $p = .05$.

Of those reporting an expectation of their imaging results ($n = 85$), 34% ($n = 29$) anticipated that their tumor would be smaller, 15% ($n = 13$) not changed, and 7% ($n = 6$) larger; 44% ($n = 37$) reported that they didn’t know what to expect. Expectations of results was not related to distress levels on imaging day or preferences for delivery of results. Following delivery of results, 84 participants reported actual results to research personnel. Of these, 39% ($n = 33$) reported their tumor as smaller, 42% ($n = 35$) not changed, and 12% ($n = 10$) larger; results were inconclusive for 6 participants. Concordance between patients’ expected and actual results was not associated with imaging day or post-result distress levels.

Discriminant analysis was also conducted to assess the effect of age, time since diagnosis, and participation in a clinical trial on imaging day and post-result distress levels; results showed no significant associations.

4. Discussion and conclusion

4.1. Discussion

Contrary to expectations, patients in our study reported relatively low levels of distress and anxiety on both the day of imaging and at the time of post-result assessment. There may be several reasons for this finding. First, although our study, like others, found no effect of time since cancer diagnosis on distress levels, it is possible that there is a degree of habituation that occurs with multiple and frequent scans required in treating metastatic lung and gastrointestinal cancer [5,18]. Undergoing scans may take on an almost routine quality in these patients, especially if the findings remain stable, and as a result, may cease to cause significant distress over time. This result is consistent with Peteet et al. who not only found that patients' anxiety decreased from their initial to their subsequent CT scans but also that their overall discomfort and fears about the CT process and equipment decreased from baseline to the follow-up assessment, supporting the possibility of habituation [1]. Second, of those patients who expected an outcome for their scan result, the majority believed that their tumor would either be smaller or the same. As general optimism has been inversely associated with distress in cancer patients, it is possible that optimistic or neutral expectations of results, both of which would be considered positive outcomes for metastatic patients, lessened the degree of distress experienced by participants in this study [14].

Not surprisingly, given what we know about preferences for notification of results following biopsy, the majority of participants with metastatic cancer preferred notification quickly, within 2 days of the imaging examination [8,9]. Regardless of the outcome, wanting to know the results quickly is likely a universal preference for most patients. Similar to women's preferences for delivery of abnormal mammogram results, the majority of participants in this study also preferred delivery of results in a face-to-face meeting by the physician responsible for ordering the examination [10]. It is possible that face-to-face delivery allows patients to receive immediate support from their providers and offers them the opportunity to easily ask any follow-up questions or discuss next steps in treatment. In our study, face-to-face delivery of results was perceived as particularly important for patients who had lower health literacy. Patients with metastatic disease who have lower health literacy may feel more comfortable receiving results in a forum that allows for a dialogue about the results and perhaps the use of other easily understandable cues (e.g., visual cues). Although concordance in timeframe of notification, method of delivery, and notifying personnel had no impact on imaging day or post-result distress, concordance for notifying personnel was significantly associated with a decrease in distress from imaging day to post-result assessments, suggesting that receiving results from preferred personnel might provide a psychological benefit to patients with metastatic cancer.

As expected, distress was associated with symptoms of anxiety and depression on both the imaging day and at the post-result assessment. At both points, patients who reported higher levels of anxiety and depression also reported higher levels of distress. This relationship is consistent with previous work showing significant correlations between scores on the distress thermometer and both the HADS anxiety and the HADS depression scale scores [19,20]. Taxonomic studies of anxiety and depression also show that anxiety and depression share a "substantial component of general affective distress," especially at lower levels, providing a likely explanation for the relationship between distress, anxiety, and depression in our study [21].

Although we expected that higher social isolation and lower emotional and instrumental support would be associated with distress, surprisingly only higher social isolation was associated with distress in this study. Given previous research, we expected that more positive social support would be associated with less distress [22]. For example, we expected that individuals with “someone to confide in or talk to about myself and my problems” would have lower distress because they have outlets for discussing their concerns. However, it is possible that when distress is low, social support does not confer any protective benefit. In contrast, higher social isolation may have a uniformly negative effect regardless of level of distress [18]. That is, individuals who report “feel(ing) left out” and “isolated from others” may not have outlets to discuss their concerns, which even at lower levels of distress, can have a negative effect on their psychological well-being. In fact, recent literature suggests that social isolation, due to the pervasive feeling of being alone, may in fact be a more robust predictor of deleterious mental and physical health outcomes than positive support [23]. Future research would benefit from further exploration of how social isolation in patients, especially among those with advanced disease, may increase risk for poor psychological outcomes at times of uncertainty during treatment.

This study has several limitations. As most participants were over the age of 60 and white, generalizability of our findings to younger patient populations and other races/ethnicities may be limited. In addition, results may not be applicable to patients with non-metastatic disease. Our participants did not have access to any type of patient portal; thus, preferences for notification of test results and levels of distress may differ in patients who have access to different notification options through these systems. As we did not control for the potential use of anti-anxiolytic medications, the degree of distress patients reported immediately prior to scans may have been minimized through the use of pharmacotherapy. Finally, although members of the research team were not instructed to interact with patients in any type of therapeutic manner, we cannot exclude the possibility that engagement with the team was an intervention in and of itself, and that distress was minimized by involvement in this study.

4.2. Conclusions

In summary, this study helps to clarify the preferences that patients with metastatic cancer have regarding delivery of imaging results and their relationship to distress surrounding imaging examinations. Contrary to our expectations, overall distress related to imaging examinations was low. However, distress was higher for some groups of patients, and attending to the preferences of these subgroups may help to minimize distress at a potentially psychologically vulnerable time.

4.3. Practice implications

Our findings, derived directly from patient participation in this study, support the importance of identifying patients with metastatic cancer who may be at higher risk for distress relative to their peers. In order to efficiently utilize supportive care services, those patients who screen positively for distress on the Distress Thermometer, which is already widely used in practice during intake evaluation, could be referred to a social worker or behavioral health specialist for additional screening prior to imaging examination. Interventions that would likely be of value to patients with social isolation should pay attention to increasing the availability of support that patients receive, bolstering existing support systems, and reducing the impact of negative support. For those who screen positively for depression and anxiety, a referral to a behavioral health specialist for treatment of comorbid psychiatric symptoms would be expected to be of benefit. Finally, matching patient preferences for personnel who deliver the results of imaging tests to patients with metastatic disease, and face-to-face meetings for those with lower levels of health literacy, may be particularly useful.

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Table 1

Participant Characteristics (N = 87)[a].

	N	% or M (SD)	Range
Age	87	61.5 (10.91)	32-84
Gender (Female)	87	55.2%	
Race/Ethnicity	52	59.8%	
Caucasian	33	37.9%	
African American	1	1.1%	
Middle Eastern	1	1.1%	
American Indian			
Education	7	8.0%	
Less than high school	25	28.7%	
Graduated high school	22	25.3%	
Some college	21	24.1%	
Graduated college	12	13.8%	
Postgraduate degree			
Annual Income	26	31.7%	
Less than $20,000	11	13.4%	
$20,000-$39,999	15	18.3%	
$40,000-$59,999	7	8.5%	
$60,000-79,999	23	28.0%	
More than $80,000			
Health Literacy	18	20.9%	
Marginal to Limited	68	79.1%	
Adequate to Higher			
Frequency of Scans (in months)	**87**	**2.04 (1.55)**	**1-12**
Distress - Day of Imaging	78	3.73 (2.60)	0-10
Distress - Post-result	75	3.91 (2.69)	0-10
HADS - Day of Imaging	84	6.12 (3.98)	0-21
Anxiety	86	4.36 (3.40)	0-21
Depression			
HADS - Post-result	85	5.32 (4.31)	0-21
Anxiety	87	4.34 (3.68)	0-21
Depression			
PROMIS (Scaled T-score)	85	57.53 (8.03)	25.7-62.0
Emotional Support	83	43.09 (8.13)	34.8-74.2
Social Isolation	84	59.05 (6.24)	29.3-63.3
Instrumental Support			

[a] Due to omitted responses from patients, not all ns are equal to the total numbers of participants.

Table 2

Notification Preferences, Expectations, and Actual Notifications.

	Preference (day of imaging)	N	% or M (SD)	Actual (receiving result) N% or M (SD)	
When Notified	37	43.0%		13	14.9%
Within 24 hours of imaging	29	33.7%		11	12.6%
1-2 Days after completing imaging	8	9.3%		26	29.9%
3-5 days after completing imaging	12	14.0%		37	42.5%
One week following the imaging					
Who Notified	62	72.9%		63	72.4%
Your Oncologist	4	4.7%		14	16.1%
The PA who works with Oncologist	5	5.9%		6	6.9%
The Nurse who works with Oncologist	14	16.5%		4	4.6%
The first available person/Other					
How Notified	58	67.4%		78	89.7%
Face-to-Face during a visit	4	4.7%		1	1.1%
Email	24	27.9%		8	9.2%
Telephone call					
Expectations vs Results	29	33.3%		33	37.9%
Cancer or tumor is smaller	13	14.9%		35	40.2%
Cancer or tumor has not changed	6	6.0%		10	11.5%
Cancer had progressed or tumor is larger	37	42.5%		6	6.9%
I don't know/Results are inconclusive					

[1] Due to omitted responses from patients, not all *ns* are equal to the total numbers of participants.