

# The Role of the Oncology Nurse Navigator in Distress Management of Adult Inpatients With Cancer: A Retrospective Study

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According to the National Comprehensive Cancer Network (NCCN, 2007), patients with cancer experience varying levels of distress about their disease, treatment, and prognosis. Frequently, the distress may be severe enough to impair patients' daily lives and abilities to comply with treatment regimens. One-third of all patients with cancer experience prolonged and high levels of distress that contribute to ongoing adjustment difficulties and can interfere with treatment compliance (Sellick & Edwardson, 2007; Vitek, Rosenzweig, & Stollings, 2007). Still, the healthcare system is doing little to adequately and responsibly attend to this issue (Bultz & Holland, 2006).

Several governmental and professional organizations recommend that patients with cancer be screened routinely for the presence of heightened psychological distress. The NCCN (2007) recommends that all patients with cancer be screened at the initial visit and at appropriate intervals thereafter. Several methods have been developed to screen for distress in patients with cancer. The Distress Thermometer (see Figure 1) is similar to the rating scale used to measure pain: 0 equals no distress and 10 equals extreme distress. The tool has been proven to be valid and reliable (Hegel et al., 2008).

The Distress Thermometer as used at Saint Elizabeth Regional Medical Center serves as a baseline, single-question screening tool to identify distress coming from any source, even if unrelated to cancer. The nurse asks the patient, "How distressed are you on a scale of 0 to 10?" A score of 4 or more indicates a significant level of distress that, according to NCCN, should be evaluated.

A relatively new type of professional, the oncology nurse navigator (ONN) is an RN trained in cancer care who guides and supports patients through the challenges of having cancer, from diagnosis to recovery. An ONN collaborates with all members of a patient's

**Purpose/Objectives:** To determine whether the oncology nurse navigator (ONN) role as an intervention decreases the distress of adult inpatients with cancer.

**Design:** Retrospective chart review was used to collect information about patient distress scores at admission and discharge. Scores were compared to determine whether the ONN role is effective in lowering patients' distress levels.

**Setting:** 261-bed regional medical center in the midwestern United States.

**Sample:** Convenience sample of 55 inpatients with diagnoses of cancer.

**Methods:** Nurses asked patients with cancer to rate their distress daily during their stays. Correlation studies and two-tailed t tests were used to assess the relationship between the change in distress and the ONN intervention.

**Main Research Variables:** Distress scores of patients seen by the ONN versus distress scores of patients not seen by the ONN.

**Findings:** Patients seen by the ONN tended to have lower distress scores on dismissal ( $p = 0.1046$ ). The difference was clinically significant to warrant providing an ONN for patient distress. ONN visits have a statistically significant effect on distress scores of inpatients 65 years of age or younger ( $p = 0.044$ ) and those from rural settings ( $p = 0.045$ ).

**Conclusions:** An ONN can lower patients' cancer-related distress scores. Other research has shown that ONNs can help increase patient satisfaction; this research shows that the satisfaction may be related to a decrease in distress and increase in overall quality of life.

**Implications for Nursing:** Patients experience high distress levels that can interfere with treatment compliance. This research shows that patients benefit from having an ONN to answer their questions and provide them with education about their diseases.

medical team to ensure that information about the diagnosis and plan of care is understood by all team members, including doctors, nurses, ancillary staff, and especially the patient and his or her family members.

## Figure 1. National Comprehensive Cancer Network Screening Tool for Measuring Distress

To view the most recent and complete version of the guideline, go online to [www.nccn.org](http://www.nccn.org). These guidelines are a work in progress that will be refined as often as new significant data become available.

At Saint Elizabeth Regional Medical Center, after the Distress Thermometer assessment, a patient is asked if he or she is interested in seeing the ONN. If the patient agrees to a visit and the physician orders the referral, the ONN sees the patient and reviews the Distress Thermometer problem list with the patient. The problem list, which is on the same page as the Distress Thermometer, asks the patient to identify individual problem areas: physical, practical (e.g., transportation, financial), psychological, social, or spiritual. The completed list is reviewed jointly by the ONN and the patient. Using this list, the ONN acts as an educator and patient liaison with various departments and agencies to alleviate as much of the patient's distress as possible, thus facilitating healing. If the patient's distress level is mild (score 0–3), the primary oncology team may choose to handle the problem without calling the ONN or to recommend a support group.

Although most studies involving the ONN role report that it is a strong patient satisfier, its effectiveness

and impact on clinical outcomes need further study (Schwaderer & Itano, 2007). Distress can interfere with a person's quality of life (QOL); in patients with cancer, it can interfere with treatment compliance and affect patient outcomes. This pilot study attempted to determine whether the ONN role as an intervention affects the distress level of adult inpatients with cancer.

### Review of the Literature

Nurses face increasing patient-care tasks and mounting paperwork; coupled with lack of time, nurses often are prevented from achieving as deep and important therapeutic relationships with their patients as they would like (King, 2006). Many assessments have been identified as important to comprehensive care of patients with cancer, but time constraints may keep nurses from performing such assessments on a timely basis. Nurses generally do not conduct early formal nutrition assessments on patients with advanced cancers, nor do they

continually assess nutrition status; families more often bring the issue forward (Dewey & Dean, 2007). Patients rarely are assessed for sexual dysfunction (Mick, 2007). Women typically report high levels of anxiety after an abnormal mammogram, which could be alleviated by access to a healthcare professional responsible for providing support in such situations (Pineault, 2007). A source of disparity that often is overlooked is distance to a treatment center. According to Lyons (2004), rural women travel greater distances for appointments and feel more isolated during treatment. Compared to women who live in urban settings, rural women experience a more cumbersome process while attempting to access needed resources. Finally, rural women are less likely to know what information is available and are less likely to take steps to access existing healthcare resources (Lyons).

Ropka and Padilla (2007) reported that patients receiving cancer therapy find that their coping abilities and QOL are negatively affected by hospital stays, fatigue, distress, and disruption of normal activities. Symptom burden is a concept of symptom management that contributes to the understanding of patients' physiologic and psychological functioning. Appropriate and timely management of disease symptoms is needed, as well as treatment of side effects that adversely affect comorbidities (Gapstur, 2007). Patient education provided in a concise and efficient manner, tailored to patient need (e.g., literacy, motivation, computer knowledge), has been shown to be correlated with improved patient outcomes (Treacy & Mayer, 2000).

Patients with cancer have a deep desire to be heard, want to be able to tell their stories, and need someone to listen. Healthcare providers should be patient advocates by listening as well as providing information about issues following treatment (Lackey, Gates, & Brown, 2001). Detmar, Aaronson, Wever, Muller, and Schornagel (2000) reported that most patients are willing to discuss their physical symptoms and functioning, but only a few are willing to discuss their emotional symptoms and functioning. Healthcare-provider-led discussions are needed for all symptoms a patient is experiencing, not just physical symptoms (Detmar et al.)

Nurses tend to rate patients' QOL as lower or worse than patients rate it themselves (King, Ferrell, Grant, & Sakurai, 1995). Therefore, patients must assess their own QOL. Clinical nurses can have a significant effect on various aspects of QOL for individuals with cancer.

## Tools for Measuring Quality of Life and Distress

When assessing symptoms, healthcare professionals should quantify assessments and demonstrate that

interventions are utilized and effective. A QOL tool usually is used, but the QOL assessment and the symptoms targeted or types of interventions may have no significant relationship. To affect a patient's QOL, clearly defined interventions must be identified, underscoring the importance of standard, proven tools (Buchanan, O'Mara, Kelaghan, & Minasian, 2005).

Oncology nurses may not consistently use a standard assessment for psychosocial issues in patients with cancer. This may be because of their concern with more immediate physical symptoms and the greater difficulty of assessing and addressing psychosocial issues. If a clinician does not attend to the difficult questions, a patient may not bring them forward. Therefore, a standard QOL assessment, incorporating all aspects of a patient's life, should be initiated (Buchanan et al., 2005).

One useful QOL assessment, the NCCN Distress Thermometer, can be integrated easily into patient assessment (Fulcher & Gosselin-Acomb, 2007; NCCN, 2007). Fulcher and Gosselin-Acomb cautioned that the level of intervention needs to be well-defined and patient-focused to positively affect the degree of patient distress. They found an increase in patient satisfaction when clinicians inquired about their distress. However, no specific intervention was found to statistically lower a patient's distress score (Fulcher & Gosselin-Acomb). Other variables to consider are the possibility of poor intervention or incorrect administration of the Distress Thermometer. Integration of distress assessment into patient assessment is needed in all cancer settings; in addition, for all patients scoring 4 or higher on the Distress Thermometer, a multidisciplinary approach to intervention is needed (Vitek et al., 2007).

## The Role of the Oncology Nurse

The role of the nurse as one of the principal patient educators has developed over the years. Oncology nurses are vitally involved in the education of patients, families, peers, and the public. Advances in cancer care have required frequent reviews and revisions of patient teaching methods and materials. Physicians inform patients of treatment plans, alternative treatments, and risks and benefits of proposed treatments, as well as how responses will be evaluated. This leaves patients with a need for information about side-effect management, nutrition, emotional coping, and other skills that can be developed and nurtured. Traditionally, patients who receive less education have a greater potential for re-accessing the system, either by telephone or unscheduled visits. Unanticipated calls and visits stress the system and can translate into a need for additional staff, overtime pay, or a reduction in the quality of care. Preventive education and adequate time with patients before treatment saves resources (Schulmeister, 1991). Faced with mounting demands, floor nurses often have time only for the essentials. Even

with floor nurses' best efforts, patient education, though essential, may be fragmented and incomplete. This is where ONNs can be of immense benefit.

Providing all of the education necessary for positive patient outcomes requires more time and support for patients. With increasing consumer and governmental demands for reporting of patient satisfaction, clinical quality, and outcome measures, healthcare facilities are designating personnel who have the time to perform such needed tasks; some cancer centers are employing ONNs.

ONNs must be knowledgeable about appropriate nursing interventions for side-effect management and complications. Theoretically, anyone knowledgeable about the dynamic yet convoluted nature of cancer care can be a navigator. However, oncology nurses are best suited for the task because of their understanding of all aspects of oncology (Seek & Hogle, 2007). In addition, ONNs are able to help with cancer survivors' many symptoms that affect their ability to cope with their disease and QOL. Such patients need a qualified oncology nurse to provide education and explanations about their care plans, manage side effects from disease and treatment, and help them develop coping mechanisms (DeSanto-Madeya, Bauer-Wu, & Gross, 2007).

Navigation involves using trained professionals to assist patients with improved access to care, thus impacting patient outcomes by providing early contact with resources and education. Establishing a single person to work consistently with a patient at every visit provides continuity for the patient and allows for a deeper and more therapeutic relationship. Satisfaction with the patient navigator role has been attributed to patient navigators' help with addressing barriers to care common in disparate populations (Gopal, 2005; Schwaderer & Itano, 2007). Nurse navigators have been implemented easily in all care settings and have been helpful to the multidisciplinary team for the cohesive continuum of patient care from diagnosis to survivorship (Fillion et al., 2006).

## The Oncology Nurse Navigator

The nurse navigator role has many dimensions. Some roles focus on socioeconomic issues, others target access to care and disparities, whereas others act as advocates, helping patients overcome barriers to care. The cost-effectiveness of the navigator role needs validation, although most programs are not set up to test this (Dohan & Schrag, 2005). From a healthcare system standpoint, the navigator role may help decrease length of stay and lower the rate of readmission by educating patients to understand and handle their diseases and treatments. More standards for the navigator role will be developed, and professional organizations will assist in overall cohesiveness and competency of the evolving navigator role.

As a result of this review, several themes help direct exactly what and who an ONN is. An ONN should be a nurse trained in oncology. For the purposes of lowering patient distress, an Oncology Certified Nurse (OCN<sup>®</sup>) is best able to discuss side-effect management, treatment plans, further options, resources, and support. Most importantly, an OCN<sup>®</sup> is able to reassure patients about their fears based on experiences with other patients.

More educated patients are less likely to stress the system during their treatment. The main purpose of an ONN is education regarding the effects of treatment and management strategies, as well as education of next steps to follow and resources available to get through treatment. An ONN must be available to patients for questions and be able to direct them to the correct answers and resources.

Patients also need physical navigation through the complexities of health care, and an ONN can make sure patients get to treatments on the right days and follow through with their intended courses. In this respect, an ONN is able to be a liaison between a patient and the healthcare team. This single point of contact is important for decreasing confusion and allows for a deeper and more therapeutic relationship to develop.

The ONN is able to provide ongoing follow-up regarding patient QOL because the ONN reviews the Distress Thermometer with the patient at each visit. Additionally, providing a single contact to review such information with a patient could increase patient compliance with treatment.

Finally, an ONN needs to be a person with insight into the cancer experience, not necessarily a cancer survivor, but someone who is able to provide a high level of compassion and patience every day. An ONN must be able to treat everyone with dignity and without judgment of their current situations and be able to see each person holistically.

## Purpose

The primary objective of this retrospective study was to determine whether the ONN role as an intervention decreases the distress of adult patients with cancer. The researchers believed that distress levels in oncology inpatients seen by the ONN during hospitalization would decrease from admission to discharge significantly more than the distress levels of oncology inpatients not seen by the ONN.

## Methods

The study was conducted by retrospective chart review. The NCCN Distress Thermometer has been in use at Saint Elizabeth Regional Medical Center since March 31, 2008. Currently, nursing staff ask patients with



cancer to rate their distress at bedtime every evening during an inpatient stay.

Education was provided to the oncology department nurses regarding the distress score and appropriate intervention. The education was provided on three occasions to attain maximum attendance. Attendance of floor nurses to the sessions was 33% ( $n = 14$ ), and all rated the information useful in their practice; the other 67% ( $n = 30$ ) received copies of the presentation with an attached quiz, which half completed. The nurses were educated about the distress score to provide continuity of care in case a patient refused to see the ONN; this education also was helpful to verify that the nurses understood how to administer the distress questions appropriately.

All patients with at least two self-reported distress scores were included in the study's statistical data, and all oncology inpatients during the time frame were reconciled. The first charted distress score was recorded as the initial score; the last distress score prior to discharge was recorded as the discharge score. Additional demographic information collected included age, gender, diagnosis, and reason for admission. Information on race and ethnicity, following the National Institutes of Health definitions, was collected when available. Rural or urban status also was tracked. Urban was defined according to the U.S. Department of Agriculture Economic Research Service (2003) Rural-Urban Continuum code definition as a metropolitan centralized urban county. Rural Nebraska was, therefore, any Nebraska address outside Lancaster, Sarpy, and Douglas counties.

## Subjects

Charts were reviewed for patients admitted to Saint Elizabeth Regional Medical Center between April 1, 2008, and August 31, 2008. Additional inclusion criteria included the following.

- Patient was 19 years or older.
  - Patient had a primary or secondary oncology diagnosis.
  - Inpatients spent more than 24 hours in the hospital.
  - Patient agreed to see the ONN.
  - Physician order was received for ONN visits.
  - Distress Thermometer question was answered on at least two separate dates during a single inpatient stay.
- Charts were excluded when patients did not provide answers to the Distress Thermometer question on two separate occasions during the hospitalization.

The retrospective chart review was approved by the hospital research council and did not require subject consent. A convenience sample of subjects was selected from adult inpatients who were admitted during the first three months after implementation of the distress assessment. Each subject was identified by a unique study number, and completed data collection forms were secured in the Saint Elizabeth Regional Medical

Center Cancer Institute on a password-protected computer. The data collection forms were deleted from that computer six months after the conclusion of the study.

A total of 79 charts were reviewed, 23 of which contained only one distress score and were excluded from the data analysis. The lack of a second score was most likely caused by the relative newness of the tool in the oncology patient care plan at the facility, despite education and a follow-up quiz administered to all nurses performing the assessment. One patient with a starting distress score of 0 was seen initially by the ONN and subsequently refused any additional visits. That patient also was excluded from the data analysis despite recording a second distress score of 0. The ending sample size was 55 subjects.

The sample included 20 women (36%) and 35 men (64%). Their ages ranged from 44–87 years, with a mean of 66.2 years ( $SD = 10.83$  years). Because race and ethnicity are not required questions at the facility and were reported in only 30% of the charts, race and ethnicity were not reported for this study. Nineteen (35%) of the eligible subjects were classified as rural residents, according to the U.S. Department of Agriculture Economic Research Service (2003). The other 65% ( $n = 36$ ) were considered to reside in urban counties.

Most of the subjects had a diagnosis of cancer before the hospital admission ( $n = 51$ ), with only a few subjects receiving a diagnosis of cancer during the admission. Gastrointestinal cancers accounted for 29% ( $n = 16$ ) of the cases, followed by lung cancers (23.6%,  $n = 13$ ), leukemia and lymphomas (16.4%,  $n = 9$ ), and breast cancer (11%,  $n = 6$ ). Genitourinary cancers, head and neck cancers, melanoma, brain cancers, and sarcomas also were represented in the sample population as principal diagnoses.

## Data Analysis

Correlation studies and two-tailed  $t$  tests were used to assess the relationship between the change in distress and the interventions of the ONN. A  $p$  value  $\leq 0.05$  was set for statistical significance. Descriptive statistics (frequencies, means, and standard deviations) were obtained for all variables, including age, gender, diagnosis, and length of time between scores. All missing data points were noted and tracked (see Table 1).

## Results

Data analysis showed that ONN visits did not significantly affect distress levels in inpatients with cancer during their stays when compared to levels in those who did not see the ONN ( $p = 0.1046$ ). However, patients seen by the ONN ( $n = 33$ ) showed a mean decrease in scores of 1.4 points, whereas patients not seen by the ONN had a mean increase of 0.23 ( $SD = 3-3.75$ ).

**Table 1. Mean High Initial Scores, Average Changes in Distress Scores, and p Values**

Population	$\bar{X}$ High Initial Score	$\bar{X}$ Change in Scores	p
<b>General sample</b>			0.1046
Seen by ONN	4.03	-1.4	
Not seen by ONN	2.76	0.23	
<b>Rural patients</b>			0.045
Seen by ONN	5.36	-3.64	
Not seen by ONN	2.63	0.53	
<b>Urban patients</b>			0.5961
Seen by ONN	3.52	-0.38	
Not seen by ONN	2.6	0.53	
<b>65 or younger</b>			0.044
Seen by ONN	5.21	-2.63	
Not seen by ONN	3.55	-0.09	
<b>66 or older</b>			0.868
Seen by ONN	2.43	0.36	
Not seen by ONN	1.91	0.55	

ONN—oncology nurse navigator

Further comparisons based on demographics showed some significant differences. First, the inpatient ONN visits had a statistically significant effect ( $p = 0.044$ ) on the distress scores of inpatients who were 65 years of age or younger ( $n = 16$ ) when compared to the distress scores of inpatients in the same age bracket who did not see the ONN ( $n = 11$ ). No significant difference was noted in the distress scores of those older than 65 years of age ( $p = 0.868$ ).

Similarly, an unpaired t test on the rural patients seen by the ONN ( $n = 11$ ) compared to rural patients not seen by the ONN ( $n = 8$ ) showed a significant difference in distress scores ( $p = 0.045$ ). Rural inpatients seen by the ONN experienced a mean decrease in scores of 3.64, whereas rural inpatients who did not see the ONN had no difference in their mean scores. Conversely, for the urban population, no statistically significant effect of the ONN on distress scores was found ( $p = 0.5961$ ). No statistical differences existed in distress scores between women seen ( $n = 14$ ) and women not seen ( $n = 6$ ), with a two-tailed  $p$  value of 0.7656. Similarly, men seen ( $n = 19$ ) and men not seen ( $n = 16$ ) had no statistical difference in their scores ( $p = 0.0874$ ).

One somewhat unexpected finding was related to the optimal number of visits the ONN should make to have a significant difference on distress scores. Inpatients experienced the greatest benefit from the ONN visits when they were seen three or four times during their stays. Patients who were seen three or four times had a mean decrease in scores of 3.88 ( $n = 8$ ), whereas those seen fewer than three times or more than four had a mean

decrease of only 0.42 ( $n = 24$ ). The two-tailed  $p$  value was significant at 0.0223. The mean length of stay for those patients seen by the ONN was 11.8 days ( $SD = 8.3$ ).

## Discussion

This pilot study revealed no significant difference in general distress scores between inpatients with cancer who saw the ONN and those who chose not to see the ONN. However, a trend of lower distress scores was seen in patients seen by the ONN when compared to those who did not. This leads the authors to believe that patients who see the ONN often will leave the hospital with a lower distress score than those who do not see the ONN. Given the sample size and relative novelty of the distress score question for the staff, the test may need to be repeated in the future for further confirmation of this finding because the trend suggests a possible correlation.

However, significant decreases occurred in distress scores in patients 65 years of age or younger who chose to see the ONN as well as in patients who resided in rural areas and chose to see the ONN.

Living with the side effects of cancer in a rural area tends to be predictive of a lower QOL score (Lyons, 2004). Lyons found no difference between rural and urban patients in knowledge levels regarding diagnosis and treatment, but rural patients were less likely to be aware of the array of available information and less likely to take steps to take advantage of accessible health care. The authors have found that the ONN can play a significant role in decreasing the distress scores of such patients while they are in the hospital. Conceivably, the ONN played a more significant role in making the information available. The ONN also would have helped develop plans for follow-up visits for rural patients, assisted with transportation needs, and provided information about making fewer trips out of the rural area for treatment, follow-up, or emergencies. The ONN provides all patients with information regarding side effects of treatment and when to call the physician for more assistance. Perhaps such information is beneficial to someone from a rural area who may believe that a physician is inaccessible to them. Possibly, the rural patients were glad to know that they could call one person for needed information. Regardless of the reason, the results are compelling enough to undertake more research with this particular population.

The researchers were more challenged to explain the significant decrease in the distress of those 65 years of age and younger. Several theories can be proposed. First, perhaps the younger population has more stressors in their lives in addition to a cancer diagnosis than those who were older than 65. Therefore, the ONN was able to affect more areas of distress and decrease it more significantly. This possibility would need to be evaluated by

an initial measurement of the number of stressors each patient indicates on the Distress Thermometer. Second, although people younger than 65 may have more stressors, the stressors may be types impacted with more readily attainable interventions. For example, finding help for a young mother who has distress about child care for her 6-year-old is easier than helping a newly retired 66-year-old man distressed about not being able to follow through on plans to travel with his wife. Although both situations present situations of distress that can be managed, finding child care for the young mother is easier than working with the retiree and his emotional well-being. Also, the ONN researcher has found that, in general, the younger population seems more open to relating the origins of their distress, making the distress easier to address. Using the earlier examples, the young mother is more able to admit that she needs help with her child than the man is able to admit that he did not get to do certain things in his life. Again, this theory needs further research to determine its validity.

## Conclusions and Implications

The healthcare team should understand that patients' distress decreases when they have an ONN as part of their healthcare team. The ONN serves as an advocate and provides information on disease, treatment processes, resources, and support. The impact of this type of assistance is not one that easily lends itself to categorization, but rather leads a nurse to believe that an ONN will have a varied effect on all patients, generally helpful.

On average, the ONN intervention showed a reduction in all patients' distress scores but had the greatest effect on significantly reducing distress for rural patients' and those 65 or younger. Additionally, the ONN had the greatest effect on patient distress after three or four visits with a patient. This is beneficial for the ONN to understand. Although this study's main objective was to determine the effectiveness of the ONN on patient distress, it found that the ONN had a stronger effect on rural and younger patients, which should help ONNs prioritize their workloads. ONNs have a finite amount of time that they get to spend with each patient. Some larger institutions have ONNs who specialize in cancer type; perhaps this study shows that rural populations and those younger than 65

may need their own specific navigators. The greatest effect on patient distress was evident at three or four visits. Some patients may not need to be seen every time they access the system, but ONNs can let patients know that they are always available to help them.

From an institutional perspective, having a qualified ONN may be seen as a financial drain, as most insurance companies do not reimburse the facility for this service. However, this study shows compelling evidence that the ONN helps lower patient distress related to disease.

## Limitations and Future Research

This study was limited by the sample size and the use of only one facility. Another limitation was the study's retrospective nature; however, other researchers have documented recruitment challenges when attempting to randomize a population into a study of this type (Skrutkowski et al., 2008). The use of convenience sampling is a limitation to this pilot study. Furthermore, the use of multiple nurses asking the distress question carries a potential for the introduction of bias to the study, although every attempt was made at reducing bias by scripting the verbiage for the nurses on the actual assessment tool.

Research is needed with a larger sample and a multicenter approach to determine the impact of the ONN on inpatients with cancer. The researchers recommend that a single nurse administer the distress question to all subjects in an attempt to diminish bias. Perhaps a quasiexperimental, interrupted time series design, where each patient serves as his or her own control, would be an option to increase patient participation while still providing the services of the ONN.

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