

# Integrating a Question Prompt List on an Inpatient Oncology Unit to Increase Prognostic Awareness

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**Background:** Many patients with incurable cancer do not accurately understand their prognosis, which can lead to aggressive and, often, futile treatment. Improved prognostic awareness can help patients to appropriately de-escalate aggressive treatment sooner in an illness trajectory.

**Objectives:** The purpose of this article is to introduce a patient-initiated discussion aid (question prompt list) on an oncology unit to increase prognostic awareness by promoting patient-provider dialogue, which could lead to limitation of life-sustaining treatments at the end of life and increased do-not-resuscitate (DNR) orders and hospice referrals.

**Methods:** Medical records of consecutively admitted patients with a solid malignancy who were urgently admitted to the inpatient setting were reviewed for three months to determine the percentage of DNR orders and referrals to hospice care. After inclusion of the communication aid in admission packets, records of consecutively admitted patients to the inpatient setting were reviewed for three months to reassess the percentage of DNR orders and referrals to hospice care.

**Findings:** An increase was seen in the percentage of patients with active DNR orders and in hospice referrals after a discussion aid was included in admission packets.

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Metastatic cancer, a mostly incurable disease, is the second leading cause of death in the United States (American Cancer Society, 2016). Despite this grim diagnosis, the current trend in oncology care does not actively promote transition to less aggressive care in a patient's final weeks of life. The Commission on Cancer ([CoC], 2012) implemented a blueprint of essential aspects of cancer care that spans the full spectrum of the disease from prevention through end-of-life care. The standards outline specific quality standards directed at "patient-centeredness," which aims to engage patients and their providers in the development of a personalized treatment plan that takes into account not only medical information, but also the values, needs,

and expectations unique to the patient (Balogh et al., 2011; CoC, 2012). Unfortunately, barriers to the implementation of patient-centered care still exist, particularly at the end of life (Shockney & Back, 2013). Impeding factors include lack of provider time and communication skills, as well as patients' comorbidities, low health literacy, and high emotional states (Balogh et al., 2011). *Prognostic awareness*, or the "capacity to understand prognosis and the likely illness trajectory" (Jackson et al., 2013, p. 894), is another factor that is fundamental to patient-centered care in oncology but often is underdeveloped and overlooked as an important factor in care decisions. In patients with cancer, prognostic awareness has been conceptualized as initiation of do-not-resuscitate (DNR) orders, as well as earlier entry into

hospice care (Applebaum et al., 2014; Kao et al., 2014; Yun et al., 2011). The purpose of this quality improvement (QI) project was to increase prognostic awareness by promoting patient–provider dialogue through use of a communication aid that could lead to limitation of life-sustaining treatments at the end of life, increased completion of DNR orders, and increased hospice referrals.

## Background

Nurses are all too familiar with the sense of frustration that develops when caring for a failing patient who does not seem to have an understanding of a poor prognosis or limited life expectancy. Such sentiments are common in oncology; research indicates that patients who have side effects from the disease or treatment that are severe enough to require hospitalization have a median survival of six months (Rocque et al., 2013). Similar results were found in the oncology department of this project when a review of consecutive patient admissions during a three-month time period revealed that 64 of 128 (50%) patients were deceased six months later during a follow-up audit. Even more unsettling is this finding: Although the majority of patients with cancer express a desire to die peacefully at home, many will die in the hospital and significantly less than half will receive hospice services (Koesel & Link, 2014). Review of the discharge destination of the 128 patients in this project supported this finding and also revealed that 21 patients (16%) accepted hospice services at discharge and another 16 (13%) died during their hospitalization.

Prognostic awareness is a factor that has been positively associated with reduced patient psychological distress, enhanced end-of-life planning, and improved overall quality of life (Diamond, Corner, De Rosa, Breitbart, & Applebaum, 2014). In addition, those with an accurate prognostic awareness are more likely to accept earlier entry into hospice and to implement DNR orders sooner in their illness (Kao et al.,

2014; Yun et al., 2011). Studies estimate that from one-third to one-half of patients with advanced cancer are inaccurate in their understanding of their prognosis (Jackson et al., 2013; Robinson et al., 2008; Shields et al., 2009; Temel et al., 2011). The lack of a complete and accurate understanding of prognosis and timely selection of hospice services is not surprising; the metaphor of war or “waging a battle” has been used in cancer care, creating a barrier to the development of prognostic awareness. Oncologists and patients alike are urged to “win the battle,” denying the incurability of advanced-stage cancer and the near certainty that patients, ultimately, will lose their lives (Ellis, Blanke, & Roach, 2015). This mindset often was observed on the oncology units at the project site medical center, with oncologists continuing to offer treatment to patients with a poor prognosis. Specifically, 79 of the 128 patients (62%) had received chemotherapy within 30 days of hospital admission, and, of those 79 patients, 37 were deceased at six months—10 during their hospitalization. Because the decision to continue chemotherapy late in a cancer illness is associated with other types of aggressive care, this may be an important indicator of patients’ poor prognostic awareness (Mack et al., 2015). Despite the obvious obstacles within the current culture of oncology for accurate prognostic awareness, oncology nurses and providers owe it to patients to explore ways to help them increase their capacity to understand and initiate discussions about their prognosis.

A review of the literature suggests that the use of communication or discussion aids, such as a question prompt list (QPL), has been successful in improving aspects of patient–provider communication. The Australian Health Services Research Institute completed a systematic review, citing 20 studies and 14 summarizing articles concerning the use of QPLs in health care (Sansoni, Grootemaat, Duncan, Samsa, & Eagar, 2014). Most of the studies demonstrated an overall high intention-to-use rate (91%), but, in actuality, usage only averaged near 50% (Sansoni et al., 2014). In studies specifically concerning patients’ use of question prompt tools, the content area of prognosis was described as most significant (Sansoni et al., 2014). Brandes et al. (2014) corroborated that the provided QPL was useful to patients in initiating conversations about prognosis, with 57% of questions asked by patients arising from the tool. Many participants adapted the questions to their own words rather than asking the questions verbatim, supporting the role of QPLs in the development of shared decision making by promoting patient involvement (Brandes et al., 2014). Tang et al. (2014) correlated interventions that promoted end-of-life discussions between patients and providers with DNR order implementation and other limitations on life-sustaining measures. The authors hypothesized that such discussions allowed patients to be better informed about the benefits or burdens of care and, subsequently, helped them to develop improved prognostic awareness (Tang et al., 2014). Overall, evidence in the literature supports the use of a QPL as an effective aid for patient–provider discussion. The purpose of this QI project was to use a prognosis-focused discussion aid (the QPL) given to patients with cancer who had been urgently admitted as a way of increasing DNR orders and hospice referrals.

- What does this hospitalization mean for my treatment?
- What is currently happening with my cancer?
- What are the chances of controlling my cancer?
- What can I expect in the future?
- Will this cancer shorten my life?
- What is the best-case scenario?
- What is the worst-case scenario?
- What is the aim of my cancer treatment?
- Is it still possible to cure my cancer?
- What are the pros and cons of more cancer treatment?
- How likely will treatment control my cancer?
- How likely will treatment help me live longer?
- Will more treatment make me feel better or worse?
- Should I consider stopping anti-cancer treatments and focus more on treatments to make me feel better?
- Should I consider a do-not-resuscitate order?

### FIGURE 1. Prognostic-Focused Question Prompt List

*Note.* Based on information from Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine, 2013; Walczak et al., 2014.

# Methods

## Theoretical Framework

The Plan-Do-Study-Act cycle, a scientifically proven framework to implement rapid but evidence-based change, guided the implementation of the project (Institute for Healthcare Improvement, 2015). The initial step of planning involved gaining support from the medical director of oncology as well as the nurse manager of the oncology unit. The inpatient environment had been resistant to prognosis discussions because many of the oncologists approached de-escalation of care much like the war metaphor—losing the battle. Obtaining medical support required several discussions with the medical director. In addition, a brief presentation about the local data obtained from the initial chart audits was given during a medical group staff meeting, with a review of the concept of prognostic awareness and its potential impact on patient care outcomes. The presentation included the use of a QPL discussion aid. Nursing management was more easily convinced of moving forward with the project. Overwhelmingly, nursing staff members expressed interest in the project and its intended goal as a first step toward improved patient prognostic awareness.

A QPL discussion brochure was created using a list of broad, open-ended questions about prognosis that were taken from previously used QPLs found in the literature (see Figure 1). The cited QPLs were developed from expert panels that used content analysis of focus groups and patient interviews performed by researchers and had content validity (Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine, 2013; Walczak et al., 2015). Prior to final printing, laypersons, as well as physician and advanced practice nurse peers, reviewed the created QPL for understandability and clarity.

## Setting and Sample

The two dedicated oncology inpatient units in which the project was implemented were within a large tertiary medical center, which was part of a regional medical system associated with a state university. The majority of patients admitted to the units were under the care of the university-affiliated oncology group. Data obtained from the electronic health record were de-identified and reported in aggregate format to protect patient privacy.

Baseline data included 152 admissions from a cohort of 128 individual patients who met eligibility criteria, and the postintervention data included 196 eligible admissions from a cohort of 166 individual patients; some patients had more than one admission. For detailed patient characteristics, see Table 1. The criteria used to determine which patients to include were those who were (a) being urgently admitted or transferred to one of the two inpatient units, (b) having been previously diagnosed with a solid tumor malignancy, and (c) being considered “incurable” by the primary treating oncologist. Patients not included in the data collection were those with (a) a planned or non-acute admission (e.g., chemotherapy administration), (b) a newly diagnosed malignancy during the same admission, (c) a hematology-based

TABLE 1. Sample Characteristics

| Characteristic                   | Preimplementation<br>(N = 128) |    | Postimplementation<br>(N = 166) |    |
|----------------------------------|--------------------------------|----|---------------------------------|----|
|                                  | n                              | %  | n                               | %  |
| <b>Gender</b>                    |                                |    |                                 |    |
| Female                           | 67                             | 52 | 88                              | 53 |
| Male                             | 61                             | 48 | 78                              | 47 |
| <b>Race</b>                      |                                |    |                                 |    |
| Caucasian                        | 71                             | 55 | 91                              | 55 |
| African American                 | 53                             | 41 | 75                              | 45 |
| Other                            | 4                              | 3  | —                               | —  |
| <b>Malignancy</b>                |                                |    |                                 |    |
| Lung                             | 46                             | 36 | 59                              | 36 |
| Breast                           | 21                             | 16 | 25                              | 15 |
| Gastrointestinal                 | 16                             | 13 | 24                              | 14 |
| Gynecologic                      | 10                             | 8  | 8                               | 5  |
| Pancreatic                       | 10                             | 8  | 7                               | 4  |
| Biliary or liver                 | 8                              | 6  | 17                              | 10 |
| Head and neck                    | 6                              | 5  | 5                               | 3  |
| Prostate                         | 4                              | 3  | 5                               | 3  |
| Sarcoma                          | 3                              | 2  | 1                               | 1  |
| Bladder                          | 1                              | 1  | 4                               | 2  |
| Brain                            | 1                              | 1  | 2                               | 1  |
| Kidney                           | 1                              | 1  | 4                               | 2  |
| Melanoma                         | 1                              | 1  | 3                               | 2  |
| Skin                             | —                              | —  | 2                               | 1  |
| <b>Time since last treatment</b> |                                |    |                                 |    |
| Fewer than 30 days               | 79                             | 62 | 101                             | 61 |
| 1–3 months                       | 18                             | 14 | 19                              | 11 |
| 4–6 months                       | 7                              | 5  | 13                              | 8  |
| 7–9 months                       | 1                              | 1  | 5                               | 3  |
| 10–12 months                     | —                              | —  | 1                               | 1  |
| More than one year               | 10                             | 8  | 11                              | 7  |
| During admission                 | 6                              | 5  | 8                               | 5  |
| Never                            | 7                              | 5  | 8                               | 5  |
| <b>Discharge destination</b>     |                                |    |                                 |    |
| Home                             | 92                             | 72 | 118                             | 71 |
| Hospice                          | 19                             | 15 | 29                              | 17 |
| Nursing facility                 | 1                              | 1  | 6                               | 4  |
| Death                            | 16                             | 13 | 13                              | 8  |

*Note.* Participants in the preimplementation group had a mean age of 61.9 years, with a range of 30–84 years. Participants in the postimplementation group had a mean age of 64.2 years, with a range of 30–91 years.

*Note.* Because of rounding, percentages may not total 100.

malignancy, or (d) an overall treatment goal indicated by the primary oncologist as curative.

## Implementation

Patient information was collected from a review of the electronic health record of patients obtained from the units’ admission, discharge, and transfer log. Baseline data were collected for three months and then continued for an additional three months postintervention implementation. Data included general demographics, as well as the two main outcomes of an active DNR order and the patients’ discharge destination. All data were collected using a Microsoft Excel® spreadsheet and analyzed using descriptive statistics, with results displayed in categorical format.

**TABLE 2. Do-Not-Resuscitate Order Implementation by Month**

| Month                   | n  |
|-------------------------|----|
| November 2014 (N = 52)  | 18 |
| December 2014 (N = 68)  | 14 |
| January 2015 (N = 32)   | 6  |
| April/May 2015 (N = 67) | 23 |
| May/June 2015 (N = 76)  | 27 |
| June/July 2015 (N = 53) | 24 |

The QPL patient discussion aid was included in an oncology-specific admission packet that was given to all patients with cancer who were admitted to the two specified oncology units. In addition to the QPL, the packet included a welcome letter from the nursing administration of cancer services and unit manager with a list of telephone contact information, as well as brochures on the cancer navigator program, available survivor wellness programs, the state's central cancer registry, available support groups for survivors and their families, and a cancer guide from the American Cancer Society.

## Results

The percentage of patients with an active DNR order in the preintervention time period was 24%, and this increased to 39% in the postintervention period. The individual month totals for DNR order implementation are in Table 2. The baseline hospice referral rate was 13%, and this increased to 22% in the postintervention period. Individual monthly totals for discharge to hospice care are in Table 3.

## Discussion

The use of QPLs as a discussion aid is recognized as an effective tool in health care, and QPLs have been described as simple to use, inexpensive, and useful to patients (Dimoska, Tattersall, Butow, Shepherd, & Kinnersley, 2008). Previous work with QPLs has been done in outpatient settings and, often, early in the diagnosis (Sansoni et al., 2014). This QI project used a QPL in the tertiary care setting, another pivotal point in care, when a poor prognosis was expected. Although prognosis and prognostic awareness were not new concepts for oncologists, the oncology units on which the project was implemented were functioning in an environment in which de-escalation of care was viewed as failure. This project was the first unit-wide endeavor that was accepted by medical leadership related to using prognostic awareness as a part of the plan of care. The increase in the number of DNR orders and hospice referrals after inclusion of the QPL in admission packets supports improved patient-provider discussion and implies that patients had improved prognostic awareness. As such, the project was considered to be a success and should be viewed as a first step in the process of system changes in the oncology department to

integrate palliative care into the oncology care team earlier in the illness and treatment trajectory.

Although successful, the planning and implementation of this project were not without challenges. Overall, nursing leadership members were supportive of the project and recognized the need for change within the department, but they were concerned about adding work to the already overburdened nursing staff.

Despite this, nurses were receptive to the concept of increasing prognostic awareness and likely would have been willing to play a larger role in the project. Additional endeavors with the QPL should involve, at the very least, an introduction of the discussion aid to patients by nurses. In addition, incorporation of the concept of prognostic awareness should be included in the oncology core nursing curriculum to ensure that staff nurses are well trained and overall prepared to function as communication brokers for patients initiating prognosis dialogue. Although dialogue should be patient-initiated, nurses are often a patient's first line of inquiry as they navigate through the healthcare system.

Although the number of DNR orders and hospice referrals increased after implementing the QPL, a direct correlation cannot be made because of limitations in the project. One limitation was the inconsistency of administration of the QPL to patients. The unit secretaries were given the task of piecing the packets together and assembling the packets (with the QPL) during any downtime in a shift. As a result, the unit running out of completed packets was not uncommon during busy days. Initially, staff members were confused about which patients were supposed to receive the packets, prompting a mass email from the unit manager about two weeks into the project clarifying that all patients with cancer were to be given the packets. In addition, anecdotal feedback from nursing staff also revealed that some patients were given the admission packet as they were being discharged if it became known that the patient had not received it upon admission. The inconsistency of administration likely attributed to a considerable number of patients not receiving the QPL.

An additional limitation was the inability to determine how much increased staff and provider knowledge about prognostic awareness influenced the increase in DNR orders and hospice referrals. Recognition of the need for change was essential to move forward with the project. This awareness, no doubt, influenced some staff members to engage patients in prognostic dialogue more than usual. Although a first step for overall climate change, project results could have been affected by increased staff awareness.

**TABLE 3. Hospice Referrals by Month**

| Month                   | n  |
|-------------------------|----|
| November 2014 (N = 52)  | 10 |
| December 2014 (N = 68)  | 8  |
| January 2015 (N = 32)   | 3  |
| April/May 2015 (N = 67) | 7  |
| May/June 2015 (N = 76)  | 17 |
| June/July 2015 (N = 53) | 18 |



## Implications for Practice

- ▶ Promote patient–provider dialogue with a discussion aid in the form of a question prompt list (QPL).
- ▶ Improve prognostic awareness of patients with advanced cancer with a QPL.
- ▶ De-escalate aggressive medical care in patients with a poor prognosis.

Finally, prognostic awareness is a concept that is developed over time and is cumulative, making meaningful analysis of the effects of the QPL brochure difficult in such a short time period. Repetitive exposure to the QPL through readmissions and follow-up visits likely would influence outcomes exponentially. In addition to DNR implementation and hospice acceptance, other outcomes affected by the QPL aid and improved patient–provider dialogue could be measured in additional projects, such as a decrease in the percentage of patients receiving treatment within 30 days of their death, fewer admissions to an intensive care unit, and overall decrease in hospital length of stay. Additional projects examining the use of QPLs in this setting should consider evaluating for such evidence of de-escalation of care.

## Conclusion

Prognostic awareness is central to meaningful patient–provider dialogue but is complex and multifaceted. Nonetheless, the examined outcomes in this project increased after inclusion of the QPL discussion aid in patient admission packets. A prognosis-focused QPL brochure is an inexpensive and simple way to improve patient–provider dialogue, with potential to begin improving the prognostic awareness of patients with advanced cancer. As patients are becoming more empowered to initiate these difficult conversations, medical education, likewise, should endeavor to train providers to view prognostic-focused and end-of-life conversations as part of routine cancer care and provide guidance in their structure.

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