

# Oncology Nurses' Attitudes Toward Prognosis-Related Communication: A Pilot Mailed Survey of Oncology Nursing Society Members

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Oncology nurses constitute the largest group of oncology clinicians in the United States, are deeply involved with the care of patients with cancer across the cancer continuum, and often define their roles as patient advocates, but few studies address their attitudes toward and experiences with prognosis-related communication, which is central to defining goals of care. Literature on nurses, the nursing role, and communication about end-of-life care has focused primarily on intensive care unit nurses and advance directives. Some evidence suggests that critical care nurses play a pivotal role in clinician-family communication in the intensive care unit (Hampe, 1975; Jamerson et al., 1996; McClement & Degner, 1995). Families rate nurses' skill with such communication as one of the most important clinical skills of intensive clinicians (Daley, 1984; Hickey, 1990; Molter, 1979; Rodgers, 1983). In one meta-analysis of studies assessing the needs of family members with a loved one in the intensive care unit, eight of 10 identified needs related to communication with clinicians, and the majority of these were addressed primarily by nurses (Hickey, 1990).

One qualitative study that specifically examined hospital-based nurses' attitudes toward communication of prognosis as it related to hospice referral found that some nurses felt that communicating about prognosis was "not my responsibility," suggesting that some respondents may have felt that such communication was outside of the scope of proper nursing practice (Schulman-Greene, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005). In a study of nurses' views on disclosure of terminal prognoses in the United Kingdom, May (1993) found no evidence that respondents wanted to communicate terminal prognoses themselves. The current study's authors know of no similar studies in oncology nursing literature that address issues of prognosis-related communication with patients with advanced cancer, although oncology nurses likely face many of the same challenges.

**Purpose/Objectives:** To assess oncology nurses' attitudes toward prognosis-related communication and experiences of the quality of such communication among physicians.

**Design:** Cross-sectional study.

**Setting:** Nationwide survey in the United States.

**Sample:** 394 Oncology Nursing Society members who completed surveys.

**Methods:** Pilot mailed survey.

**Main Research Variables:** Demographic variables, measures of attitudes toward and experiences of prognosis-related communication.

**Findings:** Nurses had mixed views of prognosis-related communication and identified common barriers to their own more effective participation in prognosis-related communication. Nurses with more experience and those who worked in inpatient settings were more likely to be present for physicians' prognosis-related communication with patients.

**Conclusions:** Respondents identified uncertainties regarding the scope of oncology nurses' role in prognosis-related communication. Respondents also identified opportunities for improved interdisciplinary communication, most importantly the inclusion of oncology nurses in prognosis-related communication.

**Implications for Nursing:** Opportunities for oncology nurses to bridge some gaps in prognosis-related communication likely exist, although barriers surrounding nurses' role, education, and communication within the context of the larger healthcare team need to be clarified if potential solutions are to be developed.

Patient education is a clearly defined role of nursing, and coordinating care within the healthcare team is a well-defined role for oncology nurses. Nurses are well situated to facilitate communication about hospice and palliative care with patients with advanced cancer in inpatient and outpatient settings. Nurses spend significant time with patients compared to other clinicians and often may uncover gaps in understanding and gain insight into treatment preferences. However,

the extent to which nurses engage in prognosis-related communication is unclear (Wilkinson, 1991; Wilkinson, Roberts, & Aldridge, 1998). Traditionally, physicians have taken responsibility for communication of prognosis and hospice referral, yet research suggests that nurses may have important opportunities for communication with patients (Mezey, Evans, Golub, Murphy, & White, 1994; Oddi & Cassidy, 1998). In Schulman-Green et al.'s (2005) study of nurses' communication of prognosis and implications for hospice referral, nurses' discomfort with discussing prognosis was among the top five obstacles to communication. Part of that discomfort seemed to originate in nurses' questions about whether facilitating discussions about prognosis was their responsibility. Nurses also clearly act as intermediaries between patients and physicians (Baggs, 1993; May, 1993).

Prognosis-related communication has a clear impact on transitions to palliative care and hospice. In a study of 174 nurses, Bradley et al. (2000) found that the likelihood of referral to hospice was reduced when clinicians and patients had limited discussion of prognosis and treatment options. Nurses in the study reported that patterns of prognosis-related communication were variable: 27% did not discuss prognosis at all with their terminally ill patients, 21% did so with all of their terminally ill patients, and less than 50% of respondents discussed hospice care with any of their terminally ill patients (Bradley et al., 2000). In contrast, nurses discussed prognosis and hospice more frequently with the families of terminally ill patients. Sixty-two percent of respondents routinely talked about prognosis with the families of all patients, and 64% discussed hospice care with family members at least some of the time.

Poor communication between doctors and nurses and between doctors and patients and their families regarding prognosis often is perceived as an obstacle to better care of dying patients (Baggs et al., 1997; Cartwright, Steinberg, Williams, Najman, & Williams, 1997). Studies suggest that physicians and patients are ambivalent about talking about death and often avoid such discussions (Baile, Lenzi, Parker, Buckman, & Cohen, 2002; Cherlin et al., 2005; Christakis, 1999; Gordon & Daugherty, 2003; Hagerty et al., 2004; Helft, 2005; Lamont & Siegler, 2000; Leydon et al., 2000; Ptacek, Ptacek, & Ellison, 2001; Selman et al., 2007; The, Hak, Koeter, & van der Wal, 2001). Although many cancer clinicians engage in end-of-life communication in experienced and expert ways, evidence shows that deficits in end-of-life communication continue to exist and may contribute to overly aggressive care at the end of life. In the largest study done to date of patients with cancer receiving palliative chemotherapy, only 39% of patients reported that prognosis was discussed with them by medical oncologists (Koedoot et al., 2004). In a longitudinal study of hospitalized patients for whom death was believed imminent, 62% of families reported that the attending physician never discussed

the possibility of death, and no one on the medical team discussed the possibility of death with the patients in 39% of cases (Sullivan et al., 2007). In another study, according to patients' recollections, physicians initiated a discussion about hospice about half the time, and patients and families initiated one-third of discussions (Casarett, Crowley, & Hirschman, 2004).

Observational studies regarding oncologists and patients with advanced cancer in actual communication interactions are lacking. Of the few studies that exist, most report that prognosis is discussed infrequently (Chan & Woodruff, 1997; Kim & Alvi, 1999; The et al., 2001). One study found that if a prognostic discussion had occurred, it most commonly took place between the doctor and someone other than the patient (Bradley et al., 2001). When prognostic discussions occurred, a considerable lack of clarity existed in the information, estimates of expected survival often were not given, and doctors and patients tended to avoid acknowledging or discussing prognosis by focusing on the treatment plan (Bradley et al., 2001; Kim & Alvi, 1999). One study reported that patients were well informed of the aim of their treatment and the incurable status of their disease, but fewer were informed of their expected survival (Gattellari, Voigt, Butow, & Tattersall, 2002). The authors could identify no studies that directly examined oncology nurses' assessments of prognosis-related communication among the physicians with whom they worked.

Because of the relative lack of information about oncology nurses' experiences with prognosis-related communication in patients with advanced cancer and their attitudes toward such communication among the oncologists with whom they work, the authors undertook a random national survey of oncology nurses to assess their attitudes toward and experiences of prognosis-related communication with patients with advanced cancer as well as their views of the quality of such communication among the physicians with whom they work.

## Methods

### Participants

Participants were selected from the membership roster of the Oncology Nursing Society (ONS), a national association of more than 35,000 registered nurses and other healthcare professionals dedicated to excellence in patient care, research, administration, and education in the field of oncology (ONS, 2009). A randomly generated list of 5% of ONS membership at the time ( $n = 1,338$ ) with one or more years of oncology experience was purchased from ONS. A survey and self-addressed return envelope were mailed to potential participants, along with a cover letter explaining the purpose of the study and discussing consent to participate, in May 2007. Return of the completed survey represented

consent. The study underwent review and approval by the institutional review board of Indiana University–Purdue University at Indianapolis.

## Survey Instrument

The study investigators developed the survey instrument following an extensive review of the literature, iterative discussion among study team members, and informal discussions with practicing oncology nurses. The instrument was tested in a cohort of 20 practicing oncology nurses who were ONS members at the Indiana University Melvin and Bren Simon Cancer Center. During this process of revision, items that were difficult to understand, questions that were identified as ambiguous, and issues perceived to be unclear, invalid, or inconsistent with nurses' experience were altered or discarded to create the final instrument.

Definitions of the terms *prognosis-related communication* and *advanced cancer patient* were offered at the outset of the survey. Demographic questions included respondent age, gender, self-identified race or ethnicity, years as a nurse, years working with patients with cancer, highest level of education achieved, oncology nursing certification, primary practice setting, number of oncologists in the respondent's practice, and the amount of formal education regarding prognosis-related communication. Survey items included 20 fixed response items using a four-point Likert-type scale to measure the extent of disagreement or agreement (i.e., strongly disagree to strongly agree), 14 items with a five-point Likert-type scale to measure frequency (i.e., always/almost always, often, sometimes, rarely, never), and two open-ended questions. Surveys were printed in booklet form and participants received one mailing, which included a self-addressed, stamped return envelope.

## Statistical Analyses

All participant demographics were summarized using descriptive statistics (i.e., mean and standard deviation for continuous measures and count and percent for categorical measures). Associations between demographic variables and individual response variables were tested using Student's *t* tests, Fisher's exact tests, analysis of variance, and simple linear regression. Missing values were omitted from the analyses. Because of the large number of comparisons being made, only associations where *p* was 0.001 or less were considered significant.

## Results

The instrument was sent to a final cohort of 1,338 ONS members. Three hundred ninety-four nurses completed surveys for an overall response rate of 29%. Respondent demographics are shown in Table 1.

## Prognosis-Related Communication

More than 90% of respondents agreed or strongly agreed that patients can make good decisions about their care, hospice enrollment, and additional anticancer therapy (e.g., clinical trial enrollment) only if they understand their prognosis (91% [*n* = 349], 95% [*n* = 364],

**Table 1. Sample Characteristics**

| Characteristic                  | N   | $\bar{X}$ | SD   |
|---------------------------------|-----|-----------|------|
| Age (years)                     | 356 | 47.9      | 10.6 |
| Years as an RN                  | 383 | 19.4      | 11.6 |
| Years with patients with cancer | 378 | 13.7      | 9.3  |

  

| Characteristic  | n   | %   |
|---|-----|-----|
| <b>Gender (N = 384)</b>                                   |     |     |
| Female  | 371 | 97  |
| Male  | 13  | 3   |
| <b>Race (N = 382)</b>                                     |     |     |
| White or Caucasian  | 338 | 89  |
| African American  | 10  | 3   |
| Hispanic or Latino  | 13  | 3   |
| Asian   | 16  | 4   |
| Other   | 5   | 1   |
| <b>Clinical patient contact (N = 383)</b>                 |     |     |
| Yes   | 370 | 97  |
| No  | 13  | 3   |
| <b>Education level (N = 385)</b>                          |     |     |
| Associate degree (nursing)                                | 112 | 29  |
| Bachelor's degree (nursing)                               | 154 | 40  |
| Master's degree (nursing)                                 | 65  | 17  |
| Doctoral degree   | –   | –   |
| Other   | 54  | 14  |
| <b>Certified OCN® (N = 380)</b>                           |     |     |
| Yes   | 243 | 64  |
| No  | 137 | 36  |
| <b>Primary practice area (N = 381)</b>                    |     |     |
| Staff, hospital   | 130 | 34  |
| Staff, outpatient clinic                                  | 147 | 39  |
| Advanced practice nurse                                   | 43  | 11  |
| Case manager  | 6   | 2   |
| Educator  | 1   | < 1 |
| Researcher  | 1   | < 1 |
| Consultant  | –   | –   |
| Nurse coordinator   | 16  | 4   |
| Other   | 37  | 10  |
| <b>Mostly inpatient patients (N = 375)</b>                |     |     |
| Yes   | 148 | 40  |
| No  | 227 | 61  |
| <b>Number of oncologists (N = 378)</b>                    |     |     |
| 1–3   | 145 | 38  |
| 4–6   | 128 | 34  |
| 7–10  | 56  | 15  |
| More than 10  | 49  | 13  |
| <b>Education regarding prognosis discussion (N = 382)</b> |     |     |
| None  | 145 | 38  |
| A little bit  | 150 | 39  |
| Moderate amount   | 72  | 19  |
| A lot   | 15  | 4   |

Note. Because of rounding, not all percentages total 100.

and 93% [n = 355], respectively). In addition, 80% of respondents (n = 291) agreed or strongly agreed that they cannot advocate for their patients as well as they would like when patients do not understand their prognosis.

**Nurses' role:** Ninety-six percent of respondents (n = 367) agreed or strongly agreed that oncology nurses have a responsibility to help patients prepare for the end of their lives. Seventy-five percent (n = 284) agreed or strongly agreed that answering questions regarding prognosis-related information was within the scope of nursing practice. Increased age, number of years working as an RN, number of years working with patients with cancer, and education level all were associated with agreement. However, 82% of respondents (n = 315) disagreed that they should provide an estimated life expectancy when asked. Forty-three percent of respondents (n = 165) agreed or strongly agreed that uncertainty regarding their role in prognosis-related communication was a major barrier to helping patients understand prognosis-related information. Only 53% (n = 203) agreed or strongly agreed that they felt comfortable telling patients they probably will die from cancer if asked. Sixty-two percent of respondents (n = 236) agreed or strongly agreed that they were willing to initiate a discussion regarding prognosis-related information.

**Attitudes:** The authors asked several questions to assess nurses' attitudes toward and experiences of prognosis-related communication with patients with advanced cancer. When asked how frequently they cared for patients who did not appear to understand their prognosis, 46% of nurses said they always or often cared for such patients. Responding nurses reported frequently not knowing how much their patients understood about their prognosis, with 57% of respondents (n = 222) reporting that they always or often did not know how much their patients understood about their prognosis. When asked how often cultural barriers prevented them from sharing prognosis-related information with patients, 43% of respondents (n = 166) reported that cultural barriers sometimes played a role. Fifty-nine percent of nurses (n = 228) always or often encountered questions suggesting that patients with advanced cancer wanted more prognosis-related information. Those reporting increased frequency were more likely to work in an inpatient setting ( $p \leq 0.001$ ).

Forty-six percent of nurses (n = 178) sometimes, often, or always avoided talking with patients about prognosis-related information because they were uncomfortable giving bad news. Responding nurses had mixed responses on the question of whether they should tell patients they probably will die from cancer if asked: 53% of respondents (n = 203) agreed or strongly agreed and 47% (n = 178) disagreed or strongly disagreed. Increased age, number of years working as an RN, number of years working with patients with cancer, level of education, and education regarding prognosis-related communica-

tion all were associated with agreement ( $p \leq 0.001$ ). Sixty-two percent of responding nurses (n = 245) reported that they always or often asked patients whether they had an advance directive. The frequency of that finding was associated positively with working in an inpatient setting and with respondent age ( $p \leq 0.001$ ).

**Ethical issues and nurses' presence:** Fifty-two percent of nurses (n = 199) sometimes, often, or always felt ethically conflicted when patients or family members asked about prognosis-related information. Forty percent (n = 152) disagreed that they were well equipped to engage in prognosis-related communication, and 93% (n = 360) agreed that nurses should have more education about prognosis-related communication. Sixty percent (n = 220) and 67% (n = 245) agreed that lack of time and fear of taking away patients' hope, respectively, were major barriers to prognosis-related communication. Increased age, number of years working as an RN, and number of years caring for patients with cancer all were associated negatively with feeling uncomfortable ( $p \leq 0.001$ ).

**Team-related aspects:** The authors also asked respondents about their attitudes toward and experiences of care team aspects of prognosis-related communication. About 85% of respondents (n = 327) agreed or strongly agreed that physicians are primarily responsible for discussing prognosis with patients. About 98% (n = 377) agreed or strongly agreed that nurses are responsible for initiating discussion with the physician about a patient's prognosis if the patient has questions; however, 55% of nurses (n = 202) sometimes, often, or always felt pressured not to provide patients with advanced cancer with prognosis-related information because they did not want to contradict what physicians had said. Twenty-five percent of nurses (n = 92) agreed that the oncologists with whom they worked rarely or never kept them informed about their prognosis-related communication with patients with advanced cancer, and 43% (n = 165) were rarely or never present when prognosis-related information was discussed. Increased number of years of experience, number of years working with patients with cancer, and having a master's degree all were associated with increased frequency of being kept informed about physicians' prognosis-related communication ( $p \leq 0.001$ ). Nurses who reported working in outpatient settings and those who reported lower levels of education regarding prognosis-related communication were less likely to be present when prognosis-related information was discussed ( $p \leq 0.001$ ). In addition, inpatient nurses were more likely than outpatient nurses to report that they were routinely present during oncologists' prognosis-related communication ( $p \leq 0.001$ ).

**Education:** Sixty-one percent of respondents (n = 233) agreed or strongly agreed that they felt well equipped to discuss prognosis-related information with patients with advanced cancer. Increased age, experience as a nurse, experience with patients with cancer, and

education regarding prognosis-related communication all were associated with feeling well equipped. Although 93% of respondents (n = 360) agreed or strongly agreed that oncology nurses should have more education on how to handle prognosis-related questions, 68% (n = 259) agreed or strongly agreed that oncology nurses generally have enough information to answer prognosis-related questions posed by patients with advanced cancer.

#### **Nurses' assessments of oncologists' communication:**

The authors asked several questions to assess nurses' assessments of prognosis-related communication among physicians with whom they worked. Twenty-six percent of respondents (n = 95) disagreed or strongly disagreed that the physicians with whom they worked were skilled at prognosis-related communication. Seventy-two percent of the respondents (n = 262) agreed or strongly agreed that physician discomfort with giving bad news was a major barrier to helping patients and families understand the prognosis. Thirty percent of nurses (n = 115) felt that oncologists rarely or never addressed end-of-life issues early in the course of an illness, and 33% (n = 126) agreed that when patients did not appear to understand their prognosis, it was because oncologists had not discussed it fully. Nurses working in an inpatient setting were more likely to agree with the latter statement ( $p \leq 0.001$ ).

## **Discussion**

In this pilot mailed survey of oncology nurses in the United States, responding nurses reported that they frequently engage in prognosis-related communication with the patients they cared for, but they had mixed views of their roles in prognosis-related communication. Moreover, they identified common barriers to their own more effective participation in prognosis-related communication with patients with advanced cancer.

Despite the majority of respondents agreeing that answering prognosis-related questions was within the scope of nursing practice, respondents generally were uncomfortable providing estimates of life expectancy. Furthermore, nearly half of respondents reported some uncertainty about their role in prognosis-related communication. The data suggest that the boundaries of nurses' engagement and role in prognosis-related communication require more delineation. Respondents appeared equally split on the question of whether nurses should tell patients they probably will die from cancer if asked. More than half of responding nurses agreed that lack of time and fear of taking away patients' hope were major barriers to prognosis-related communication. In a recent study of oncology nurses' perceptions of obstacles and supportive behaviors at the end of life, "being called away from patients" was identified as the

third-highest obstacle to end-of-life care (Beckstrand, Moore, Callister, & Bond, 2009). All of these findings are consistent with the hypothesis that oncology nurses face significant uncertainty regarding their role in prognosis-related communication with patients with advanced cancer, despite the fact that they encounter such communication frequently.

Although responding nurses reported frequently encountering evidence that the patients with advanced cancer they cared for had deficits in prognostic understanding or desired more information about their prognosis, respondents reported often not knowing how much their patients understood about their prognosis. That suggests that significant deficits remain in nurses' abilities to engage in effective prognosis-related communication, which almost all respondents agreed was very important.

The authors were able to make several observations regarding the effects of the setting in which oncology nurses work and about the effects of experience and education. Although lack of presence during prognosis-related communication between physicians and patients appears to be a frequent and important deficit, inpatient nurses were more likely to report being present for such communicative interactions. Increased opportunity for presence seems intuitively plausible because bedside nurses may be available during physician rounding at least part of the time. The authors were surprised that outpatient nurses, who presumably have proximity to physicians and patients during clinical encounters (i.e., are in the same building, clinical space, or area), were less likely to be present for prognosis-related communication than inpatient nurses. That suggests that nurses are excluded, choose not to participate for various reasons, or have other pressing responsibilities that preclude participation. That finding merits further investigation because the authors believe that presence of the physician and nurse during prognosis-related communication is a critical part of assuring continuity of team-based communication with patients and family members. Nurses who reported higher levels of education were more likely to be present when prognosis-related information was discussed, but the reasons for that were not specifically examined. Higher levels of education may lead to a greater level of seeking out opportunities to be present during prognosis-related communication or more frequent work in roles that permit nurses access to physician-patient encounters in which prognosis-related information is discussed. That question merits further study.

Gaps in prognosis-related communication between physicians and patients with advanced cancer clearly exist, and evidence shows that these gaps lead to increased intensity of care near the end of life. In Beckstrand et al.'s (2009) study in the inpatient setting, oncology nurses identified physicians who insist on aggressive care until the patient is actively dying and physicians who are overly optimistic to patients and families within the top

15 rated obstacles to end-of-life care. Participants also rated having physicians who agree about the direction of patient care as the fourth most supportive behavior in end-of life-care (Beckstrand et al., 2009). Similarly, the current study's authors found that inpatient nurses were more likely to agree that deficits in oncologists' prognosis-related communication contributed to patients' lack of prognostic understanding.

The current study suggests that oncology nurses may be positioned to play an important role in bridging gaps in end-of-life communication because they frequently encounter and identify information deficits and are able to identify patients who desire more specific prognosis-related information. The majority of respondents felt that engaging in prognosis-related communication was within the scope of nursing practice, although they also identified with concerns that such communication might conflict with information previously provided to a patient by the physician. Few studies have elucidated that problem in greater detail.

About half of the respondents (n = 199) felt that their communication with patients and family members regarding prognosis-related information raised ethical issues at least some of the time. Related to that, the authors found that nurses frequently agreed that pressure to be consistent with physicians' previous communication (the content of which, evidence suggests, frequently is not known to the nurse) were barriers to prognosis-related communication. A majority of nurses in the current study appeared to believe that discussing prognosis was primarily the physician's responsibility, although three-quarters of respondents agreed that answering questions about prognosis-related information was within the scope of nursing practice. Almost all responding oncology nurses felt that it was their role to relay knowledge of patients' deficits in prognosis-related information to physicians. How often they actually engage in the bridging of such information gaps remains unknown, as the authors did not ask respondents how frequently they initiated such discussions.

Finally, respondents reported mixed views of prognosis-related communication among oncologists with whom they worked. One-quarter of responding oncology nurses disagreed that the physicians they worked with were skilled at prognosis-related communication, and three-quarters identified physicians' discomfort with giving bad news as being a major barrier to prognosis-related communication. Those findings are corroborated by Koedoot et al.'s (2004) study, performed in the Netherlands, which found that prognosis was not discussed with 40% of patients. In the current study, about 43% of responding nurses (n = 165) reported that they were rarely or never present when prognosis-related information was discussed, and 25% of respondents agreed that oncologists rarely or never kept them informed of their prognosis-related com-

munication with patients and family members. Given the pressure responding nurses reported experiencing not to contradict information provided to patients by physicians, that lack of inclusion in physician-patient encounters in which prognosis-related information is discussed appears to be an important barrier to increased participation by nurses in prognosis-related communication.

## Limitations

The current study should be interpreted in light of several limitations. Although the authors provided participants with written definitions of the terms used throughout the survey, those terms may have meant variable things to different individuals; thus, responses may reflect varying understandings. The survey included only oncology nurses who were ONS members and the response rate was low, consistent with many studies of healthcare professionals, so it may not entirely be representative of the views of oncology nurses. Finally, although the authors developed the survey tool carefully and thoughtfully in the absence of a previously validated instrument to measure these phenomena, the instrument was not formally validated using accepted psychometric methods, so the authors cannot absolutely be certain of the reliability of the tool or the validity of the findings.

## Implications for Nursing Practice

Oncology nurses who are ONS members with at least one year of experience working with patients with advanced cancer frequently engage in prognosis-related communication with patients and identify significant deficits in prognosis-related communication between the oncologists with whom they work and the patients for whom they provide care. Those perceived deficits center on oncologists' skills and comfort with delivering prognosis-related information, as well as the timing of prognosis-related communication in patients' disease courses. Responding nurses also identified opportunities for improving aspects of interdisciplinary communication, most importantly the inclusion of oncology nurses in episodes of prognosis-related communication. Opportunities for oncology nurses to bridge some gaps in prognosis-related communication appear to exist, although ethical barriers surrounding nurses' roles, education, and consistency with physicians' communication need to be clarified if potential solutions are to be developed.

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