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# Does Death Anxiety Affect End-of-Life Care Discussions?

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## Abstract

**Objectives—**The aim of this study was to determine if a gynecologic cancer patient's comfort level discussing end-of-life care issues with her caregivers is related to her death anxiety level.

**Materials/Methods—**Gynecologic oncology clinic patients were asked to rate their degree of agreeability with 4 statements regarding comfort level discussing end-of-life care issues. Participants also completed the Hoge's Intrinsic Religiosity Scale and Templer's Death Anxiety Scale.

**Results—**Four hundred one surveys were distributed. One hundred twenty-nine patients participated, with a response rate of 32.2%. The median age of the sample was 55 years. Most patients were white (72.9%), married (58.9%), and Christian (85.3%). Most patients had ovarian cancer (40.4%). Of the 74 patients who knew their cancer stage, 59% had been diagnosed with advanced (stage III-IV) disease. Thirty-three percent were currently in remission, and 17% had recurrent disease. Of all patients surveyed, 32.6% were currently receiving treatment. Chemotherapy was the most common treatment (62% of those being treated). Higher level of comfort discussing end-of-life care topics such as do-not-resuscitate orders with family members was significantly associated with decreased death anxiety ($P = 0.008$ and $P = 0.001$). There was no significant association between comfort level when patients discussed do-not-resuscitate orders with physicians and patients' death anxiety ($P = 0.14$). After controlling for age, race, marital status, education level, current treatment status, and religiosity, linear regression analysis demonstrated that the relationship between a patient's increased comfort level when discussing end-of-life care topics with family members and decreased death anxiety remained statistically significant ($P = 0.005$ and $P = 0.001$).

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**Conclusions—**Conversations regarding goals of treatment are an important component of caring for cancer patients. Death anxiety may contribute to decreased communication between patients and their family members regarding the patient's end-of-life care wishes. Obtaining a better understanding of the role death anxiety plays in end-of-life care discussions may help patients receive the end-of-life care they desire.

### Keywords

Advance care planning; Anxiety; End-of-life

Communication regarding goals of care at the end of life is an important component of treating patients diagnosed with a gynecologic cancer. These conversations, known as advance care planning, include discussions regarding the type of medical care that the patient desires at the end of life as well as the implementation of advance care documents such as a medical power of attorney, living will, or do-not-resuscitate (DNR) orders.(1) Although the primary purpose of advance care planning is to align medical management with patient desires, early advance care planning has many additional benefits for the patient.(2,3) Patients who have early advance care planning discussions with their providers receive less aggressive care surrounding death, experience improved utilization of hospice care, improved quality of life, and decreased medical costs.(4–7)

Despite the benefits of early advance care planning, most physicians and patients do not engage in conversations regarding end-of-life care decisions until approximately 1 month before the patient's death.(4,8) Delaying this discussion often limits the patient's ability to make decisions regarding her medical care because she may be incapacitated by illness. As a result, family members are often asked to make decisions regarding end-of-life care received by debilitated patients based on the substituted judgment standard.(9) The substituted judgment standard is a decision-making standard which assumes that family members would act in accordance with the patient's wishes.(9) However, this is not always the case. Prior studies have demonstrated incongruence between patient desires and the family's perception of patient desires regarding treatments administered at the end of life.(9,10) These data suggest that family members may not make decisions in accordance with the patient's true desires. In addition, studies have demonstrated that family members responsible for making these decisions for their loved ones experience stress, anxiety, and depression resulting from the significant burden of these choices.(11) It is clear that improved communication regarding advance care planning topics may not only improve compliance with patient desires regarding end-of-life care, but may also reduce the psychological burden experienced by family caregivers.

To facilitate advance care planning discussions, clinicians must identify possible barriers to communication between the patient, her family members, and her health care provider. Several previously identified barriers to advance care planning include patients' feeling that providers are too busy to engage in such conversations, patients' perception that conversations regarding end-of-life care may not be appropriate to their health state, patients not wanting to cause unnecessary stress to family members, and patients not wanting to participate in medical decision making at the end of life.(12,13) These findings provide some insight into the factors inhibiting advance care planning and suggest that many barriers to advance care planning are centered upon the emotional state of the patient.

One such emotional barrier to advance care planning conversations may be anxiety. High levels of anxiety may prevent patient communication with providers by making patients feel less comfortable when asking their physicians health-related questions and less trustful of their physicians' treatment recommendations.(14) Death anxiety is a specific component of anxiety that represents the negative feelings experienced when one reflects upon the inevitability of their death.(15,16) Cancer patients are at a high risk for experiencing death anxiety because they face existential challenges when contemplating the meaning of not only their lives, but also of their deaths.(15) Patients able to reconcile this existential crisis may feel more peaceful and less distressed.(17) Because of this, decreased anxiety may permit more honest and practical advance care planning.

Gynecologic cancer patients experience elevated anxiety when compared with those without a gynecologic cancer diagnosis.(18,19) This increased anxiety is experienced both by gynecologic oncology patients receiving active treatment for their cancer and those in surveillance.(20) Accordingly, the primary aim of this study was to describe if a gynecologic oncology patient's level of comfort discussing end-of-life issues with her caregivers is related to her death anxiety level.

## Materials and Methods

This study was approved by the institutional review board of the Johns Hopkins Medical Institutions, Baltimore, MD. Women 18 years and older, with a diagnosis of gynecologic cancer (active or in remission) seen at the Gynecologic Oncology Clinic at the Johns Hopkins Hospital in Baltimore, MD, were enrolled in this cross-sectional survey between February 2012 and June 2012. After consent was obtained, women completed a self-administered survey packet that included the following measures:

### Background Questionnaire

This questionnaire contained 13 basic demographic and medical information questions. Demographic information included age, ethnicity, marital status, sex, educational background, and religious classification. Medical information was obtained via patient self-report and included the following: the patient's type of cancer, cancer stage, clinical status (ie, active disease or remission), and current treatment (if applicable).

### Comfort With Discussing End-of-Life Care Issues

Because no validated method of assessing a patient's comfort level with having end-of-life care discussions with her caregivers exists, the investigators developed 4 statements to assess a patient's comfort level with these discussions. These statements were developed by a gynecologic oncology fellow, a social psychologist who specializes in measurement development, and a gynecologic oncology attending as an exploratory method to evaluate patients' comfort level with end-of-life care discussions. The 4 statements used in this study were developed from these providers' clinical experience with patients and were designed to measure patients' most commonly reported topics of discomfort with end-of-life care discussions.

The 4 statements used in this study were selected in the following manner: topics relating to patients' discomfort with end-of-life care discussions were condensed into 10 statements relating to end-of-life care decisions among gynecologic oncology patients. These 10 statements explored patients' comfort with discussing end-of-life care issues, feelings regarding aggressive anticancer treatment at the end of life, and opinions on how quality of life would impact their decision to continue anticancer treatment. These 10 statements were further narrowed by the creators of the statements to evaluate more specifically end-of-life care discussions between a patient and her family. This resulted in the 4 statements that were used in this study. Gynecologic oncology clinic patients were asked to rate agreeability with the 4 statements (Table 1). Agreeability was scored on a 7-point Likert scale (1, strongly disagree; 7, strongly agree).

## Templer's Death Anxiety Scale

The Death Anxiety Scale (DAS) is a validated scale composed of 15 true/false questions that assess an individual's level of death anxiety.(21) A higher score indicates increased death anxiety.(22)

## Hoge's Intrinsic Religiosity Scale

This validated scale contains 10 statements about religious belief or experience. Participants were asked to indicate the degree to which statements were true for them on a 5-point Likert scale (1, definitely true; 5, definitely not true). A higher score indicated less religiosity.(23,24) This scale was included in the questionnaire packet because high levels of intrinsic religiosity are known to negatively correlate with death anxiety, and we wanted to control for this factor in our analysis.(16)

Patients completed the questionnaire packets while waiting in the examination room to see their physician. The questionnaire was anonymous, with no identifiers that would enable responses to be linked with the medical record. Once the questionnaire was completed, it was returned to the clinic nurse who placed it in an envelope with other questionnaires. A research assistant removed the surveys from the envelope, randomly assigned patient identification numbers to each questionnaire, and entered responses into an electronic database.

## Analytical Approach

Data were analyzed in STATA (v.13) using descriptive statistics and Pearson correlations (with calculated P values) to determine the relationship between variables. In addition, linear regression was utilized in an attempt to control for factors such as intrinsic religiosity and disease status that may influence the relationship between death anxiety and patient comfort level when discussing end-of-life care with physicians and family members. In these linear regressions, death anxiety scores were used to predict comfort with discussing end-of-life care while statistically controlling for age, marital status, race (white vs nonwhite), education level (higher education vs high school or less), treatment status (currently receiving treatment vs not), and intrinsic religiosity score.

# Results

## Demographics

Four hundred one surveys were distributed. One hundred twenty-nine patients participated, resulting in a response rate of 32.2%. The median age was 55 years. Most patients were white (72.9%), married (58.9%), and listed their religious affiliation as Christian (85.3%). Most patients had ovarian cancer (40.4%). Fifty-seven percent stated that they knew their cancer stage, whereas the remaining 43% did not know their cancer stage. Of the 74 patients who knew their cancer stage, 59% had been diagnosed with advanced (stage III-IV) disease. Thirty-three percent of all patients surveyed were currently in remission, and 17% had recurrent disease. Of all patients surveyed, 32.6% were currently receiving treatment. Chemotherapy was the most common treatment (62% of those being treated) (see Tables 2 and 3 for demographics and clinical characteristics).

## Relationship Between Death Anxiety and Comfort Discussing End-of-Life Care Issues

There was no significant association between death anxiety and agreeability with question number 1, “I am comfortable with my physician bringing up conversations about how to make my transition to the end of life easier” or with question number 3, “I am comfortable with my physician discussing end-of-life issues such as DNR orders,” (P = 0.40 and P = 0.14, respectively). Decreased death anxiety was significantly associated with increased agreeability with question number 2, “I am comfortable discussing end-of-life issues with my family members, such as DNR orders and how to handle my affairs once I am gone” (r = -0.23, P = 0.008) and also with question number 4, “I openly talk with my family about end-of-life issues (eg, DNR orders, handling my affairs)” (r = -0.29, P = 0.001; Table 1).

## Linear Regression Evaluating Relationship Between Death Anxiety and Comfort Discussing End-of-Life Care Issues

The relationship between death anxiety and comfort discussing end-of-life care issues such as DNR orders with family members (question numbers 2 and 4) remained significant (P = 0.005 and P = 0.001) when controlling for age, marital status, race, treatment status, education level, and intrinsic religiosity (Table 4 for regression). Stage could not be added to the regression models due to the large percentage of patients (42.6%) who stated that they did not know their cancer stage.

# Discussion

The results of this study provide a glimpse into how death anxiety may be related to a patient's comfort with discussing end-of-life care issues and advance care planning with her various care providers and family members. These results suggest that a patient's level of death anxiety is not associated with her level of comfort when talking to her health care provider regarding end-of-life care issues. However, there does seem to be a relationship between a patient's level of death anxiety and her level of comfort when talking to her family members regarding similar topics. Patients with higher levels of death anxiety were less comfortable engaging in end-of-life conversations with their family members. These findings suggest that patients experience advance care planning conversations differently with their provider when compared with their family members.

Research examining end-of-life conversations between providers and their patients demonstrate that providers often wait to discuss end-of-life care issues with patients until their disease has significantly progressed.(1,25,26) Providers have indicated that they wait to have these conversations with their patients because they are concerned that the patient might not be comfortable with advance care planning and may experience distress as a result of discussing end-of-life care topics.(26) Despite these provider concerns, research demonstrates that patients whose providers had end-of-life care discussions with them before the patient's death benefitted from longer hospice stays and less aggressive medical care when compared with those patients whose provider did not discuss these topics.(27,28) The findings of our study contradict provider preconceptions that advance care planning conversations are associated with distress among patients by demonstrating no association between death anxiety and patient comfort level with discussing end-of-life care issues with their physicians.(26) These findings are encouraging and provide reassurance that patients are comfortable when talking to their providers regarding end-of-life care issues.

Although important, patient-physician discussions regarding end-of-life care issues are not the only interactions that impact advance care planning. Conversations with the patient's family members also play an important role in advance care planning. In fact, advance care planning discussions between patients and their family members often occur before conversations with health care providers.(29,30) Accordingly, end-of-life care conversations with family members are often the initial step in advance care planning and can lead to the creation of advance care documentation that will guide physician treatment and relieve family members of the burden of making medical decisions.(31) Although our study did not find an association between death anxiety and comfort discussing end-of-life care issues with health care providers, it did demonstrate that there is a significant association between death anxiety and comfort with discussing end-of-life care issues with family members. These findings may reflect the order in which patients have end-of-life care discussions with their caregivers. As previously mentioned, patients often discuss end-of-life care issues with their families before talking to their provider.(29,30) Perhaps death anxiety initially acts as a barrier to end-of-life care planning discussions with family members, but once these topics are broached with the family, death anxiety dissipates and patients are comfortable discussing these matters with their physician.

A better understanding of the role that death anxiety plays in advance care planning will allow us to identify and remove barriers preventing early discussion. Future studies should examine the way in which gynecologic cancer patients cope with death anxiety and are able to discuss end-of-life care issues with their physicians and family members. Particular attention should be placed on ways to encourage open communication between the patient, her family, and her provider regarding advance care planning topics.

Although this study improves understanding regarding the association between death anxiety and comfort with discussing end-of-life care issues with family and physicians, it has several limitations. First, it was a cross-sectional study involving women with different types of gynecologic cancers who were at different stages of treatment. Accordingly, temporality cannot be established. Second, our study had a low response rate of only 32.2%. This is, at least in part, due to the way in which study enrollment was attempted. Because of staff limitations, patients were given a questionnaire packet by the clinic nurse that included an introduction letter from the principal investigator and the questionnaires. There was no direct contact with research staff during enrollment. Informed consent was obtained by the patient reading the introduction letter and choosing to fill out the questionnaire. This lack of direct patient interaction with research staff prevented patients from being able to ask questions regarding the study and probably decreased our participation rate. Third, our study was limited by the fact that information related to cancer stage and management was missing in 43% of our study sample due to patients being unsure of their cancer history. Unfortunately, because of the completely anonymous nature of this study, there was no way to confirm cancer history via the medical record. Fourth, this study did not interview family members to evaluate their level of comfort with end-of-life care discussions. A family member's unwillingness to discuss their loved one's end-of-life care wishes may impact the patient's comfort level with these conversations.

Advance care planning is important but often overlooked and delayed. Providers must advocate for patients and encourage them to contemplate and vocalize what they desire to occur should their cancer progress. To implement the patient's desires for end-of-life care, communication must be strengthened between the patient and the 2 groups most intimately involved with the patient during her decision-making process: her family and her health care provider. Open communication between this triad of patient, family, and provider is integral to ensuring that patients have the opportunity to frankly discuss the available treatments, expected outcomes, and preferred management of their illness with those most intimately involved in their care. The findings in this study suggest that death anxiety may be a barrier to end-of-life care discussions with family members. By understanding all the factors that contribute to a honest and effective discussion regarding end-of-life care issues, providers may foster a productive dialogue with the patient that encourages her to explore her desires and communicate them to her loved ones.

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## Table 1

## Correlation between end-of-life discussion questions and Templer's DAS

| Question | Pearson Correlation (*r*) with Tempter's Death Anxiety Score | *P* |
|---|---|---|
| 1. I am comfortable with my physician bringing up conversations about how to make my transition to the end of life easier. | −0.08 | 0.4 |
| 2. I am comfortable discussing end-of-life issues with my family members, such as DNR orders and how to handle my affairs once I am gone. | −0.23 | **0.008** |
| 3. I am comfortable with my physician discussing end-of-life issues such as DNR orders. | −0.13 | 0.14 |
| 4. I openly talk with my family about end-of-life issues (eg, DNR orders, handling my affairs) | −0.29 | **0.001** |

Bold values indicate statistical significance ($P < 0.05$).

## Table 2

### General demographics (N = 129)

| Characteristics | n (%) |
|---|---|
| Race | |
| White | 94 (72.9) |
| African American | 24 (18.6) |
| Asian or Pacific islander | 5 (3.9) |
| Hispanic | 3 (2.3) |
| Other | 3 (2.3) |
| Marital status | |
| Married | 76 (58.9) |
| Single | 28 (21.7) |
| Widowed | 13 (10.1) |
| Divorced | 12 (9.3) |
| Religious affiliation | |
| Christian | 110 (85.3) |
| Islamic | 1 (0.8) |
| Jewish | 2 (1.6) |
| Eastern | 2 (1.6) |
| No religion | 5 (3.9) |
| Other | 9 (7.0) |

## Table 3

## Cancer demographics (N = 129)

| Characteristics | n (%) |
|---|---|
| Type of cancer [*] | |
| Cervical | 24 (18.6) |
| Uterine | 25 (19.4) |
| Ovarian | 52 (40.4) |
| Vulvar | 9 (7.0) |
| Other | 23 (17.8) |
| Stage of cancer | |
| I | 19 (14.7) |
| II | 11 (8.5) |
| III | 32 (24.8) |
| IV | 12 (9.3) |
| Unknown [†] | 55 (42.6) |
| Stage in cancer management | |
| Initial diagnosis | 21 (16.3) |
| Recurrence | 22 (17.1) |
| Remission | 42 (32.6) |
| Unknown [‡] | 30 (23.3) |
| Missing [§] | 14 (10.9) |
| Receiving treatment currently | |
| Yes | 42 (32.6) |
| No | 86 (66.7) |
| Missing | 1 (0.8) |
| Current cancer treatment [//] | |
| Chemotherapy | 26 (20.2) |
| Radiation | 7 (5.4) |
| Hormonal therapy | 12 (9.3) |
| Complementary/alternative medicine | 3 (2.3) |

[*] Some patients reported more than 1 cancer type.

[†] Patients did not know stage of cancer or left information regarding cancer stage blank.

[‡] Patients did not know what stage of cancer management they were in.

[§] Patients did not answer this question.

[//] Some patients reported more than 1 treatment.

## Table 4

## Linear regression analysis for end-of-life questions with significant correlations to Templer's DAS

| EOLC Question | B coefficient | SE | 95% Confidence Interval | *P* |
|---|---|---|---|---|
| 2 | −0.113 | 0.040 | −0.19 to −0.035 | 0.005 |
| 4 | −0.150 | 0.045 | −0.238 to −0.061 | 0.001 |

[*] Model-dependent variable is the score on end-of-life care question. Independent variable is the score on Templer's DAS. Model includes the following covariables: intrinsic religiosity score, age, whether or not receiving cancer treatment (yes vs no), marital status (married vs not), race (white vs nonwhite), and education level (higher education vs high school or less).

EOLC, end-of-life care.