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A light in the dark: end-of-life conversations in advanced cancer patients improve caregiver grief

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ABSTRACT A clinical decision report using:

Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, Mitchell SL, Jackson VA, Block SD, Maciejewski PK, & Prigerson HG. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300(14):1665-1673. <https://doi.org/10.1001/jama.300.14.1665>

for a patient with end stage cancer and an anxious caregiver.

Keywords: *advanced care planning, end-of-life, caregiver bereavement*

Clinical-Social Context

Ms. Dee Buck (pseudonym) is a 76-year-old African American female who presented to the ED after her son found her on her bathroom floor. Ms. Buck was unable to answer questions due to altered mental status. Her past medical history was significant for endometrial adenocarcinoma complicated by extensive metastasis to the lung, peritoneum, bone, and liver; bilateral pulmonary embolisms on anticoagulation; essential hypertension; and type 2 diabetes. In the ED she was found to have hypernatremia, hypercalcemia, hypokalemia, and hypomagnesemia that required admission to correct. After days correcting her electrolytes, Ms. Buck was still altered and unable to tolerate oral intake. It was evident to the team after reviewing her most recent oncology notes she had exhausted all available interventional therapies and had been slowly declining; transfer to comfort care was inevitable. Although she lived alone in an apartment, her son was her primary caretaker, and it was his decision whether to initiate hospice. He went to all her doctor appointments with her but admitted they never talked about her death for a reason unknown to our care team. Despite many recent notes documenting severely decreased oral intake, this news was very unexpected for her son, and he didn't want to make a decision until his siblings could be present in three days. The family dynamics were very unclear to the team; however, Ms. Buck's son insisted that other family members be given the opportunity to voice their opinion in person. This created a difficult situation because she was stable for discharge, nonetheless, the care team waited an additional three days until the family decided. Decisions about a loved one's disposition for imminent death are extremely intimate. The care team could tell the decision for hospice caused the son considerable anxiety, and we wondered if an end-of-life conversation with her doctor, son, and Ms. Buck could have eased her son's anxiety regarding her care in the last days of her life.

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Clinical Question

Do end-of-life discussions among patients with advanced cancer, their caregivers, and their physicians aid in caregiver decision-making and grief?

Research Article

Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, Mitchell SL, Jackson VA, Block SD, Maciejewski PK, & Prigerson HG. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA.* 2008;300(14):1665-1673. <https://doi.org/10.1001/jama.300.14.1665>¹

Description of Related Literature

The Pubmed database was searched for articles using the advanced search with the keywords “advanced care planning” OR “end of life discussion” AND “caregiver” AND “bereavement” OR “grief” OR “anxiety” OR “depression” AND “cancer” OR “oncology”. The “Adult: 19+ years” age filter was added, and the time frame was set to 2000-2020. This yielded 63 results. Titles were skimmed for relevancy, and abstracts were read of titles that sounded applicable to the question. Specific focus was devoted towards identifying articles that mentioned end-of-life discussions, advanced directives, or advanced care planning. Additionally, because attitudes surrounding end-of-life care and death are heavily influenced by culture, research that did not take place in the United States were excluded. In total, this left six studies to be analyzed and considered for appraisal.

A longitudinal study from 2002-2008 by Garrido and Prigerson² aimed to identify factors in advanced cancer patients’ end-of-life care that affected caregiver bereavement as possible intervention points in future oncologic care. This study had several advantages including multi-state recruitment, a long follow-up period, and multiple outcomes measured. Caregivers completed an in-person baseline interview, 2-4-week post-mortem interview, and a 6-month interview. Of the 361 caregivers that completed baseline and follow-up interviews, almost 1/3 did not complete the 6-month bereavement adjustment interview, and the authors did not collect information about non-completion. Because the topic of death is sensitive and emotional by nature, non-completion should not be ignored since it could potentially bias outcomes with people who are still grieving less likely to respond.

Levoy et al.³ gauged caregivers’ perception of the patient’s death using the Health and Retirement Study (HRS) Exit Interview data, which is a prospective national survey of over 20,000 Americans aged 50 years and older. Participants were surveyed every 2 years. After a participant death, a “proxy informant” (i.e., caregiver) answered questions surrounding the end-of-life experience. The authors chose to limit the cohort to cancer related deaths between 2002-2014 where an end-of-life decision was made, leaving 983 deaths. An advantage of this study was its use of the HRS data, although a few aspects limited its relevance to our clinical question. For example, no data were provided as to whether the “proxy informant” was the person who made the end-of-life decision, as in Ms. Buck’s clinical scenario. Additionally, patient engagement in advanced care planning (ACP) was reported by the caregiver in the exit interview after the participant’s death. Lastly, the main study outcome was caregiver’s perception of death using proxy variables such as place of death, death expectation, death preferences honored, etc.³ No data were collected on caregiver anxiety surrounding decision making or grief, making it not applicable to our clinical question.

Fried and O’Leary⁴ conducted a qualitative study of caregivers to patients who died of advanced cancer, chronic obstructive pulmonary disease, or heart failure. Patients identified caregivers as part of a larger, longitudinal study of treatment preferences. Sixty-four caregivers completed face-to-face interviews from which the researchers identified themes related to their attitude surrounding the ACP process. Although this study provides quotes and possible areas for future investigation, the qualitative nature is highly subjective and difficult to translate into a meaningful, evidenced based answer to the clinical question.

Patel et al.⁵ used a randomized controlled trial to assess veterans with advanced stage cancer and their experiences using a lay health worker (LHW) to deliver end-of-life care over 6-months versus those who received the usual care. Veterans in the intervention group identified a caregiver who was invited to participate in a quantitative survey regarding their experience as well as a qualitative interview 15-months after death. Although randomized controlled trials generally provide strong evidence in forming conclusions, this study was not chosen because the participants were all male veterans which is not relevant to Ms. Buck. Additionally, the quantitative data focused on if they used the LHW intervention, whether it was helpful, and if they would



recommend it to others. Data on whether the intervention prepared the caregivers for their loved one's death or aided in grieving were collected in a qualitative manner. As mentioned earlier, qualitative data is very personal and difficult to use to form a generalized conclusion.

Ray et al.⁵ analyzed data from a larger multi-site, longitudinal study of patients with advanced cancer and their caregivers. Patients completed baseline interviews which included demographics, self-reported peacefulness, interpretation of their health status, Structured Clinical Interview for the DSM-IV, the McGill Quality of Life Questionnaire, and Yale Evaluation of Suicidality. They were asked whether they had a DNR, living will, or durable power of attorney for health care (DPOA). Caregivers were interviewed 6 months after death, providing data on their regrets, perception of the death, and their health and well-being after patient death. This study is relevant because it directly asks about patient DNR, living will, or DPOA status. However, it was ultimately not chosen due to lack of baseline assessment of caregivers' mental health before patient death which made it impossible to interpret whether patient acceptance of their illness impacted caregivers' well-being after patient death.

All of the previously mentioned studies presented unique, valuable information for furthering oncology care in a patient-centered approach. Ultimately, a prospective longitudinal study by Wright et al.¹ was chosen for critical appraisal due to study design aspects that made it superior. Compared to the Garrido and Prigerson² study, the patient and caregivers' mental health were assessed far more extensively at baseline and follow-up using two different, in-depth assessments. Additionally, Wright et al.¹ analyzed statistically quantitative measures for caregivers' well-being after patient death to highlight important differences. This helped form a more meaningful conclusion to the clinical question. Although the studies by Fried and O'Leary⁴ and Patel et al.⁵ provided interesting data that can guide future research, their qualitative nature makes it extremely difficult to extrapolate to the clinical scenario. Compared to the Ray et al. study,⁵ Wright et al.¹ had a major advantage of having more comprehensive measures of caregiver grief, as well as baseline assessments to examine how caregivers' well-being changed after death.

Critical Appraisal

Wright et al.¹ conducted a longitudinal, multisite cohort study from September 2002 until February 2008 at 7 different sites in different states. The study's primary aim was to assess psychosocial factors influencing terminal cancer patients end-of-life care and how they relate to caregivers' bereavement after death. Inclusion criteria were diagnosis of advanced cancer defined by distant metastasis or refractory to first line chemo, over 20 years of age, an informal caregiver, and clinic staff assessment that patients had enough stamina to complete interviews. Of the 917 patients eligible, 638 consented; however, only the 332 patients who passed away were included in the study analyses. The level of evidence of this study as reported by the Strength of Recommendation Taxonomy is 2b.⁷ The deceased cohort differed significantly from the non-deceased in that they were more debilitated at baseline and more likely to be younger, female, uninsured, and identify as an ethnic minority.

Patients were interviewed at baseline to determine whether they had discussed their wishes for care at death with their doctor. Psychosocial factors assessed included advanced care planning, acknowledging illness is terminal, religiousness, and the patient physician relationship. Lastly, baseline mental health, functional status, and comorbid conditions were measured. Caregivers' sociodemographic measures were recorded and their mental health assessed using the Structured Clinical Interview for DSM-IV and Medical Outcomes Study 36-item Short Form Survey (MOS SF-36).

Participants were interviewed weekly. After a patient's death, researchers reviewed the patient's chart for the care received, specifically looking for aggressive care measures. Furthermore, caregivers were asked how they would rate their loved one's quality of life in their last week on a Likert scale. At a median time of 6.5 months following the death, caregivers were interviewed to assess their grief adjustment and repeat the mental health assessments.

With the two cohorts being those who had end-of-life conversations and those who did not, the authors completed a propensity weighted analysis to balance patient and caregiver characteristics that differed significantly. This was done to pseudo-control and adjust for potential confounding variables that affected whether end-of-life discussions were done. For item non-response (i.e., the patient didn't answer) in the statistical analysis, the median values were used. For each item, the non-responses were less than 10%, except for a question assessing patient preference for life-extending therapy which had a non-response rate of 11.6%.

Despite this study's strengths, it had limitations. A minor limitation was that patients who self-reported their race and ethnicity as Hispanic were analyzed as such, regardless of whether they additionally reported being Black or Caucasian. Culture has been well documented to impact end-of-life preferences and could have impacted the propensity weighted analysis, which was used to further calculate the outcomes of the study.⁸ Another limitation was that little data was collected on the content of the advanced care planning conversations, who initiated it, when it was done, and the outcome of the discussion. All information was reported by the patient and recall of such conversations can be limited, possibly due to misunderstanding, denial, or memory impairment. This could have led to potential recall bias in forming the cohort groups. Additionally, the researchers recorded whether hospice was utilized; however, not who made the decision to initiate hospice— whether it was the patient or the caregivers, as in our situation. Surrogate decision making has been shown to increase anxiety and could have been an additional confounding variable that influenced outcomes.⁹ Similarly, the median survival time after the baseline interview was 131.5 days. The authors followed up every week; however, no additional information was reported on whether additional patients in the non-end-of-life conversation group went on to have those conversations. Ideally, a randomized controlled intervention trial with larger patient populations would be done to assess the impact of advanced care planning on caregivers.

Ultimately, the authors found that patients who reported having end-of-life discussions with their physician were significantly less likely to receive aggressive care as defined as ICU admission, ventilator use, resuscitation, feeding tube, etc. After controlling for possible confounding variables such as caregivers' sociodemographic and baseline mental health, the authors found a significant association between aggressive end-of-life care and subsequent caregiver major depressive disorder, experiencing regret, and feeling unprepared for the patient's death when compared to caregivers of patients who did not receive aggressive care.

Clinical Application

After Ms. Buck's family made their decision, she went into hospice and died peacefully within a few days. Using the information presented by Wright et al.¹, her son's anxiety surrounding her death could have been eased by prior conversations about what she wanted in her final days. Typically, these discussions explore a multitude of topics including how aggressive patients want their treatment to be once their disease is terminal, whether they want full resuscitation attempts should their heart stop, what role religion plays in their care, where they prefer to die, and when to enroll in hospice. The main factor limiting the external validity of the paper to our scenario is that direct analysis exploring the impact of advanced care planning on caregivers' grief was not done. The paper by Wright et al¹ supports the notion that having end-of-life discussions with the caregiver could have relieved some of Ms. Buck's son stress. These discussions could have allowed a more streamlined approach to care to occur. Finally, these discussions may help prevent some depressive disorders within caregivers. With this in mind, I propose that oncology or palliative care clinics require a collaborative class to facilitate the discussion of end-of-life treatment. This may ease patient acceptance of their diagnosis, as well as prevent caregiver anxiety or depression, allowing for a more peaceful end-of -life.

New Knowledge Related to Clinical Decision Science

I propose that oncology or palliative care clinics require a collaborative class to facilitate the discussion of end-of-life treatment. This may ease patient acceptance of their diagnosis, as well as prevent caregiver anxiety or depression, allowing for a more peaceful end-of-life.

Conflict Of Interest Statement

The author declares no conflict of interest.

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