

Original Article

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“You think you got it down and then the moment comes”: The certainty of uncertainty in end-of-life decision making

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Abstract

Objectives. Some observers have proposed that physicians may die differently compared with the average patient. Semi-structured interviews with family members of physicians who died offer an opportunity to better understand how patient preferences and wishes are perceived and acted on by family members at the end of life. The decision-making experiences of these family members for a loved one who was a physician may have implications for the lay person at end of life.

Methods. The Johns Hopkins Precursors Study includes individuals who matriculated into the graduating classes of 1948 to 1964 of the Johns Hopkins University School of Medicine. From this cohort, we interviewed 26 family members of physicians who died. Interviews were coded and analyzed using a comparative, iterative process.

Results. We found that family members of physicians who died described the uncertainty at end of life. This overarching theme was organized into the following: (a) the certainty of uncertainty; (b) the preparation for uncertainty; and (c) brokering of decisions in the face of uncertainty. Despite careful end-of-life preparation by well-informed physicians, family members were still left to broker decisions as they navigated the wishes of the physician and what the family and medical care team believed to be in the best interest of the physician.

Significance of results. Our findings suggest that our family members were not immune to uncertainty. The clinical momentum at the end of life may contribute to challenges faced by patients and family members when brokering decisions. Normalizing uncertainty in medical training and for families may aid in addressing the stress of uncertainty at end of life.

Introduction

Given the extensive knowledge physicians have about healthcare, some observers have proposed that doctors may die differently compared with the average patient (Murray, 2012). Several large studies have attempted to address this assertion and drawn inferences about physician end-of-life decision making based on claims and registry data of healthcare service use by physicians (Blecker et al., 2016; Matlock et al., 2016; Weissman et al., 2016; Wunsch et al., 2019). In general, the design of such studies is to compare the use of services and end-of-life outcomes (e.g., place of death) among physicians and nonphysicians. Compared to nonphysicians, physicians had both more ICU days and increased use of hospice and palliative care services at the end of life (Matlock et al., 2016; Wunsch et al., 2019). Physicians with cancer were 28% more likely to receive chemotherapy in the last 6 months of life than were nonphysicians with cancer (Wunsch et al., 2019). While comparisons of service use are useful descriptions, such studies cannot shed light on decision making and are not indicative of quality of end-of-life care.

Even though physicians, as a group, express preferences for limited care in end-of-life scenarios, they too may be unable to “overcome” compelling factors that drive care regardless of individual preferences (Gallo et al., 2003). Particularly at the end of life, family members become increasingly involved in care and decision making; as the person reaches end of life, their family is charged with upholding their wishes and preferences. A careful look is needed to understand what processes are driving care at end of life: personal wishes, the decisions of family and healthcare providers, and how the culture within which one receives care facilitates or constrains choices. We reasoned that if we studied family members of physicians who died, we could focus our attention on the experience of end of life for a population with, arguably, the greatest understanding of their health situation. Our inquiry was guided by the following questions: (1) What was the experience of these family members at the end of the

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physician's life? and (2) Did the fact that the patient was a physician impact the end-of-life decision-making process for the family?

We took advantage of a rare and time-limited opportunity to interview family members of physicians who died, about experiences with end-of-life care decision-making. The physicians were participants in the Johns Hopkins Precursors Study, designed in 1946 by Caroline Bedell Thomas to identify characteristics associated with premature cardiovascular disease and death which has become one of the longest running studies of aging in the world (Thomas, 1951). By interviewing family members of deceased cohort members, we had the opportunity to explore if medical education and training of the physician-patient could alter their end-of-life experience for themselves and their family.

Methods

We conducted a qualitative descriptive study of family members of deceased physician-patients in the Johns Hopkins Precursors Cohort. The Precursors study was originally established in 1947 to study risk factors for cardiovascular disease and consists of physicians who were medical students at Johns Hopkins between 1948 and 1964 (Klag et al., 1993; Gallo et al., 2003). Our analysis was guided by qualitative description, a phenomenologically informed method of qualitative inquiry that provides a comprehensive description of events frequently using language expressed by the informants (Sandelowski, 2000; Lambert and Lambert, 2012).

The Johns Hopkins precursors cohort

All 1,337 students in the Johns Hopkins Precursors study who matriculated into the graduating classes of 1948 to 1964 of the Johns Hopkins University School of Medicine were eligible for this study. Study procedures were reviewed and approved by the Johns Hopkins Medicine Institutional Review Board.

Sample selection

We classified the deceased Precursors participants ($N=213$) according to previous survey responses to a scenario in which an advance directive could be used to guide treatment (Gallo et al., 2003). They had been asked to consider what types of treatments they would want if they suffered irreversible brain damage that left them unable to speak understandably or to recognize people (Gallo et al., 2003). We previously reported three clusters of preferences: "most aggressive," "intermediate care," and "least

aggressive" as well as transitions between the clusters (Wittink et al., 2008). For selecting a purposive sample for semi-structured interviews, we sorted the Precursors sample into four groups: (A) consistently expressing preferences for "most aggressive" care; (B) changing preference to "most aggressive" care; (C) changing preferences to "intermediate or least aggressive" care; and (D) consistently expressing preferences for "intermediate to least aggressive" care (Wittink et al., 2008). A subsample of individuals was selected at random ($N=73$), stratified by group, to be sure we sampled across levels of preferences for aggressive care. Family members had been identified by the physicians in their final survey prior to death as an individual whom the team could contact to learn about the care and death of the physician-patient (Table 1).

Interview strategy

We sent a letter with a response sheet to family members of physicians who died with instructions to return the form to indicate their willingness to participate in telephone interviews on end-of-life decisions ($N=73$). Mailers were sent December 2015 through June 2017. Of the 73 interest letters mailed, 35 responded; of those 35 responses, 30 agreed to be interviewed.

Because the cohort is geographically dispersed, phone interviews were the most practical way to obtain interviews. Interviews began in December 2015 and were completed by November 2017. At the beginning of each interview, we obtained oral consent to proceed with the interview and with recording. After expressing condolences, we began by asking whether the physician-patient had discussed their wishes or preferences for end-of-life care ("Walk me through a typical conversation you had with [your husband/father/etc.] about his (her) end-of-life care.") and if their healthcare providers referred to the patient, family, or end-of-life documents in guiding medical care. Then we asked the family member to talk about decisions that had been made, and whether there were decisions that they felt good or regretful about.

By scripting the interview questions, we enhanced fidelity of the interview while still allowing the interviewers to follow the lead of the family member. The semi-structured interview guide questions were intended to gain an understanding of the decision-making process that occurred at the end of the physician-patient's life. The research team iteratively developed the interview guide, which was modified throughout data collection. For example, the question, "Thinking about the medical care towards the end of his (her) life, did Dr. (name) express to you what he (she) wanted?" was confusing for family members to answer. The

Table 1. The response rate(s) of the family members of physicians who died by physician preference for level of aggressiveness of care

	Total	Group A: Consistent Most Aggressive	Group B: Change to Most Aggressive	Group C: Change to Least Aggressive	Group D: Consistent Least Aggressive
Total number in group	213	38	11	7	157
Randomly selected subset invited to participate in interview	73	23	15	6	29
Number of responding	35	8	9	4	14
Number who agreed to interview	30	6	8	4	12
Number of interviews	26	6	7	4	9
Number of received refusals	5	2	1	0	2

question was modified to: “Walk me through a typical conversation that you had with Dr. (name) about his (her) end of life care.”

Interviews were conducted by two team members, a clinical nurse with research experience and the first author (CAC) who was a Masters in Public Mental Health Research student with academic preparation in medical anthropology and mental health. Typically, the interviews were 45–60 min. For more information, full details of our interview strategy have been published elsewhere (Abshire et al., 2020).

Each recorded interview was transcribed, with identifying names and places redacted in the final transcripts. NVivo Pro 11, a qualitative data management and organization software, was used to facilitate coding and analysis of transcripts.

Analytic strategy

Coding of transcripts involved sorting the data into high-level categories arrived at through group consensus in team discussion (broad coding) (Rubinstein, 1992; Miles and Huberman, 1994). Team members suggested large subject areas (e.g., “burden”) that were present in the interview. We then created a definition for each code to ensure integrity of application across interviews. We strove to identify codes generated from meaning inherent in the data rather than pre-specified categories (Mishler, 1991; Packer, 2013). Themes were identified, developed, and used to summarize the meaning of experiences (in this study, about end-of-life planning and decisions) (Packer, 2013). The constant comparative method guided the identification of themes and involves moving iteratively between codes and text to derive themes related to end-of-life decision making (Glaser and Strauss, 1967; Malterud, 2001; Boeije, 2002).

A working codebook was developed through weekly team meetings to reach consensus on emerging codes and address the need for additional codes. Team members independently coded the assigned transcripts, noting text that was not covered by existing codes for discussion at team meetings. New codes were generated in an iterative fashion based on continuing review of the data and codes. Following individual coding, we reviewed the transcripts as a team, discussed any discrepancies, and reached consensus on how best to address those discrepancies. We then fine coded the transcripts within the broad codes. Trustworthiness of our data was enhanced at the data collection phase by regularly debriefing with the interviewers to encourage standardized administration of the questions (Morrow, 2005). During data analysis, we used several strategies to address trustworthiness including immersion in the data through close multiple readings, frequent discussion by the study team, and searches for discrepant cases.

Results

Sample description

In all, 26 family members of physicians who died were interviewed for this study. Family members of physicians who died were interviewed, on average, 3 years after the death of the physician (range: 0–11 years). Most family members of physicians who died were female (77%), and, in relation to the deceased physician, 14 were spouses, 9 were children, and 1 identified as a friend.

Uncertainty

Three themes relevant to uncertainty emerged when analyzing interviews of family members of physicians who died: (a) the certainty of uncertainty; (b) the preparation for uncertainty; and (c) brokering decisions in the face of uncertainty.

The certainty of uncertainty

Family members of physicians who died acknowledged uncertainty at end of life. Numerous participants mentioned uncertainty in decisions made at the end of life, and uncertainty was sometimes expressed as lack of preparation for those decisions. The deceased physician’s extensive knowledge of disease and prognosis did not protect family members from uncertainty when confronted with decisions.

I was extremely panicked about making the decision, you know? (Family member, ID5)

The adult daughter below describes how the family approached the death of her physician mother.

I was not very sure. My brother who is a physician was a little more sure than I was but I don’t think any of us were close to 100 percent certain. My dad was maybe a little more sure of the right decision. I think I had more—I was a little more dubious than any of them but ultimately I mean I think it was as right as I could get at the time. (Family member, ID2)

In contrast to the idea of limiting uncertainty, family members of physicians who died recognized that planning and thinking about decisions beforehand was very different from the actual experience at end of life. Family members of physicians who died described making decisions about treatment under conditions of uncertainty and then regretting a negative outcome. Even knowledge of the possibility of the negative outcome in advance did not protect them from this regret.

He had a slight stroke and infection afterwards and was deathly ill and never really recovered from it. ... So I had a bit of guilt because we sort of encouraged him. Being a surgeon he sort of didn’t— he knew the downsides of surgery. And so, he hesitated and we hoped it would help him but it didn’t at all. (Family member, ID3)

The weight of these decisions and the inherent uncertainty was difficult to bear even when family members knew the wishes of the physician who was dying.

Prepared may not be the right word. You’re never prepared. You are aware and conscious of the decision making that led to that so that it was understood. It’s still a gut blow. Right? (Family member, ID4)

The preparation for uncertainty

Given the uncertainty expressed by family members of physicians who died, they also discussed the ways they prepared for that uncertainty. Family members talked about taking one small decision at a time and mentioned the instructions were useful for the decisions that had to be made after the death of their physician loved one.

Having that express conversation with both of them was incredibly helpful because it helped sort of put the continuum in play so we could, me and my brother, could understand really clearly where they both were. So she

was really clear that she wanted some reasonable measures. She wanted to be comfortable. She wanted some reasonable measures. But depending on what the circumstances were, she did not want anything extraordinary. ... Being able to discuss it openly with each other as well as with our children made it a lot easier. (Family member, ID4)

Preparing for uncertainty was not only expressed as a general theme for decision making for treatments, but decisions for specific treatments that really were a series of “smaller” treatments. Even when physicians were careful to discuss their wishes and to provide documentation of their wishes, the decisions to be made were not as clear cut as implied by those discussions and documents because the decisions planned for devolved into a series of smaller decisions.

I think she was septic, and she went to the hospital and we made it clear that she was a DNR, but then they started asking me questions like, “Yes, she’s septic right now. If she got put on pressers temporarily, she could do fine.” And so they kind of started breaking down the DNR order to individual decisions...it’s, whew, much more complicated.” (Family member, ID5)

Brokering decisions in the face of uncertainty

With the themes of uncertainty and strategies to prepare for uncertainty came descriptions of how decisions were “brokered” among the physician–patient, the family member(s), and the medical care team.

In some circumstances, the family members of physicians who died described a strong assertion of the physician to maintain control of the end-of-life situation. Even though the physicians were trying to extend their influence on decisions even into incapacity, family members of physicians were left to broker decisions between what they knew about the goals of their loved one and the healthcare team.

She very, very much did not want to relinquish any control over any medical decisions. So she wanted and sought help from me on taking care of paperwork or bills or other life things, but she was extremely headstrong that no one would make medical decisions but her. (Family member, ID10)

Some family members, even those who were physicians themselves, expressed uncertainty about the benefits and burdens of treatments and then regretted their role in encouraging treatment when the physician was reluctant, and the outcome was unfavorable. In other circumstances, a course of action was brokered that met both patient and family goals for care. In the quote below, the family members of physicians who died worked in solidarity to circumvent the healthcare team’s “clinical momentum” to continue treatment by making a pact with the patient beforehand that honored “goals” of care rather than the “content” of care.

He said, “Well, what would you do if I had a heart attack?” I said, “Well, I would call 911.” He said, “Well, what happens if I don’t want you to call 911?” and I said, “Well, this is the deal I’ll make with you. I’ll walk around the house two times and then I’ll come in and call 911,” and so we agreed on that. That I was honoring him but I was also honoring myself. (Family member, ID12)

Discussion

Uncertainty emerged as an overarching theme when we talked with family members of physicians who died about end-of-life

decision making. Family members were left to broker decisions, taking account of the expressed wishes of the physician–patient, and the approaches to decision making of the family, and the medical team. Our family members of physicians who died were describing the unavoidability or “certainty of uncertainty.”

Given the professional and lived experiences of our authors, we reflected on how our own assumptions and biases regarding what we think is important in care at the end of life could have influenced our coding of the transcripts. We assumed that the knowledge and experience of physicians would limit uncertainty at the end of their life. We did not anticipate the many dimensions of uncertainty that arose in narratives of end-of-life decision-making among family members of physicians who died.

Before considering the findings and implications, we need to discuss the limitations of our study. On average, 3 years had elapsed between the physician–patient’s death and the interview with the family member. Our sample included family members whose physician–patient died 6 months prior to the interview or 11 years prior. Perspectives may differ among our sample depending on how recently the physician–patient died in relation to the interview; however, the “lifespan” of grief is not limited by chronological time. Our focus was on the experience of decision making and planning for the end of life and the interpretation and meaning attached to those experiences. The opportunity that family members had to reflect on their experiences, to select salient aspects, and to order experiences into a story provided an advantage as storytelling is a “meaning making” activity that puts the spotlight on decision making (Tetley et al., 2009).

Despite limitations, our findings deserve attention because participating family members elucidated the ways in which uncertainty influenced the challenges of end-of-life care decision making. Gleaning what we can from the experiences of the family members about how to face uncertainty may inform supportive care for nonphysician families struggling with uncertainty at end of life. We would expect physicians to be a group that has maximal understanding and minimal uncertainty at end of life with regard to healthcare decision making because of their medical knowledge and experience. The uncertainty that existed for our family members of physicians who died speaks to pervasive, indiscriminate nature of uncertainty.

The fears that some family members recounted about their physician–patients’ concerns about receiving unwanted aggressive care at the end of life were well-founded given what Kruser and colleagues refer to as the “clinical momentum” of unwanted care in the intensive care setting (Kruser et al., 2017). Although we did not conduct our analysis through the lens of Kruser et al., we found this framing to aid in describing the implications of our findings. Clinical momentum occurs when signs and symptoms lead automatically to invasive treatments without deliberation regarding likely outcomes and patient goals of care. There is a momentum to applying interventions and so an initial decision for intervention leads to a series of interventions or decisions that need to be made. We depict how our results fit within the concept of “clinical momentum” in Figure 1. The clinical momentum trajectory begins with “certainty of uncertainty,” which our family members described in their discussions of end-of-care wishes and experiences. This existence turns to preparation as the clinical momentum begins to take hold. This “preparation for uncertainty” was illustrated by family members describing the advance directives and documentation that their physician–patient created for the end of their life. As the clinical momentum trajectory peaks and falls, there is a change in the

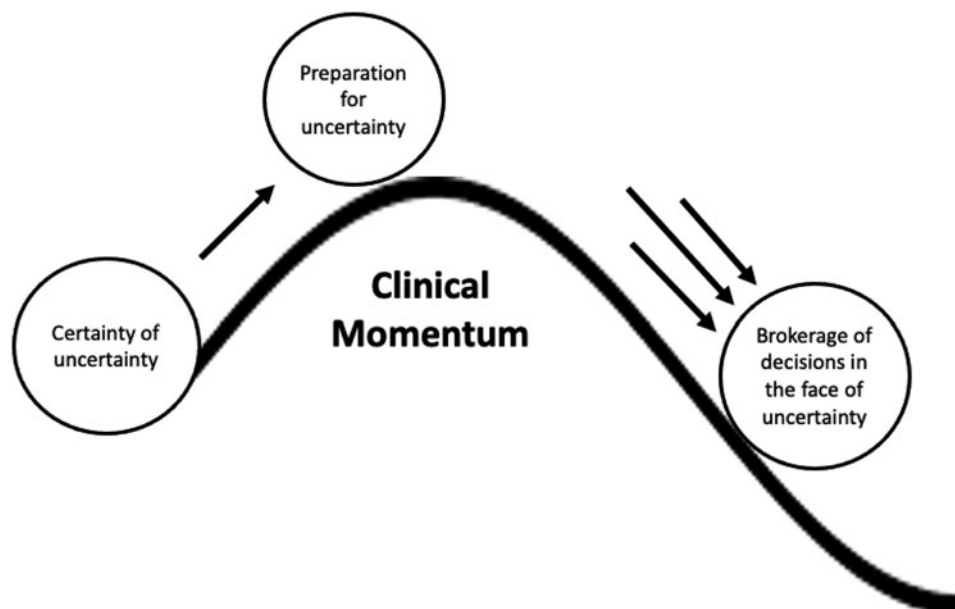


Fig. 1. The “certainty of uncertainty” and Kruser et al. (2017) concept of clinical momentum.

speed of clinical decision making and action. We now see brokering of decisions in the face of uncertainty, which is further complicated by the momentum surrounding that clinical experience. Our findings, though not specifically intended to address clinical momentum, fit within this construct.

The uncertainty experienced by family members of physicians who died was similar to that experienced by family members of nonphysician patients. The interplay that family members describe between themselves and the patient in our study and others suggests that interventions to promote managing uncertainty at end of life should consider addressing the issue at multiple levels. “Shared uncertainty” is an important concept related to shared decision making — acknowledging the unknown and unknowable. In a systematic review of interventions to promote advance care planning, physicians in some of the intervention studies acknowledged a shared sense of uncertainty about the disease and its progress with patients and their families (Lund et al., 2015). Future physicians should learn about the power of managing uncertainty using shared decision-making communication strategies and decision aids (Stacey et al., 2014; Shay and Lafata, 2015). Families need for physicians to acknowledge the difficulty of navigating uncertainty (Kimbell et al., 2016). Evans et al. (2009) found that almost 90% of family decision makers wanted physicians to discuss prognosis and the uncertainty around each decision. Such discussions help families trust providers, understand treatment, hope with realistic expectations, and prepare for possible bereavement (Evans et al., 2009). Overall, shared decision-making interventions improve knowledge, inform choice, and participation in decision-making, and reduce decisional conflict, even among disadvantaged patients such as those with low health literacy (Durand et al., 2014). Communication and agenda-setting interventions that help patients and caregivers prepare for visits with providers have improved patient-centered communication (Wolff et al., 2018). Finally, all bereaved caregivers deserve guideline-directed bereavement support and some with high decisional regret or complicated grief may require tailored specialty support (Hudson et al., 2012). Assuring the family that they

have done a good job in decision making in the face of much uncertainty can be a source of comfort, especially for those family members experiencing some decision regret (Steinhauser et al., 2009).

As it is impossible to eliminate uncertainty, healthcare professionals caring for persons with advanced illness should share this uncertainty about illness progression and engage in shared decision making with an openness about changing treatment plans as the illness progresses. Greater integration of palliative and end-of-life care throughout medical school and different processes for deliberating about the appropriateness of treatments for persons with advanced illness, particularly in critical care settings, are needed. By normalizing uncertainty at the start of medical training, physicians may be more apt to share uncertainty with family members and others at end of life. This shared uncertainty would, in turn, normalize the stress of uncertainty for patients and their families.

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Conflict of interest. The authors declare none.

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