

Surrogate Decision Makers' Perspectives on Family Members' Prognosis after Intracerebral Hemorrhage

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Abstract

Background: Surrogate communication with providers about prognosis in the setting of acute critical illness can impact both patient treatment decisions and surrogate outcomes.

Objectives: To examine surrogate decision maker perspectives on provider prognostic communication after intracerebral hemorrhage (ICH).

Design: Semistructured interviews were conducted and analyzed qualitatively for key themes.

Setting/Subjects: Surrogate decision makers for individuals admitted with ICH were enrolled from five acute care hospitals.

Results: Fifty-two surrogates participated (mean age = 54, 60% women, 58% non-Hispanic white, 13% African American, 21% Hispanic). Patient status at interview was hospitalized (17%), in rehabilitation/nursing facility (37%), deceased (38%), hospice (4%), or home (6%). Nineteen percent of surrogates reported receiving discordant prognoses, leading to distress or frustration in eight cases (15%) and a change in decision for potentially life-saving brain surgery in three cases (6%). Surrogates were surprised or confused by providers' use of varied terminology for the diagnosis (17%) (e.g., "stroke" vs. "brain hemorrhage" or "brain bleed") and some interpreted "stroke" as having a more negative connotation. Surrogates reported that physicians expressed uncertainty in prognosis in 37%; with physician certainty in 56%. Surrogate reactions to uncertainty were mixed, with some surrogates expressing a negative emotional response (e.g., anxiety) and others reporting understanding or acceptance of uncertainty.

Conclusions: Current practice of prognostic communication in acute critical illness has many gaps, leading to distress for surrogates and variability in critical treatment decisions. Further work is needed to limit surrogate distress and improve the quality of treatment decisions.

Keywords: cerebral hemorrhage; palliative care; prognosis; qualitative research

Introduction

SURROGATE DECISION MAKERS are often asked to make life-and-death decisions for family members with acute critical illness. Many surrogates are unprepared to serve in this role and

are at risk for long-term adverse psychological outcomes such as symptoms of post-traumatic stress.¹⁻³ While other studies have examined surrogates in the general hospital ward^{4,5} or intensive care unit,⁶⁻⁹ relatively little research concerns surrogate decision makers for patients with acute stroke.

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Accepted March 2, 2018.

Understanding the experience of surrogates specifically in stroke is warranted for several reasons. First, do-not-resuscitate (DNR) orders are more common in hospitalized stroke patients compared with other conditions,^{10,11} particularly after intracerebral hemorrhage (ICH)¹² which is the deadliest subtype of stroke.^{13–15} Second, stroke is the fifth leading cause of death in the United States.¹⁶ Third, the acute onset of disease limits the ability of the surrogate to discuss disease-specific end-of-life treatment preferences with the patient in advance. Finally, early neurological prognostication is challenging and can vary across physicians.^{17,18}

Given the importance of surrogates' interpretations of prognosis in ICH, combined with the long-term risk of adverse surrogate psychological outcomes, it is essential to better understand surrogates' perspectives on prognostic communication. Therefore, we conducted a semistructured interview study of ICH surrogates, focusing on their experiences communicating with the medical team to better understand current processes and assist in design of future strategies to improve prognostic communication.

Materials and Methods

Eligibility and recruitment

Eligible patients had spontaneous nontraumatic ICH or intraventricular hemorrhage (referred to collectively as "ICH") and required a surrogate decision maker during the hospitalization. Patient age was restricted to ≥ 45 years as end-of-life decisions were expected to be rare in younger individuals. Surrogates were ≥ 18 years of age, could read and communicate in English, and had self-identified as playing a key role in decision making for an eligible patient. Enrollment was limited to one surrogate per patient. Participants were recruited from five sites (University of Michigan Health System, Henry Ford Hospital, Rhode Island Hospital, Corpus Christi Medical Center, and CHRISTUS Spohn Health System) between December 2011 and April 2015, with details of recruitment methods shown in the Appendix A1. Patient medical records were reviewed for key descriptive clinical data. Use of formal prognostic models such as the ICH score¹⁴ was at the discretion of treating clinicians or site protocols. Quantitative study data were collected and managed using REDCap electronic data capture tools hosted at the University of Michigan.¹⁹

Interview content and procedures

A semistructured interview guide was developed to cover topics of prognosis and medical decision making. This article focuses on prognosis; results relevant to medical decisions will be reported separately. Interviews occurred either face-to-face (University of Michigan site only) in a private room away from the medical unit or by telephone. Interviews were conducted by trained study staff (M.E.R. or A.F.F.), audio recorded, and transcribed for analysis.

Analysis of interview data

Deidentified interview transcripts were uploaded to Dedoose, a software package for qualitative data analysis.²⁰ Preliminary codes were developed based on the interview guide and anticipated themes of interest, with the code tree revised iteratively during the analysis phase. Initial coding

was done by group consensus of the study principal investigator (D.B.Z.) and the two interviewers. Once adequate reliability across coders was demonstrated on independent coding (pooled kappa > 0.75 for key codes),²¹ individual team members coded subsequent interviews separately, although questions about code application were discussed and resolved by consensus. Minor comments or utterances that did not impact the meaning have been edited out of quotations for clarity and concision. Quotes that illustrated major themes of sources of surrogate distress or conflict with the medical team concerning prognosis were collected. A theme of surrogate reactions to physician expressions of prognostic uncertainty was specified a priori and explored in the interview guide. A theme of surrogates using factors other than information provided by the medical team to assess prognosis was anticipated based on prior literature,⁸ although the interview guide did not focus on this topic in detail. Other themes presented in this study emerged during the analysis.

Consent and IRB approvals

This study was approved by the University of Michigan Institutional Review Board (IRB) and the IRBs of the other enrolling centers. All surrogates provided either written or verbal telephone consent per local IRB. Patients were enrolled for record review either under an IRB-approved waiver of consent or with surrogate consent.

Results

Of the 175 eligible surrogate-patient pairs contacted by the study team, 52 (30%) enrolled (see Appendix A1 for details on those not enrolled and Tables 1 and 2 for those enrolled). Multiple themes relevant to surrogates' experiences discussing prognosis with the medical team were identified during qualitative coding. Themes associated with potential surrogate distress or conflict with the medical team are highlighted below.

Surrogate perceptions of discordant prognosis from the medical team

Surrogates reported hearing different prognostic information from different members of the medical team in 10/52 (19%) of the cases. In 8 of these 10 cases, surrogates explicitly reported that hearing discordant prognostic estimates was confusing and/or distressing (Table 3, examples 1 and 2). In three cases, a difference in prognosis from different members of the healthcare team contributed to a change in the decision on whether to perform potentially life-saving brain surgery. In one illustrative case (Table 3, example 3), the initial prognosis communicated through telephone was poor. Shortly after arrival to the hospital, a different attending physician took over the care of the patient and communicated a discordant prognosis. In this case, the fact that one physician described the likely outcome as "rehab," while the other physician used the term "nursing home," seemed to be particularly important for the surrogate. The initial plan for withdrawal of mechanical ventilation was changed, and the patient was taken to the operating room for a decompressive craniotomy and, ultimately, discharged to a rehabilitation facility. Since we did not interview physicians and are dependent on the surrogate's report, is it unclear whether the

TABLE 1. PATIENT CHARACTERISTICS

Patient characteristics	% or Median (25th—75th percentile)
Age in years	72 (57.5–83.5)
Female	65%
Race ethnicity	
White	60%
Black	12%
Hispanic	21%
Other	8%
Hypertension ^a	77%
Atrial fibrillation ^a	10%
Prior ischemic stroke or TIA ^a	
None	83%
Ischemic stroke	6%
TIA	6%
Dementia ^a	19%
Initial Glasgow coma scale	8 (6–13)
Hemorrhage volume (in cubic centimeters)	25 (6–50)
Mechanical ventilation used ^a	54%
Tracheostomy ^a	15%
External ventricular drain ^a	23%
Feeding tube placement ^a	38%
DNR order ^a	
New during hospitalization	46%
Preexisting	4%
Transition to comfort measures only ^a	31%
Length of stay in days	8 (4–18)
Patient status at time of interview	
Hospitalized	17%
Rehabilitation or nursing facility	37%
Deceased	38%
Hospice	4%
Home	6%

^aData missing between one and three cases for these items. Missing cases were included in the denominator for calculating percentages.

TABLE 2. SURROGATE CHARACTERISTICS

Surrogate characteristics	% or Median (25th—75th percentile)
Age in years	55 (47.0–65.5)
Female	60%
Race ethnicity ^a	
White	58%
Black	12%
Hispanic	21%
Other	8%
Relationship to patient	
Spouse, partner, or living as married	37%
Surrogate is patient's child	44%
Sibling	6%
Surrogate is patient's parent	4%
Other	10%
Lived with patient before admission ^a	54%
Days from admission to interview	35.5 (15.5–47.0)

^aData missing for one case.

physicians had objectively different estimates of the prognosis, although this case illustrates the potential impact of minor differences in terminology or how information is presented.

Surrogate reactions to physician certainty versus uncertainty in the prognosis

Surrogates reported that the physicians expressed general uncertainty in the prognosis in 19/52 (37%) cases and certainty in 29/52 (56%) (one case reported both uncertainty and certainty expressed at different times; in four cases certainty could not be determined). When surrogates reported physician certainty, this was most commonly in the setting of a certain poor prognosis (22/29, 76%). While it was difficult to ascertain if any negative emotional reaction was related to the actual prognosis or to the way the information was conveyed, in one case it was clear that the surrogate had a strong negative reaction to the physician expressing complete certainty in the poor prognosis:

Surrogate 1030: I got one doctor that just kept saying “never, none, zero.” ...and that was just upsetting. I just personally don't feel that those words should ever be used in a medical area. Now the words “improbable”; “one percent”; “one in a billion”; those I can understand being used. But not the “zero, never.”

Among the 19 cases where surrogates reported hearing uncertainty from physicians, reactions were mixed. In some of these cases (8/19, 42%) the surrogate reported a negative emotional reaction, such as anxiety, due to the uncertainty.

Surrogate 1043: I don't know what he is going to be able to do... It made me anxious I guess is probably the best way to describe it. I wanted answers and they really were not able to give me answers.

However, a similar number of surrogates (10/19, 53%) expressed understanding or acceptance of the uncertainty, including four cases where both understanding and a negative reaction were expressed simultaneously.

Surrogate 4021: They couldn't really give me an answer.

Interviewer: How did that make you feel?

Surrogate 4021: Kind of frustrated... not knowing is helpless. It is a helpless feeling, I guess is a good word for it. But I knew that they were telling me the truth because there is no way to know.

Another surrogate explained that the uncertainty in prognosis allowed her to maintain some degree of hope for her husband's chance of recovery.

Surrogate 2033: It kind of works two ways. It kind of gives you hope. Your hope sort of overrides. Our hope that he would continue to recover and improve sort of overrides the possibility that he won't.

Medical terminology: differential use of term “stroke”

Another theme that contributed to surrogate distress was confusion surrounding medical terminology, specifically the differential use of the term “stroke” (9/52 cases, 17%). While ICH is considered a type of stroke, medical teams varied in whether they referred to ICH as a “stroke.”

TABLE 3. EXAMPLES OF SURROGATE PERCEPTIONS OF DISCORDANT PROGNOSIS

Example	Quotation	Notes
1	<p><i>Surrogate 4088:</i> Well, one doctor I spoke to, he was the attending, he said that, he thinks she's [grandmother] gonna be okay. But every other doctor we talked to, they were like, "We can't tell you. We don't know." You know, "We'll be able to tell more after the first 3 days."</p> <p><i>Interviewer:</i> And how did that make you feel to hear one person say that they thought it was going to be okay, and the others not to...</p> <p><i>Surrogate 4088:</i> Really not good. Because I kept holding on to that one doctor, what he said, that "Oh, we think things will be okay," but then no one else would tell me that, so I'm like "Well why would he say that? Is he lying to me? Do they not think she's okay?" Like, you know, it was probably the worst day of my life...</p>	Different prognosis contributed to substantial surrogate distress
2	<p><i>Surrogate 4059:</i> One doctor we saw saw her in the morning and said, "Oh, she is doing great! She opened her eyes to my commands." And then the neurosurgeon came in and said, "No, she is not doing that," or the nurse came in and said, "She is not doing that for me." So it is confusing when you are seeing five different people and they are all telling you five different things.</p>	Different interpretations of examination were confusing to the surrogate
3	<p><i>Surrogate 1020:</i> ... the one doctor was telling me he would be in a hospital ... or a nursing home maybe for the rest of his life, and the other one was telling me rehab, which brightened up a little bit. And of course, my kids were there with me, and they asked the doctor questions. I personally didn't ask him no questions because ... it was just all mind-boggling. And I was going to pull the plug at 3:25 that day ... on Wednesday. I was going to have them pull the plug [withdraw the ventilator and not perform brain surgery], and I thought ... the kids talked to me and they were saying, "Mom, the doctor's saying rehab for a while, and we will have daddy for a little bit longer." I says, "Okay ... we'll keep him ... we're going to keep him with us."</p>	Plan to withdraw life-sustaining treatment changed when a new attending took over; patient underwent brain surgery and was later discharged to a rehabilitation facility

Surrogates reported commonly hearing terms such as "brain bleed" or "intracranial hemorrhage" initially, with some noting that other providers used the term "stroke" later in the course of treatment. In most of these cases where differential terminology was noted (7/9), it resulted in distress or confusion. One surrogate first heard the term "stroke" in an educational pamphlet.

Surrogate 4059: I left my mother's room for a little while and when I came back, she was sleeping and on her..., the tray was a booklet about stroke. How to deal with, ... when someone in your family has had a stroke. And that's when I turned to the nurse and I said, "Did my mother have a stroke?" ... That was how...it was the first time the word was used anywhere in that room was when it was on that book. And I have no idea who put it there...

For some surrogates, the term "stroke" seemed to carry a more negative prognostic connotation. However, we did not explicitly ask about the emotional reaction to the term "stroke" in most cases and so cannot comment on how common this negative reaction was.

Interviewer: How did you feel when they used the word [stroke] that the other doctors hadn't used before?

Surrogate 1023: You felt pessimistic. And I told them; I said to them, "No one has used that. The other team never used the word "stroke" with me."

Factors that influenced perceptions of prognosis

We identified multiple examples of surrogates relying on factors beyond information provided by the healthcare team to form internal estimates of prognosis (16/52 cases, 31%). These examples largely fell within a previously proposed framework⁸ and included factors such as faith or optimism,

the patient's intrinsic strength or history as a "fighter," and the patient's physical appearance. In the current study, whether the patient responded to the family or external stimuli seemed to be a particularly important (10/52 cases, 19%) indicator of either a positive or negative prognosis.

Surrogate 2047: She asked for a pen. I said, "Her mind is there, doc... She's moving her right hand. She's telling us things... We just can't ... take her off of the vent." To me that's like killing her.

Surrogate 2042: I felt it in my heart that he wasn't... going to make it. I just, you know, he was already not ... responding to anything.

Prognostic misunderstanding

We also identified several examples where the healthcare team made statements that appeared to be interpreted by the surrogate in a different manner than was intended. These examples are summarized in Table 4. While these may have been isolated cases, they are presented in this study in aggregate to highlight potential misunderstandings of statements that clinicians may have thought were clear at the time.

Discussion

We describe the experience of ICH surrogate decision makers when discussing prognosis with the healthcare team. We identified several examples where different prognostic estimates or varied terminology among members of the medical team contributed to surrogate distress. Furthermore, we identified cases where discordant prognostic information resulted in different decisions with life-and-death implications for the patient. This suggests that some patients may have

TABLE 4. EXAMPLES OF SUSPECTED MISUNDERSTANDING OF PROGNOSIS

Terminology	Quotation	Notes
Small bleed	<i>Surrogate 3007</i> : I didn't even know until ... she ended up in ICU, and I'm like, "But they said it was a small bleed." So I'm thinking it's minor. And it's not minor. She's in ICU, unconscious, and I'm like, "What is going on?"	Surrogate initially told that hemorrhage was small, which she assumed meant a more favorable prognosis
90% certainty	<i>Surrogate 2027</i> : After we had made the decision [to transition to hospice], and to tell you the truth, he [neurologist] almost said something to where we were questioning almost, because he said something like, "Well, you know really there's just 90% she'd never recover from this." You know you hear 90%, and then you're going, "Oh my gosh, did we do the wrong thing?"	Physician seemed to be using the "90%" as an expression of a virtual certainty of poor outcome, while the surrogate interpreted this as some hope for a small chance of recovery
Meaning of Hospice	<i>Interviewer</i> : Can you tell me maybe a little bit more about what the doctors told you? <i>Surrogate 2026</i> : Just that she needed hospice. I thought [...] physically she was going to be okay. I never ever knew what hospice was. [...] Nobody told us. Maybe the doctors knew that we knew she was going to hospice to die... <i>Interviewer</i> : So the hospice people came to speak with you and was that the first you learned of what was happening? <i>Surrogate 2026</i> : No, they were very, very nice. They said that we're going to take the best care of your daughter. We're going to do the best we can for her. That type of conversation. <i>Interviewer</i> : How did that make you feel? <i>Surrogate 2026</i> : Not terrible because they said they would take such good care of her. I didn't know she was on her deathbed.	Medical team assumed that the surrogate understood that hospice referral was equivalent to a terminal prognosis

dramatically different outcomes depending on how the prognosis is discussed by physicians and interpreted by the surrogate. These findings are complementary to our prior work showing differences in how physicians prognosticate after ICH¹⁸ and confirm that surrogates perceive these differences in physician estimates as problematic. Our hope is that these examples will help to provide motivation to prioritize research and education programs focused on improving prognostic communication after critical illness such as stroke.

These findings have several implications. For clinicians, our findings support recent calls to integrate education about communication of prognosis for all who care for stroke patients.²² To assess whether surrogates have misunderstood the prognosis, it is important for clinicians to check for surrogate understanding by asking them to restate prognostic information.²³ This technique has seldom been used²⁴ and could have helped in preventing some of the misunderstanding in perception of prognosis highlighted in Table 4. Finally, while considerable effort has been devoted to the development and validation of numerous ICH prognostic models such as the ICH score,^{14,25} there has been little effort to study how to present information from these models in a manner that meets surrogates' needs or to evaluate the impact of these models in real-world clinical practice.

Since hearing discordant prognostic estimates from the medical team was distressing to surrogates, strategies to reduce discordant prognostic estimates should be examined. In cases where there is general agreement about the likely outcome, having one clinician discuss prognosis could limit potential misunderstandings. However, cases where expert professionals legitimately disagree about the prognosis are more challenging. Explicitly mentioning potential uncertainty in early prognosis might better prepare surrogates if they do hear disparate prognostic estimates. However, we found that surrogate reactions to expressions of uncertainty

were mixed, which supports prior work suggesting that the best way to disclose uncertainty requires further study.²⁶

It may be feasible to develop targeted educational materials to better prepare surrogates for how to understand and interpret prognostic information. This information could be incorporated into a more comprehensive decision support intervention to help with not only understanding of prognostic information but also assistance with subsequent decisions on life-sustaining treatment.²⁷ We are currently developing a pilot educational tool for stroke surrogates designed to provide information to family members on prognosis and support decision making.²⁸ Furthermore, standardized information about the types of deficits that survivors may face could help prepare surrogates to have more meaningful conversations about the future, although these approaches require formal study.

A prior study of surrogate perceptions of prognosis in the intensive care unit found that surrogates used a variety of factors in addition to the physician estimate to arrive at their own understanding of prognosis.⁸ Our interviews confirm this work by identifying multiple examples that align with the framework proposed in the prior study, including belief in the strength of the individual, surrogate interpretation of the patient's physical appearance or status, and surrogate optimism or faith.⁸ Patient responsiveness to family or external stimuli (in the category of patient physical appearance or status⁸ in the prior study) seemed to be a particularly powerful indicator of either positive or negative prognosis for surrogates in the current study.

This study was limited by challenges in recruitment. We did not identify any large demographic differences between enrolled and nonenrolled patients (Appendix A1), although our anecdotal experience suggests that more overwhelmed surrogates were less likely to participate. Many surrogates initially agreed to participate, but then ultimately did not complete an

interview. Study personnel were available on weekends and evenings, so it is unlikely that lack of interviewer availability was a contributor. Better understanding of the best methods to recruit surrogates of critically ill patients while they are balancing other demands on their time is needed.

Our study had several additional limitations. Results may not apply to surrogates who do not speak English. In addition, we only interviewed surrogates and did not interview clinicians or record actual conversations nor were we able to determine reliably which clinician was speaking to surrogates in all cases. While audio recording of conversations has been done in other studies of critical illness,²⁴ recording would present logistical challenges in this setting as critical conversations for ICH often occur very early in the hospital course, before we could recruit individuals for research participation. Interviewing only one surrogate per family limited our ability to assess the varying opinions that can occur when multiple family members are involved in conversations with the healthcare team. Timing of prognostic conversations may have contributed to the level of certainty in predicted outcomes, although we were not able to reliably assess the timing of all conversations due to reliance on surrogate report.

Conclusions

In summary, we have identified multiple areas where communication of prognostic information with surrogates of ICH patients was suboptimal. Surrogates told us in their own words that having a loved one acutely critically ill with ICH was among the worst days of their lives. It is incumbent on us as healthcare providers to improve our communication skills, consistency, and processes to ensure that we do not make things worse for this vulnerable population.

Acknowledgments

Research reported in this publication was supported by the National Institute on Aging of the National Institutes of Health under award number K23AG038731 and the National Institute of Neurological Disorders and Stroke (R01NS38916 and R01NS070941). Database support was provided by the Michigan Institute for Clinical & Health Research (CTSA: UL1RR024986). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. This study was performed at the University of Michigan Health System (Ann Arbor, Michigan), Henry Ford Hospital (Detroit, Michigan), Rhode Island Hospital (Providence, Rhode Island), and the Corpus Christi Medical Center and CHRISTUS Spohn hospitals, CHRISTUS Health system (Corpus Christi, Texas).

Author Disclosure Statement

No competing financial interests exist.

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APPENDIX A1: ADDITIONAL INFORMATION ON RECRUITMENT AND ENROLLMENT

Recruitment procedures differed slightly across centers. At two centers, cases were identified from an ongoing population-based stroke surveillance study^{1,2} and recruited after completing study activities for the parent study. At other sites, research staff screened hospital wards regularly for eligible patients and approached surrogates at the bedside to offer enrollment. One site also permitted recruitment through telephone call (after introductory letter with opt-out toll free phone number) if patients died or were discharged before in-person study team approach. When patients were known to have died, the study team deferred contacting surrogates about the study for a minimum of four weeks.³

A total of 275 potentially eligible patients were identified during the study. Of these, 142 were not enrolled in the study, with 42 individuals refusing participation and 100 where there was no contact with the study team (e.g., patient died or discharged before approach, surrogate did not return recruitment calls). A total of 133 initially consented to participate, although 17 later changed their minds when contacted to schedule the interview, 56 did not return phone calls to schedule the interview, and 7 were unable to find a conve-

nient time to complete the interview. One additional audio recording had technical difficulties, leaving 52 surrogate-patient pairs enrolled with completed interviews. A screening log was maintained at 3 of the 5 sites (comprising 34 of the 52 enrolled surrogates). At those sites, there was no difference between interviewed and noninterviewed individuals on patient age, initial Glasgow coma scale, sex, or race ethnicity ($p > 0.10$ for all).

Appendix References

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