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Numeracy and Interpretation of Prognostic Estimates in Intracerebral Hemorrhage among Surrogate Decision Makers in the Neurologic Intensive Care Unit

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Abstract

OBJECTIVE—Clinicians caring for patients with intracerebral hemorrhage (ICH) must often discuss prognosis and goals of care with their patients' surrogate decision makers, and may make numeric estimates of likelihood of survival and functional independence, informed by validated prediction models. Surrogates' prognostic estimates are often discordant with physicians', suggesting that physicians' numeric statements may not be accurately interpreted. We sought to assess the relationship between numeracy and interpretation of prognostic estimates in ICH among surrogate decision makers. We also assessed surrogates' application of prognostic estimates to decisions regarding goals of care.

DESIGN—Single-center, survey-based, cross-sectional study

SETTING—22-bed neurologic intensive care unit (ICU) at an urban, academic hospital

SUBJECTS—Surrogate decision makers for patients admitted to the neurologic ICU

INTERVENTIONS—Participants completed a survey containing 5 clinical vignettes describing patients with non-traumatic ICH. For each patient, numerical estimates of survival and functional independence were explicitly provided, based on the validated ICH score, and the Prediction of Functional Outcome in Patients with Primary Intracerebral Hemorrhage (FUNC) score.

MEASUREMENTS AND MAIN RESULTS—Participants were asked to make their own prognostic estimates, as well as to describe their preferred goals of care for each hypothetical

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patient. Respondent demographics were collected, and numeracy was assessed using a modified Lipkus 11-item scale.

Poor numeracy was common (42 out of 96 subjects) in this relatively highly educated population. Most prognostic estimates (55%) made by surrogates were discordant with the provided estimates. High numeracy correlated with better concordance (OR 23.9 [5.57–97.64], $p < 0.001$), independent of several factors, including level of education and religion. Numeracy also affected goals-of-care decisions made by surrogates.

CONCLUSIONS—Poor numeracy, resulting in impaired understanding of statistics and risk magnitudes, is common among surrogate decision makers in an intensive care setting, and poses a barrier to communication between surrogates and clinicians regarding prognosis and goals of care.

MeSH key words

Decision Making; Intensive Care Units; Prognosis; Cerebral Hemorrhage; Information Literacy; Communication

Introduction

Clinicians caring for critically ill patients with non-traumatic intracerebral hemorrhage (ICH) rely on surrogate decision makers to participate in making important decisions about care (1). Given that surrogates' decisions to enact do-not-resuscitate (DNR) orders or withdraw life sustaining treatment often occur within the first 24–48 hours of these patients' presentation (2, 3), timely and effective communication between the clinician and surrogate decision maker regarding prognosis is important. While acknowledging that clinicians' prognostic ability may be limited (2, 4, 5), the majority of surrogates want physicians to discuss prognosis, even if uncertain (6, 7), and prefer that estimates be provided in numeric rather than qualitative form (8). Numeric prognostication in ICH may be informed by the use of certain validated outcome risk stratification scales. The ICH score is a predictor of 30-day mortality originally developed to help standardize communication and risk stratification for ICH clinical care and research (9). The Prediction of Functional Outcome in Patients With Primary Intracerebral Hemorrhage (FUNC) score (10) aids in prediction of likelihood of achieving "functional independence," i.e. a modified Rankin Scale (mRS) of 0–2, at 90 days.

While surrogates might desire that their physicians disclose the numeric prognostic estimates provided by these tools, they may have difficulty accurately interpreting them. This is suggested by studies demonstrating that surrogates' prognostic estimates are often discordant with physicians', even when communication is rated highly (11–14). Poor numeracy (ability to understand and apply numeric information) may impair the ability of surrogates to understand and interpret the data provided (15, 16), with lower numeracy resulting in more discordance (11). Optimism bias further influences surrogates' prognostic estimates (11–13, 17), and surrogates may be less able to accurately interpret numerical statements predicting a high likelihood of death (12).

We hypothesized that when surrogate decision makers for patients with critical neurologic illness were presented with concrete numeric prognostic estimates derived from ICH scores

and FUNC scores of hypothetical patients with ICH and then questioned about prognosis, they would fail to recapitulate the provided estimates, and instead produce estimates discordant with those provided. Additionally, we hypothesized that low numeracy would be associated with greater discordance. We also sought to identify other factors associated with poor concordance. Surrogates' decisions regarding whether to continue aggressive management or pursue comfort care for these hypothetical patients were also evaluated.

Materials and Methods

We conducted a single-center, cross-sectional study of surrogate decision makers for critically ill patients admitted to the 22-bed dedicated neurologic intensive care unit (ICU) at the University of Maryland Medical Center between September 30, 2016, and March 31, 2017. The University of Maryland Medical Center is a large urban academic center. The institutional review board of the University of Maryland Baltimore approved this study.

Surrogate decision maker participants were approached by study investigators in the neurologic ICU and in the waiting room. They were excluded if they were younger than 18 years of age, non-English speaking, pregnant, or not actively engaged in making care decisions for a critically ill patient in the neurologic ICU. They were given a self-administered survey with five clinical vignettes describing hypothetical patients with non-traumatic ICH (see supplementary material, Figures E1–E5). The hemorrhage sizes in the vignettes were chosen according to published data on ICH volumes of 118 patients with spontaneous ICH, classified by location (18). Each vignette provided clear and explicit statements of the percent chance of survival based on the ICH score (9), and the percent chance of functional independence based on the FUNC Score (10). Questions posed in response to each scenario required respondents to make their own estimates of the patient's expected survival and functional independence, framed in terms of a percentage from 0–100%. Respondents were then asked whether they would elect to continue aggressive therapy or pursue comfort care. Scenarios were presented in random order to reduce ordering bias.

Surrogate demographics were collected, and the importance of religion to the respondent, trust in the medical profession (Abbreviated Wake Forest Scale Measuring Trust (19)), perceived quality of communication (one question from the 17-item Quality of Communication questionnaire (20)), and depression (PHQ-2 depression screening tool (21)) were assessed. Numeracy was evaluated using the Lipkus 11-item scale (22), modified with questions from Woloshin *et al* (15) resulting in a set of questions phrased within a health care context that assesses basic computations, probability, and number conversions (23).

The primary outcome was the concordance of surrogates' prognostic estimates with the provided estimates. Concordance was defined as the respondent choosing a value that was exactly equal to the provided estimate. Scores for the Lipkus 11-item numeracy scale range from 0–11. Consistent with methods of prior studies, we used the median split to divide the sample into low and high numeracy groups (24, 25). Surveys were considered complete if the majority of the questions on the last page were completed, as per prior work assessing numeracy in a healthcare context (15). For the numeracy assessment, missing answers were

coded as incorrect, consistent with standard methodology (15, 22, 26, 27). For the remainder of the questions on the survey, missing answers were treated as missing, and excluded from analysis. Continuous data are presented as median values with interquartile ranges. Univariate analysis was performed to identify factors associated with concordance. P-values were calculated using the Wilcoxon Rank-sum test, Fisher's exact test, Kruskal-Wallis test, or Spearman correlation coefficient as appropriate (29). Variables with a p-value of 0.30 or better in univariate association were included in a multivariable ordered logistic regression model to assess for independent relationship between numeracy and concordance (28). Analyses were performed using STATA®, version SE 14 (STATA Corp LLC). We applied the traditional definition of $p < 0.05$ for statistical significance.

Results

Recruitment and enrollment is outlined in Figure 1. Characteristics of the 96 surrogate decision makers are described in Table 1. The majority (83%) had at least some college education. Median numeracy score was 8 (IQR 5–10); 56% of surrogates were classified as highly numerate (score ≥ 8) and 44% as having low numeracy (score < 8). Surrogates who were more often concordant tended to have higher numeracy scores (Table 1). Higher levels of education were associated with higher numeracy scores, and greater degrees of concordance. Surrogates who designated religion as “very important,” and those with a positive depression screen had lower numeracy scores and were less concordant.

A significant proportion of subjects were unable to correctly answer questions requiring basic numeracy skills (Figure 2). Almost half of the surrogates answered question 1 incorrectly, which assesses understanding of probability using a coin flip. Additionally, over one third of surrogates answered question 10 incorrectly, which evaluates basic understanding of the meaning of a percentage. Some surrogates (8%) were unable to determine that “10%” represented a higher risk of developing a disease than “1%” or “5%,” and a larger proportion had difficulty with a similar question comparing risk magnitudes in frequency format (question 5).

Overall concordance between surrogates' prognostic estimates and the provided statements was 45% (429 out of 949 total estimates). Table 2 lists each of the prognostic estimates that were described and explicitly stated in the vignettes. The percent of surrogates who produced a concordant estimate did not vary as the provided prognoses improved. Of surrogates' discordant predictions, the majority (73%) were more optimistic than the provided value. Surrogates with high numeracy were more often concordant than surrogates with low numeracy (66% versus 17% concordance, $p < 0.0001$).

Univariate analysis was performed to assess the relationship between concordance and the individual variables listed in Table 1, including numeracy. Numeracy and concordance had a correlation coefficient of 3.29 [2.21–4.38] ($p < 0.001$). In a multivariable ordered logistic regression model adjusted for all variables that met a significance of $p < 0.3$ in univariate analysis, the point estimate for correlation between numeracy and concordance remained robust at 3.17 [1.82–4.51] ($p < 0.001$), with an odds ratio of 23.9 [5.57–97.64] ($p < 0.001$). Variables adjusted for included gender, race, admission source, religion, importance of

religion, level of education, presence of signs of depression, degree of trust in physicians, and quality of communication by physicians. Numeracy also affected decisions regarding goals of care made by surrogates in 4 of the 5 patient scenarios (Table 2). For example, in the patient with the worst prognosis (90-year-old man with 0% chance of survival and 0% chance of functional independence), 23% of surrogates with low numeracy elected to continue aggressive management, whereas only 6% of surrogates with high numeracy made this decision ($p=0.01$). In the patient with the best prognosis (49-year-old man with 87% chance of survival and 66% chance of functional independence), 13% of surrogates with low numeracy elected to pursue comfort care, whereas 0% of surrogates with high numeracy chose this option ($p<0.001$).

Discussion

The majority of the prognostic estimates made by surrogates of neurologic ICU patients were discordant with provided predictions derived from validated ICH prognostic models. Poor numeracy was common in this relatively highly-educated population, in which 83% had at least some college education. Low numeracy correlated with worse prognostic concordance, even after adjustment for gender, race, admission source, religion, importance of religion, level of education, depression, quality of communication, and degree of trust in physicians. Numeracy also affected the goals-of-care decisions made by surrogates.

These findings of low numeracy in the neurologic ICU are consistent with the general American population. The National Assessment of Adult Literacy in 2003, which assessed over 19,000 adults, found that 22% of adults were “Below Basic” in quantitative literacy, as opposed to only 12–14% in prose and document literacy (30). Lipkus *et al* evaluated numeracy of a highly educated population in which 84–95% of subjects had at least some college education (22). Among them, 40% could not solve a basic probability problem or convert a percentage to a proportion (see Figure 2, questions 1 and 2), and they performed even worse at converting a proportion to a percentage (see Figure 2, question 3). In his study, almost 20% of people could not correctly identify the larger of risk magnitudes presented as proportions, or percentages (see Figure 2, questions 4 and 5).

While 83% of our surveyed sample had at least some college education, the median numeracy score was 8, which was lower than in the Lipkus *et al* study, in which subjects had a similar level of education (22). Additionally, only 58% of subjects were classified as having high numeracy. Several factors merit consideration. Unlike the subjects of numeracy studies conducted outside of the intensive care setting, our surrogate decision makers are being tested during a period of intense stress, and therefore may not perform as well as when they face numeracy challenges in their normal environment (31). The burden and stress of being a surrogate decision maker in the ICU has been examined in multiple studies, consistently showing that individuals in this environment exhibit high levels of depression, anxiety, post-traumatic stress disorder, and sleep deprivation (32–34). In our study, 15% of surrogates had a positive screening test for symptoms of depression. It is unclear exactly what effect depression has on surrogate decision makers’ ability to make medical decisions for their loved ones in the ICU, however there is extensive evidence that depression impairs the decision making process in general, and also impairs intuition (35, 36). There are also

well-established links between sleep deprivation and impaired attention and working memory, affecting subjects' performance on cognitive tasks involving numbers (37). It is even possible that in-ICU numeracy is actually overestimated in our study, as surrogates given estimates for their own loved ones would be in a more highly charged state of emotional affect, which may further worsen their cognitive processing (38).

Our findings are consistent with other studies showing a lack of concordance between prognostic estimates made by clinicians and prognostic estimates made by surrogate decision makers (11–13). Poor numeracy was independently associated with worse concordance, suggesting that an impaired understanding of the numeric statements provided by physicians contributes significantly to this discordance. Other studies have suggested that discordance could be due to surrogates considering other factors besides the physician's statement in their prognostic estimate, such as the individual attributes of the patient, and their perceived strength of character and will to live (17). This is less likely to be the case in a survey-based study employing hypothetical patient scenarios, as the emotional component is reduced, and there is minimal enmeshment between the decision maker and patient (39). Surrogates can be subject to cognitive biases, including optimism bias, recall bias, focusing bias, and the better-than-average effect when making decisions on behalf of patients (11–13, 17, 40–42). Some of these cognitive biases may have played a role in the discordance noted within our study. Most discordant estimates were more optimistic than the provided value, and median estimates of survival were higher than provided for the most pessimistic predictions, evidencing an optimism bias (Table E1). However, no difference in the rate of concordance was found when the provided prognostic statement expressed high probability of a good outcome.

Poor numeracy likely limits surrogate decision makers' ability to understand prognosis, and also appears to affect clinical decision-making regarding goals of care. Therefore, in discussing prognosis and goals of care, it is extremely important that clinicians keep in mind this potential for surrogate decision makers to have difficulty interpreting numerical statements. Clinicians may assume that surrogate decision makers with more education will accurately interpret numeric prognostic statements (26, 43). However, the majority (70%) of low numeracy surrogates had at least some college education, and concordance among them was only 17%. Clinicians also likely assume that when they express two different numerical magnitudes of risk to a patient or surrogate decision maker, that their audience will at least be able to distinguish which magnitude is larger between the two. However, as demonstrated by our results, a not-insignificant number of surrogates are unable to correctly identify the larger of risk magnitudes, presented either as proportions or percentages. The fact that even college-educated people have difficulty with these proportion and percentage concepts is important to acknowledge, because probability concepts are critical for interpreting risk, a key factor in medical decision making. We may be placing surrogate decision makers in a dilemma, in which they are provided with numerical information that they do not understand, and then asked to make decisions using that information, making it less likely that effective medical judgments on behalf of our patients are made (16, 22). Future research should focus on finding ways to make numbers transparent and comprehensible so that individuals can make informed, reasonable decisions about their health and the health of their loved ones (26). Decision aids presenting information in visual formats may be one

approach to addressing these challenges in surrogate numeracy (44). Alternatively, communicating expected prognosis using a scenario planning technique, in which physicians help decision makers visualize various potential outcomes in “best case,” “worst case,” and “most likely” scenarios, may be an even more effective approach (45).

Limitations to our study should be considered. In recruitment, subjects were approached in the ICU. These surrogate decision makers present visiting their family member may be different from those who are not present (46). Our hypothetical clinical vignette methodology does not fully replicate the circumstances and emotional responses that arise in an actual clinician-family encounter. However, we only included surrogates who were actively involved in making decisions for a critically ill loved one at the time, thus ideally capturing any psychological contributors to performance and decision making that are present in this environment. Although we found that numeracy affected surrogates’ decisions to pursue comfort care versus continue aggressive treatment, we acknowledge that because of our hypothetical scenario methodology, these are anticipated behaviors and future intentions, rather than actual behaviors. However in our survey this question was presented in the second person, and portrayed a proximal decision or behavioral intention, making it more likely that we elicited from the respondent a prediction of their true behavior (47). Another limitation of this and other studies using the modified Rankin Scale (mRS) is that this dichotomous description of a patient as functionally independent (mRS 0–2) versus functionally dependent or dead (mRS 3–6) after ICH does not fully capture the subtleties of what may constitute a favorable outcome after ICH (48). Various trials have used different dichotomized categories for the mRS, with cutoff points ranging from <2 to <4 to constitute a favorable clinical outcome (48–50). Finally, our study was conducted in a single center, which may limit its generalizability. However, the University of Maryland Medical Center’s large referral base enabled the survey of surrogate decision makers from diverse backgrounds.

Conclusion

Low numeracy is common among patients’ surrogate decision makers, and affects their ability to accurately interpret numeric prognostic statements made by clinicians. Medical decision making regarding goals of care is affected by poor numeracy as well. This dilemma of health numeracy, or people facing numerical information that they do not understand, and being asked to make decisions using that information, is important to work to resolve, particularly in an era in which shared decision making and family-centered care is emphasized and encouraged in the ICU. Further research is needed to determine how best to communicate prognostic estimates to surrogate decision makers, to help facilitate effective medical decisions for our critically ill patients, and avoid both premature transition towards comfort care, as well as overly aggressive treatment that can result in unnecessary suffering, burden and costs on patients and families.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.

Figure 2.

Table 1

Surrogate Characteristics, by Numeracy and Prognostic Concordance

Characteristics	All Surrogates	Low ^a Numeracy	High ^b Numeracy	p value	Never Concordant	Sometimes Concordant	Always Concordant	p-value
Age, years, median (IQR)	54 (41–62)	54 (42–64)	52 (39–61)	0.7	56 (42–64)	50 (39–62)	52 (37–61)	0.7
Female	67%	71%	63%	0.5	62%	61%	83%	0.1
Caucasian	64%	45%	76%	0.003	44%	68%	79%	0.02
Length of stay of loved one, days, median (IQR)	4 (3–7)	5 (2–7)	4 (3–7)	0.8	5 (2–7)	4 (3–7)	4 (2.5–9)	1.0
Loved one admitted from home	70%	86%	57%	0.003	85%	68%	50%	0.004
Do-not-resuscitate (DNR) order in place for loved one	16%	17%	15%	0.8	18%	13%	17%	0.8
Had a family meeting to discuss their loved one	93%	93%	92%	1.0	94%	92%	92%	1.0
Served as a surrogate decision maker for a critically ill loved one before,	51%	52%	50%	0.8	53%	47%	54%	0.9
Level of education				0.003				<0.001
High school or less	17%	31%	6%		35%	11%	0%	
Some college or college graduate	49%	45%	52%		44%	53%	50%	
Graduate school or degree	34%	24%	43%		21%	37%	50%	
Catholic/Christian	81%	68%	91%	0.007	67%	84%	96%	0.006
Importance of religion				0.002				0.04
“Very important”	61%	80%	46%		79%	50%	54%	
“Fairly important”	22%	10%	31%		12%	32%	21%	
“Not too important”	14%	7%	19%		6%	16%	21%	
“Not at all important”	3%	2%	4%		3%	3%	4%	
Depression screen positive ^c	14%	28%	4%	0.002	22%	14%	4%	0.06
Quality of Physician Communication ^d , median (IQR)	8 (7–9.5)	9 (7–10)	8 (7–9)	0.09	9 (8–10)	8 (6–9)	8 (7–9)	0.02
Trust in physicians score ^e , median (IQR)	18 (16–20)	18 (16–21)	18 (15–20)	0.4	19 (17–21)	17 (15–19)	18 (16–20)	0.3
Numeracy score ^f , median (IQR)	8 (5–10)	4 (2–6)	10 (9–11)	<0.001	4 (2–6)	9 (8–10)	10 (9–11)	<0.001

^aNumeracy score <8^bNumeracy score ≥ 8

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- ^c Patient Health Questionnaire 2 (PHQ-2) depression screening tool (21)
- ^d 10-point Likert scale question from the 17-item Quality of Communication questionnaire by JR Curtis (20)
- ^e Abbreviated Wake Forest Scale Measuring Trust (19)
- ^f Score ranges 1–11 using Lipkus 11-item numeracy scale, modified with questions from Woloshin et al (15,22,23)

Table 2

Numeracy, Concordance, and Goals of Care Among Surrogate Decision Makers

Patients Presented in Clinical Vignettes, with Prognostic Estimates ^d		All Surrogates	Low ^b Numeracy	High ^c Numeracy	p value
A 90-year-old man with ICH score ^d 5, which predicts a 0% chance of survival -- what do you think are the chances this patient will survive?	Percent of surrogates producing a concordant estimate:	44%	15%	67%	<0.001
		55%	23%	80%	<0.001
If this 90-year-old man were your loved one, and the doctors were asking for your decision, would you choose to continue aggressive therapy or pursue comfort care?	Aggressive Comfort care Not sure	13%	23%	6%	0.01
		71%	55%	83%	
		16%	23%	11%	
An 85-year-old woman with ICH score 4, which predicts a 3% chance of survival -- what do you think are the chances this patient will survive?	Percent of surrogates producing a concordant estimate:	46%	20%	67%	<0.001
		43%	17%	63%	<0.001
An 85-year-old woman with FUNC score 5, which predicts a 13% chance of functional independence -- what do you think are the chances this patient will be functionally independent?	Aggressive Comfort care Not sure	24%	29%	21%	0.06
		54%	48%	58%	
		22%	24%	21%	
An 83-year-old man with ICH score 3, which predicts a 28% chance of survival -- what do you think are the chances this patient will survive?	Percent of surrogates producing a concordant estimate:	40%	17%	57%	<0.001
		47%	17%	70%	<0.001
An 83-year-old man with FUNC score 4, which predicts a 0% chance of functional independence -- what do you think are the chances this patient will be functionally independent?	Aggressive Comfort care Not sure	25%	24%	25%	1.0
		54%	54%	55%	
		21%	22%	21%	
A 50-year-old woman with ICH score 2, which predicts a 74% chance of survival -- what do you think are the chances this patient will survive?	Percent of surrogates producing a concordant estimate:	47%	20%	67%	<0.001
		45%	18%	65%	<0.001
A 50-year-old woman with FUNC score 8, which predicts a 42% chance of functional independence -- what do you think are the chances this patient will be functionally independent?	Aggressive Comfort care Not sure	81%	63%	94%	<0.001
		12%	23%	4%	
		8%	15%	2%	
A 49-year-old man with ICH score 1, which predicts an 87% chance of survival -- what do you think are the chances this patient will survive?	Percent of surrogates producing a concordant estimate:	40%	15%	59%	<0.001

Patients Presented in Clinical Vignettes, with Prognostic Estimates ^a		All Surrogates	Low ^b Numeracy	High ^c Numeracy	p value
A 49-year-old man were your loved one, and the doctors were asking for your decision, would you choose to continue aggressive therapy or pursue comfort care?	A 49-year-old man with FUNC score 10, which predicts a 66% chance of functional independence -- what do you think are the chances this patient will be functionally independent?	45%	15%	67%	<0.001
		Aggressive	77%	100%	<0.001
		Comfort care	10%	0%	
		Not sure	13%	0%	

^aSee Figures E1–E5 for full versions of the clinical vignettes. Each percent chance was explicitly provided to the surrogate decision maker.

^bNumeracy score <8

^cNumeracy score 8

^dIntracerebral hemorrhage (ICH) score, developed by Hemphill et al (9).

^eFUNC score, developed by Rost et al (10). A prediction tool for functional outcome after ICH.