

Other Ways of Knowing: Considerations for Information Communication in Decision Aid Design

Negin Hajizadeh, MD, MPH, Melissa J. Basile, PhD, Andrzej Kozikowski, PhD,
Meredith Akerman, MS, Tara Liberman, DO, Thomas McGinn, MD, MPH,
Michael A. Diefenbach, PhD

Background. Patients with advanced-stage chronic obstructive pulmonary disease (COPD) may suffer severe respiratory exacerbations and need to decide between accepting life-sustaining treatments versus foregoing these treatments (choosing comfort care only). We designed the *InformedTogether* decision aid to inform this decision and describe results of a pilot study to assess usability focusing on participants' trust in the content of the decision aid, acceptability, recommendations for improvement, and emotional reactions to this emotionally laden decision. **Methods.** Study participants (N = 26) comprising clinicians, patients, and surrogates viewed the decision aid, completed usability tasks, and participated in interviews and focus groups assessing comprehension, trust, perception of bias, and perceived acceptability of *InformedTogether*. Mixed methods were used to analyze results. **Results.** Almost all participants understood the gist (general meaning) of *InformedTogether*. However, many lower literacy participants had difficulty answering the more detailed questions related to comprehension, especially when interpreting icon

arrays, and many were not aware that they had misunderstood the information. Qualitative analysis showed a range of emotional reactions to the information. Participants with low verbatim comprehension frequently referenced lived experiences when answering knowledge questions, which we termed "alternative knowledge." **Conclusions.** We found a range of emotional reactions to the information and frequent use of alternative knowledge frameworks for deriving meaning from the data. These observations led to insights into the impact of lived experiences on the uptake of biomedical information presented in decision aids. Communicating prognostic information could potentially be improved by eliciting alternative knowledge as a starting point to build communication, in particular for low literacy patients. Decision aids designed to facilitate shared decision making should elicit this knowledge and help clinicians tailor information accordingly. **Key words:** education; outcomes research; decision aids; qualitative methods; health service research. (*Med Decis Making* 2017;37:216–229)

Patients with severe chronic obstructive pulmonary disease (COPD) often face decisions about whether to accept life-sustaining treatments for acute respiratory failure (COPD exacerbation) without the chance to consider the risks and benefits prior to hospitalization. There may be an initial survival benefit in choosing life-sustaining treatments (also known as full code, or intubation) as compared to foregoing life-supporting technologies and choosing to be treated with comfort measures only (also known as "do not intubate" [DNI]). However, there may be complications resulting from

life-sustaining treatments, which lead to the inability to return home, frequent rehospitalizations, and impaired quality of life. Conversations about treatment choices and patients' preferences in advance (advance care planning) could better prepare patients and surrogates for decision making. Clinicians are important partners in these conversations due to their knowledge about individual patients' illness trajectories. However, many clinicians do not initiate these conversations with their patients mainly because these conversations are emotionally difficult, they lack the time and training, and they may not have prognostic information readily available.^{1–5} Therefore, patients and their surrogates may be unprepared to make these decisions when they suffer acute respiratory failure.^{6–8}

To facilitate clinician-patient shared decision making about choosing between life-sustaining treatments versus comfort measures only in the event of a severe COPD exacerbation, we designed the InformedTogether Web-based decision aid. InformedTogether seeks to help patients answer the following question: “If I need to be hospitalized tomorrow because I can’t breathe, and all other treatments have failed, would I choose life-sustaining treatments or DNI?” Our design process followed International Patient Decision Aid Standards and the Agency for Healthcare Research and Quality SHARE Approach.^{9,10} InformedTogether is intended to first be used in an outpatient setting by clinicians together with COPD patients. Patients can then access the decision aid at home and share with family members. It provides prognostic data using models derived from published clinical studies and a retrospective data analysis of Medicare beneficiaries treated.^{11–16} The prognosis is communicated with icon arrays/pictographs^{17–20} using plain language text.^{20,21} We have outlined elsewhere the early design of the decision aid prototype and results from a smaller usability study in which we focused specifically on an icon array presentation and the extent to which participants found using a Web-based platform easy and acceptable during a clinic visit.²² Based on the results of this initial round of usability testing, revisions were made to the decision aid. We then undertook additional usability testing in our computer laboratory testing center, recruiting a new group of research participants composed of COPD patients and clinicians, and we also included surrogate decision makers of COPD patients. This round

of usability testing focused on participants’ trust in the content of the decision aid, acceptability of content (e.g., message tone and readability), and additional recommendations for improvement.

Information provided by decision aids improves patients’ knowledge about options, reduces their decisional conflict, and stimulates patients to take a more active role in decision making without increasing their anxiety.^{23–26} Studies suggest that the acceptance or rejection of a decision aid is in large part dependent on its usability.^{27,28} Studies also suggest that comprehension of the information in the decision aid, including risks versus benefits and terminology, varies based on education, health literacy, and numeracy levels.²⁹ Usability testing allows researchers to observe users as they interface with the tool and complete given tasks. This testing also allows researchers to observe reactions to the tool and to obtain feedback before implementation. We anticipated that InformedTogether would elicit strong emotional reactions because it describes tradeoffs between dying versus potentially impaired quality of life. We were cognizant of the effect of personal experiences on these reactions because participants had personal experience with respiratory failure, had seen family/friends with these experiences, and/or had preconceived ideas about life-supporting treatments based on images seen in the media. We specifically wanted to elicit these reactions and recommendations for language and other design considerations to make InformedTogether as sensitive as possible to a range of lived experiences. We also sought feedback about acceptability and when, where, and how InformedTogether should be implemented. We therefore conducted iterative usability testing among key cohorts using small sample sizes to not only assess participants’ reactions to the decision aid and whether they could complete prespecified tasks but also to assess comprehension, trust, perception of bias, acceptability, and recommendations for improvement of InformedTogether in light of potential emotional reactions. In what follows, we present results of parts of usability testing measuring reactions to the decision aid and perceived acceptability of implementation. In particular, we highlight our discovery of the impact that lived experiences and other nonbiomedical information play on patients’ ability to derive meaning from the prognostic estimates communicated within InformedTogether specifically and on the informed decision-making process in general.

Received 5 July 2016 from the Department of Medicine, Hofstra Northwell School of Medicine, Hofstra University, Hempstead, NY (NH, AK, TL, TM, MAD); Feinstein Institute for Medical Research, Northwell Health, Manhasset, NY (MJB, MA); and Department of Urology, Hofstra Northwell School of Medicine, Hofstra University, Hempstead, NY (MAD). Portions of this work were originally presented at the 2015 Society for Medical Decision Making annual meeting in St. Louis, MO. Financial support for this study was provided entirely by grant NIA R21 #5R21AG048196-0,1 (principal investigator: NH). The funding agreement ensured the authors’ independence in designing the study, interpreting the data, writing, and publishing the report. Revision accepted for publication 31 October 2016.

Supplementary material for this article is available on the *Medical Decision Making* Web site at <http://journals.sagepub.com/home/mdm>.

Address correspondence to Negin Hajizadeh, MD, MPH, Department of Medicine, Hofstra Northwell School of Medicine, Hofstra University, 600 Community Drive, Suite 300, Manhasset, NY 11030; telephone: (516) 321-8025; e-mail: Nhajizadeh@northwell.edu.

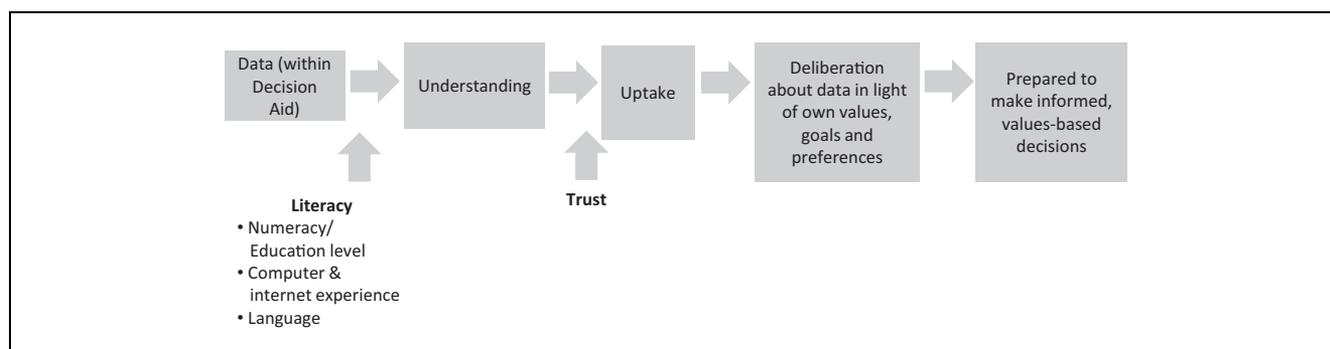


Figure 1 Conceptual model guiding usability testing questionnaire.

METHODS

Study Design and Patients

We conducted 4 usability testing sessions, 3 in English and 1 in Spanish, using a 3-phased data triangulation technique³⁰ among 3 separate cohorts: clinicians ($n = 8$), COPD patients ($n = 13$), and surrogate caregivers ($n = 5$) between 4 August 2014 and 19 March 2015. The 3 English-language sessions were stratified by cohort, so that clinicians, patients, and surrogates were in separate sessions. Due to the small number of Spanish-speaking participants, this session contained a mixed group of Spanish-speaking patients, surrogates, and 1 physician. Sessions lasted, on average, 180 minutes. We chose to work with a small sample size to ensure that each participant would have ample time to complete each phase of the study. At the start of the testing session, each participant sat at a computer terminal, and a member of the research team further explained the study and how to use the decision aid. Each person was then instructed to view the entire contents of the decision aid (Appendix 1). Following this, each person was asked to complete a series of usability tasks, for example, navigating among the pages on the Web site and writing comments in the notes section. Usability tasks were chosen based on intended functionality of the decision aid (Appendix 2). Participants were given up to 60 minutes to view the decision aid and complete the usability tasks. Next, during individual interviews, we tested participants' knowledge of the decision aid content and assessed reactions to the decision aid (Appendix 2). Finally, all participants participated in a focus group. Focus groups were facilitated by experienced qualitative researchers using a script designed to elicit feedback about the decision aid content, design, and implementation

recommendations (Appendix 2). Detailed feedback on usability was obtained during both the individual interviews and the focus group sessions, allowing us to make improvements to the decision aid. Data were collected using audio recordings and note taking. Audio recordings were professionally transcribed in order to enable a mixed-methods analytic approach. This method was chosen to not only quantitatively assess participants' feedback of our decision aid but also to qualitatively gain deeper insights into reactions to the decision aid and variations in the ability to understand the content of the decision aid (e.g., why someone might not understand the information) and perceptions of acceptability of use including emotional reactions to what they were seeing.

Recruitment. Clinicians were recruited from the pulmonary and geriatric clinics within Northwell Health, and all were engaged in the care of COPD patients. Patients and surrogates were recruited from the health system's research volunteer recruitment registry, the employee intranet, and pulmonary rehabilitation centers. Nonclinician inclusion criteria were COPD patients or surrogate caregivers for patients with COPD, aged 18 years and older, and either English or Spanish speakers.

Measures. Demographic questions asked during the interviews were chosen based on factors commonly associated with comprehension and understanding,^{31–33} as outlined in our conceptual model (Figure 1). These included questions assessing age, race/ethnicity, education levels, comfort using the Internet, self-rating of their health, and basic numeracy. Numeracy was tested using 5 questions: 3 assessing understanding of probabilities and percentages^{34,35} and 2 assessing an individual's ability to understand health information presented in a graph format^{36,37} (Table 1).

Outcomes measured were also guided by our conceptual model (Figure 1) and included questions

to assess comprehension, trust, perception of bias, acceptability of implementation, and recommendations for improvement. Comprehension of the decision aid was measured using 11 closed-ended questions (5 understanding of terminology questions, 5 understanding of icon array questions, and 1 question asking participants to apply the data to themselves) and several open-ended questions: asking if there was anything in the decision aid that the participant did not understand, gist-meaning questions (i.e., questions assessing comprehension of the general meaning of the decision aid), and asking participants to describe possible risks and benefits to someone associated with intubation and why someone might not want to receive a breathing tube.

Trust of the information contained in the decision aid was measured using 5 closed-ended questions. Perception of biased presentation of information in the decision aid was measured using 2 closed-ended questions. Acceptability of implementation of the decision aid in clinics was measured using 2 closed-ended questions. Recommendations for improvement to the decision aid and recommendations for when and where to implement the decision aid were measured using several open-ended questions. The study was approved by the Northwell Health Institutional Review Board, and we obtained written informed consent from all participants.

Data Analysis

Quantitative analyses. Data from closed-ended questions administered during 1-on-1 interviews with participants were summarized descriptively (frequency and percentage for categorical variables; mean \pm SD and median for continuous variables) (Appendix 3). These descriptive analyses included comparisons of participant characteristics for those who had high comprehension of the decision aid content versus low comprehension of the content (Appendix 4) and a comparison between participants who trusted the information in the decision aid versus those who did not (Appendix 4). The Fisher exact test was used to compare the groups for categorical variables, and the Mann-Whitney test was used to compare the groups for continuous measures. All data were stored in REDCap³⁸ and analyzed using SAS version 9.4 (SAS Institute Inc., Cary, NC).

Qualitative analyses. Initially, 2 qualitative researchers read all interview and focus group transcripts and developed an outline of the themes using deductive and inductive coding techniques.

This allowed us to include pre-identified themes from our conceptual model (which informed the development of the interview questions as described above) as well as new themes that emerged over time. Themes were iteratively refined and developed into a codebook in consultation with all investigators. Initial deductive codes that did not prove salient were eliminated, and numerous inductive codes were condensed. Nine primary themes based on topics that occurred with high frequency were included in the codebook. These were 1) barriers to using the decision aid, 2) communication, 3) value congruence, 4) decision-making process, 5) factors impacting understanding and information uptake, 6) important factors for decision making, 7) knowledge, 8) perceptions of the decision aid, and 9) recommendations for improvement. Using this codebook, all transcripts were coded by 2 coders using NVivo 10 software (QSR International, Melbourne, Australia). To test for interrater reliability, an NVivo coding comparison was conducted on 4 transcripts (1 interview transcript randomly selected from each usability session). Results showed 99.2% agreement and a Cohen κ value of .71, which indicates substantial agreement between the 2 coders (because the κ coefficient calculation takes into account the likelihood of the agreement between users occurring by chance, the value of κ can be low, even though the percentage agreement is high).^{39,40}

RESULTS

Participant Characteristics

Participant characteristics for patients, surrogates, and clinicians are detailed in Tables 1 and 2. While the small sample size makes it difficult to generalize, it is notable that 76.9% ($n = 10$) of patients and 60% ($n = 3$) of surrogates had lower numeracy, which we defined as answering incorrectly more than 1 of the 5 basic numeracy questions.^{34–36}

Questionnaire Responses

The results from quantitative analyses of closed-ended questions are outlined in Appendix 3 and summarized below. We also describe the results from qualitative analyses of open-ended questions for comprehension, acceptability, and recommendations for improvement.

Table 1 Patient and Surrogate Characteristics (Descriptive)

	Patients (n = 13)	Surrogates (n = 5)
Age, mean ± SD (median), y	58.3 ± 11.0 (62.0)	54.6 ± 10.7 (59.0)
Unmarried	8 (61.5)	4 (80.0)
Female sex	7 (53.9)	3 (60.0)
Race/ethnicity		
White	4 (30.8)	2 (40.0)
Black/African American	6 (46.1)	1 (20.0)
Hispanic/Latino	3 (23.1)	1 (20.0)
Other	0 (0.0)	1 (20.0)
Highest level of education		
9th–12th grade	10 (76.9)	1 (20.0)
Some college	1 (7.7)	1 (20.0)
College degree	2 (15.4)	3 (60.0)
Economic class		
Lower class	3 (23.1)	1 (20.0)
Lower middle class	3 (23.1)	2 (40.0)
Middle class	7 (53.8)	1 (20.0)
Upper middle class	0 (0.0)	1 (20.0)
Language(s) spoken at home		
English	13 (100.0)	4 (80.0)
Spanish	3 (23.1)	2 (40.0)
Access to home computer with Internet	9 (69.2)	5 (100.0)
Comfort with using the Internet		
Not at all comfortable	4 (30.8)	0 (0.0)
Somewhat comfortable	4 (30.8)	1 (20.0)
Mostly comfortable	1 (7.7)	2 (40.0)
Extremely comfortable	4 (30.8)	2 (40.0)
Average hours per week spent on the Internet		
Never	4 (30.8)	0 (0.0)
<5	3 (23.1)	0 (0.0)
5–11	3 (23.1)	2 (40.0)
11–30	3 (23.1)	2 (40.0)
>30	0 (0.0)	1 (20.0)
Self-rating of health in general		
Very good	2 (15.4)	3 (60.0)
Good	4 (30.8)	1 (20.0)
Fair	4 (30.8)	1 (20.0)
Poor	2 (15.4)	0 (0.0)
Missing	1 (7.7)	0 (0.0)
Lack comprehension (defined as >2 of 11 terminology and icon array interpretation questions wrong)	9 (69.2)	2 (40.0)
Low numeracy (defined as >1 of 5 numeracy questions wrong)	10 (76.9)	3 (60.0)
Low terminology (defined as >1 of 6 terminology questions wrong)	8 (61.5)	0 (0.0)
Low icon array interpretation (defined as >1 of 5 icon array interpretation questions wrong)	8 (61.5)	2 (40.0)
COPD	11 (84.6)	4 (80.0)

Note: Data are reported as n (%) unless otherwise specified. COPD = chronic obstructive pulmonary disease.

Comprehension: results of quantitative analysis. Questions measured comprehension of terminology used in the decision aid (e.g., COPD exacerbation, intubation, full code, advance directive), for which we provided clear definitions in the

text as well as a glossary at the end of the decision aid, and icon array comprehension, which was based on a person's ability to look at the icon arrays and interpret estimated survival outcomes based on what appeared in the icon arrays (Appendix 1).

Table 2 Clinician Characteristics (Descriptive)

	Clinicians (n = 8)
Age, mean ± SD (median), y	45.3 ± 10.6 (45.0)
Female sex	3 (37.5)
Years since residency completion, mean ± SD (median)	13.5 ± 11.9 (10.0)
Race/ethnicity	
White	4 (50.0)
Hispanic/Latino	1 (12.5)
Caribbean or West Indian	2 (25.0)
Missing	1 (12.5)
Born in the US	6 (75.0)
How many patients with severe COPD were treated?	
Some	1 (12.5)
About half	6 (75.0)
Most	1 (12.5)
How many patients with severe COPD have advance directives?	
Very few	4 (50.0)
Some	2 (25.0)
Most	1 (12.5)
Almost all	1 (12.5)
How many patients with severe COPD have they talked to regarding planning in case they need to make decisions about mechanical ventilation?	
Very few	1 (12.5)
About half	1 (12.5)
Most	3 (37.5)
Almost all	3 (37.5)

Note: Data are reported as n (%) unless otherwise specified. COPD = chronic obstructive pulmonary disease.

We defined low comprehension as answering incorrectly more than 2 of the 11 questions assessing terminology and icon array comprehension. Many of the patients had low comprehension (69.2%; $n = 9$; median, 5 of 11 incorrect). Fewer surrogates had low comprehension (40%; $n = 2$; median, 4.5 of 11 incorrect). Notably, half of these participants stated that there was nothing in the decision aid that they did not understand. All of the clinicians had high comprehension.

We also assessed “gist” understanding (i.e., the general meaning)³⁷ to determine if participants understood the central points of the decision aid; that is, if a person chooses to forego intubation (after all other interventions have failed), he/she will very likely die in the hospital, and many people who accept life-sustaining treatments are discharged to a nursing home and may be rehospitalized multiple times within the following year. In contrast to verbatim understanding, the majority of the patients and surrogates were able to correctly answer questions assessing gist understanding. For example, when asked what would likely happen if a person decided not to be treated with a breathing tube after all other treatments had failed, 76.9%

($n = 10$) of patients and 100% ($n = 5$) of surrogates answered correctly that without the breathing tube, a person “will die” or “not live for very long.” However, when asked questions requiring numerical responses (e.g., “Based on these pictures [showing icon arrays], if 100 people with severe COPD chose to be full code, how many people would likely be living after 1 year?”), only 38.5% ($n = 5$) of patients and 60% ($n = 3$) of surrogates answered this question correctly.

As expected, in the patient and surrogate groups, both low numeracy and low education levels were associated with lower verbatim understanding. All 10 participants with lower numeracy had low understanding of the icon arrays, and 3 of the 4 participants with no high school diploma had low understanding of the “technical terminology” (e.g., intubation, mechanical ventilation, and COPD exacerbation), despite our efforts to use lay terms alongside technical terms and testing overall language for a 9th grade readability level.⁴¹

Comprehension: results of qualitative analysis. As supported by our conceptual model and other studies assessing numeracy and health comprehension,^{42,43} for those with low numeracy levels, we noticed patterns of misunderstanding;

for example, when asked specific questions about probabilistic data, participants with low numeracy scores responded by referring to their experiences or beliefs rather than the data provided. Our initial code for these was “me-centric” responses (this became the basis for what we later broadly referred to as “alternative knowledge” [see below]). These “me-centric” responses stood in opposition to responses from participants with higher numeracy scores, which were derived from the data, that is, data-driven responses. Text from our transcripts, seen below, highlights examples of both “me-centric” and data-driven responses.

“Me-centric” response:

Interviewer: OK. And so you may or may not agree with what the decision aid said about the risk of dying for those hospitalized with the COPD exacerbation. If you personally were to be hospitalized after a bad COPD exacerbation and chose to be full code, what do you think is the chance of being alive after 1 year?

Respondent: Well, I’m a fighter, so I know I’m going to last a few years.

Interviewer: OK. So would you say after 1 year, there’s 100% chance of being alive or somewhere less than that?

Respondent: No, I’m going to go with 100%. Like I said, I’m a fighter. I’m not trying to go nowhere.
(Patient: lower numeracy)

Data-driven response:

Interviewer: You may or may not agree with what the decision aid says about your risk of dying if you are hospitalized for a bad COPD exacerbation. If you personally were to be hospitalized after a bad COPD exacerbation and chose to be full code, what do you think is the chance that you will be living after 1 year? Please answer that on a scale from 0% to 100%.

Respondent: Well, what did we say? 32 . . . 32%.

Interviewer: 32%?

Respondent: Right? Is that . . . 17 and 15 . . . right. Yeah, right . . . 32 over 100, right.

Interviewer: Can you tell me how you arrived to your answer?

Respondent: Yeah, from the chart.
(Patient: higher numeracy)

Qualitative analysis showed other examples of participants drawing on non-data-driven sources to derive meaning or understanding of the information presented in the decision aid including, for example, personal experiences or cultural frameworks. We use the term “alternative knowledge” to describe ways of knowing, understanding, or deriving meaning from data presented, not based on biomedical information. In our participant responses, we saw alternative knowledge in 2 settings. First, participants with low comprehension often drew on alternative knowledge in order to make sense of what they saw in the decision aid. In the example above, the participant was asked to interpret what the likelihood of survival with intubation would be, and in response, she drew on her lived experience (i.e., focused on herself, hence “me-centric”) rather than the data. Second, participants’ lived experiences sometimes impacted their ability to apply the information to themselves or loved ones, despite high comprehension. For example, when asked how sure participants were that estimates given in the decision aid were correct, 1 participant stated, “You know, it’s interpreting how the results were established based on people in the study versus my own experience” and adjusted the probability of survival with intubation according to his own experience. In this way, alternative knowledge stood in opposition to the biomedical knowledge being conveyed in the decision aid. We have further identified 3 subtypes of alternative knowledge rooted in peoples’ lived experiences, cultural frameworks, and embodied knowledge,⁴⁴ which we describe below.

We refer to a “lived experience” as knowledge derived from direct, first-hand experience obtained through living with, caring for, or directly witnessing the experiences of someone with an illness. For example, a researcher asked the following:

“If you needed to decide whether to accept mechanical ventilation, what factors would you think about?”

The participant responded:

“I don’t wanna use it at all. I saw a friend of mine being intubated, and I saw the look on her face, and she was on the breathing tube for 6 months until she passed away, and I will never forget that look—oh my God. Well, my mind is set already. I know what I want, and my family knows what I

want.” (COPD patient, Hispanic female, age 74 years, high school graduate)

In this situation, information presented to the participant (including prognostic estimates and a chart presenting a side-by-side comparison of the risks and benefits for each option) appears to not have been factored into her decision to decline intubation. The emotional experience that she described of witnessing a close friend’s intubation may have been the most important factor in her decision.

A “cultural framework” is another subtype of alternative knowledge that we define as social group–centric knowledge (i.e., derived from religion, ethnicity, class, sex). For example, a researcher asked the following:

“The decision aid gives a number for your chance of dying or living in a nursing home 12 months after you are hospitalized for a bad COPD exacerbation. How sure are you that the estimates given are correct?”

The participant responded:

“I do not know how advanced is the medical science now, but for me, 0%. Because machines can help, but God decides if a person should stay alive or die.” (COPD caregiver, Hispanic female, age 63 years, high school)

In this example, the researcher’s question referred directly to a series of prognostic estimates portrayed using icon arrays, which showed a greater than 50% chance of living in a nursing home. The participant’s response, however, indicated that the prognosis was determined by God. Whether this was because the icon arrays were not understood or that they were understood and ignored/not believed is unclear. However, it raises the possibility that prognostic data may not factor into a person’s decision if it is in conflict with a cultural framework.

Finally, “embodied knowledge” is defined as subjective knowledge derived from an individual’s perceptions of his/her body, how he/she feels, and the physical changes undergone by a person throughout the course of an illness.⁴⁴ For example, a researcher asked the following:

“How sure are you that the [prognostic] estimates given [in the decision aid] are correct? From 0 to 100%, how sure will you be that those estimates are correct?”

The participant responded:

“As far as basing it on myself, I’m totally not sure. But based on the results of the study, I would say

they’re probably right. You know, I’ll go with 50%. You know, it’s interpreting how the results were established based on people in the study versus my own experience.” (COPD patient, white male, age 67 years, college graduate)

In this example, the icon array indicated a 68% chance of survival. Although the participant believed that the estimate was correct for the population studied, when applying that estimate to himself, he felt that his chance was lower. This may have been because he felt his own health to be worse than those studied. In this way, he adapted the estimate based on his subjective experience with COPD.

Trust: results of quantitative and qualitative analyses. Based on our conceptual model, trust influences the uptake of health-related messages.⁴⁵ We hypothesized that if a patient did not trust the information being presented, then he/she would not incorporate it into his/her decision, regardless of whether he/she had the skills to actually understand it. Therefore, we asked a series of questions to assess trust in the decision aid. These included 1 direct question about whether participants trusted the decision aid, 1 concerning confidence in the accuracy of the estimates given, and 1 asking whether participants thought the numbers could be wrong. Most patients ($n = 11$; 84.6%) and all surrogates trusted the contents of the decision aid, stating that they trusted the source of the information (both the fact that the decision aid was linked to our health system and because the decision aid itself contains a resources section where we provide information on how the estimates were generated, including the sources from which the estimates were generated),¹³ the information was consistent with what they had experienced, and the decision aid was not linked to any advertisements or corporate sponsors. However, on average, patients and surrogates stated that they were only about 60% sure (median, 50% and 70% for patients and surrogates, respectively) that the estimates given were correct, and almost all patients and surrogates stated that these numbers could be incorrect because peoples’ outcomes vary, the research could be based on people with unspecified comorbidities, or the information was inconsistent with prior experiences. Of the clinicians, most ($n = 7$; 87.5%) stated that they trusted the contents of the decision aid. In contrast to the patients and surrogates, few clinicians ($n = 2$; 25%) believed that the numbers given could be incorrect because the numbers were

consistent with what they had seen in the patients whom they treated, the data “made sense” based on what they already knew, and they were familiar with the statistics on which the numbers were based. However, during our clinician focus group, the participants discussed the extent to which existing comorbidities among the cohorts sampled may result in different outcomes for their actual patients. Overall, most participants understood that the outcomes provided in the decision aid were estimates based on a wider population and that they might not apply to themselves/to their patients.

Additionally, we explored whether participants would apply the data to themselves for the prediction of outcomes and how this differed from the application of the data to others. We asked the following: “If you *personally* were to be hospitalized after a bad COPD exacerbation and chose to be full code, what do you think is the chance you would be living after 1 year?” Participants were again shown the icon array depicting 32% of 100 patients alive after 1 year. Despite this estimation, most people were more optimistic that they themselves would survive the scenario, with several stating that there would be at least a 50% chance that they would survive and 7 participants stating that there would be a greater than 70% chance that they would be alive. Only 1 person stated that he believed that he personally had a 32% chance of being alive after 1 year. In contrast, the following question was asked: “If 100 people *just like you* (with severe COPD) chose to be full code, how many people would likely be dead after 1 year?” In response, 44% ($n = 8$) based their answers on the information provided. Taken together, these findings suggest both a difference between trust in the data being presented versus confidence in the accuracy of the data and a difference in trust/confidence in the data versus application of the data to self.

Perception of bias: results of quantitative and qualitative analyses. Most patients and surrogates stated that the information presented for intubation versus DNI was completely balanced in the decision aid (61.5% and 80% of patients and surrogates, respectively). However, 46% ($n = 6$) of patients believed that there was bias toward full code (none believed that there was bias towards DNI). Of the surrogates, none believed that there was bias toward full code; however, 1 participant believed that there was bias towards DNI. In contrast, only 25% of the clinicians believed that the

information was completely balanced, with most believing that there was bias toward DNI ($n = 5$; 62.5%).

In seeking an explanation for these differences in the perception of bias between patient and clinician perspectives, qualitative analysis revealed that several of the patients and surrogates simply equated DNI with being dead (e.g., as stated by a COPD patient: “Either do this [choose full code], or you’re going to die.”) and so, as a result, may have seen the decision aid as being biased toward full code, which they equated with being alive. Many of the patients who felt that there was bias toward full code had both low overall comprehension and had made statements equating DNI with “choosing” death and full code with “choosing” to stay alive and stated that a person should do whatever it takes to stay alive. The 1 surrogate who stated that there was bias towards DNI had an above college education and scored highly on comprehension questions. This may suggest that if someone does not fully understand the risks of intubation, and only considers this as a choice between being alive or dead, then he/she may inherently view the decision aid as biased toward the more favorable option, that is, full code, because it would keep him/her alive longer. In contrast, clinicians, who understood that the risks of choosing full code were poor quality of life, poor functional status, and the high likelihood of dying anyway, may have seen the decision aid as being biased toward DNI because it had more favorable outcomes as perceived by the clinician. As stated by a clinician: “While they may live a little longer, they may not . . . that is, like the gist of this because if they are going to survive, they are going to be sicker, they are going to end up in a nursing home, and the differences in survival are not that great, right?” This is an example of “me-centric” knowledge (in this case, clinician-centric), that is, knowledge that is directly rooted in a clinician’s lived experiences treating COPD patients, which may have influenced their perception of bias toward DNI.

Acceptability: results of quantitative and qualitative analyses. Most participants stated that they would be very likely to recommend that actual patients use the decision aid with their doctors (mean, 8.3, 7.4, and 7.3 for patients, surrogates, and clinicians, respectively; 0–10 scale from “not at all” to “extremely likely to recommend”). For the patients and surrogates, we saw a wide range of

Table 3 Variation in Patients' and Surrogates' Preferences for Information and Emotional Reactions to Information Contained in the Decision Aid

Timing of when to use	"I think it should be given at the beginning when they find out they have COPD." (surrogate)	"I would say . . . when your COPD began to . . . when your doctor notice that it's beginning to get severe." (COPD patient)
Tone and level of sensitivity of information	"It was a slap in the face." (COPD patient)	"Tell it like it is." (surrogate)
Reaction to the images	Image of intubated patient "too graphic." (surrogate)	"I just loved that it's so graphic." (surrogate)
Depth of information	"As far as I was concerned, as long as you put those numbers up there with, you know, anything else beyond that was [unnecessary]." (COPD patient)	"I liked it—the fact that they were up-front about the personal things, the financial stability of your family, these things because when you're really sick, you're not thinking about these things." (COPD patient)

Note: COPD = chronic obstructive pulmonary disease.

responses regarding when participants thought that it was appropriate to introduce an end-of-life discussion using the decision aid with a COPD patient. Also, 44% ($n = 8$) of participants stated that the decision aid should be used early on "so you're not blindsiding the patient," and 28% ($n = 5$) of participants stated that it should be used at the point when a person was just beginning to experience more frequent exacerbations. For example, a COPD patient stated the following:

"I think primarily the patient has to have the wherewithal to understand it. So, I mean, if you're in . . . What was that word you used about the hyper state of COPD? I don't think you're in a position to really start to answer these questions, right? I mean, you're worried about breathing and stuff."

Finally, 28% ($n = 5$) stated that the decision aid should be used with a patient once his/her COPD became very severe, meaning that the need for decision making was imminent. We also saw a variety in participants' emotional reactions to the information being presented. Some participants expressed that there were elements of the decision aid that made them uncomfortable, while others stated that they liked that the information was realistic. For example, 1 COPD caregiver stated the following:

"The picture of the gentleman with all the tubes in, the EKG, and all that hooked up to him, it kind of made me a little squirmy. And that was because I had seen my sister like that several times."

Some patients in the focus group stated that the information was "in your face" or "very frightening," with 1 patient stating the following:

"So you know, the initial emotions kicked in right away, and it gets you to that defensive mode: 'OK, what else do you want to know?' So all of a sudden, I find myself just breezing through everything."

However, another patient stated the following:

"I think the pictures are good because people follow those more. And it makes them actually see reality. The pictures were like really, 'OK, this could really happen to me.' This is what's going to happen. I think that was good."

Table 3 shows the contrast in both preferences for what kind of information people wanted and their emotional reactions to the information contained in the decision aid.

Recommendations for improvement: results of qualitative analysis. Recommendations for improving the decision aid among clinicians, patients, and surrogates focused on addressing barriers to accessing the tool (e.g., offering a printout version for those who do not have access to a computer), making it easier to understand (e.g., refining the icon arrays and using even plainer/less technical language), softening the language (e.g., using terms such as "will not survive" instead of "will be dead"), and making technical improvements related to the usability of the decision aid. Clinicians also recommended offering opportunities for ad-libbing, for example, offering an abbreviated version of the decision aid that only contained images and icon arrays and offering training prior to using the tool. Additionally, in order to be better integrated into workflow, physicians recommended embedding the decision aid within the electronic health records

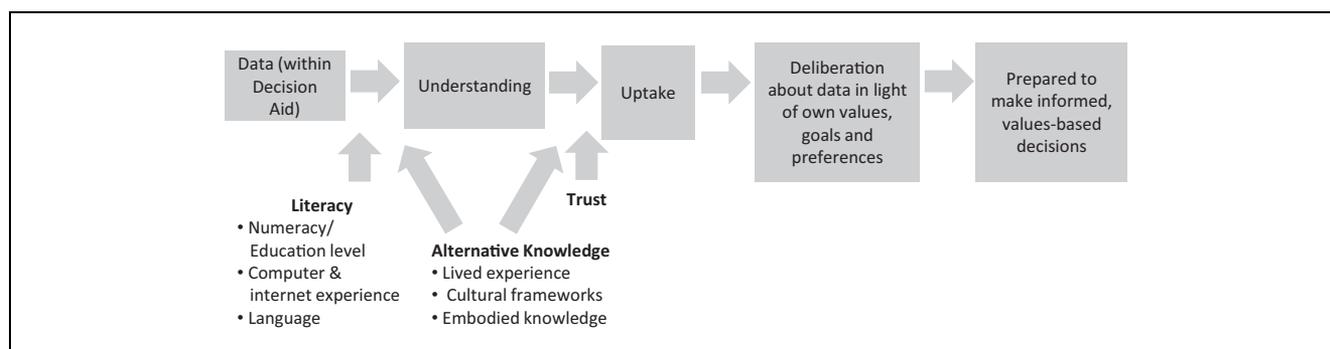


Figure 2 Conceptual model augmented after data analyzed.

and that there should be a separate visit scheduled to use the decision aid.

DISCUSSION

In general, most participants understood the content of the decision aid when tested for gist comprehension, even when verbatim knowledge was low. Almost all participants trusted the information and were very likely to recommend the decision aid to others. Although we are limited in our ability to generalize due to the small sample size of a usability study, there were several findings that emerged that may benefit from further exploration. From this study, we gained insights into decision aid content revisions needed for improved usability but realized that a “1-size-fits-all” decision aid may not be possible, as evidenced by the range of emotional reactions to terms that we initially used in the decision aid and suggestions for when to use the decision aid. It is clear in our study that alternative knowledge, including preconceived beliefs about what the treatment entails and its risks and benefits, impacts both the comprehension and uptake of information. Therefore, a decision aid designed to facilitate shared decision making should assist clinicians in tailoring communication based on individuals’ preferences for information and style of presentation. Although important, broad demographic categories such as language, sex, and race frequently used to tailor/target decision aids^{46,47} may not be sufficient because personal experiences and preferences may only be identified as patient-clinician communication is occurring. We realized that not only would we have to further simplify the presentation of data but that we would also need to include methods to enable clinicians to recognize each user’s alternative knowledge frameworks. Recognizing alternative

knowledge may facilitate the communication of information in a way that is both understood and accepted, which we have termed “uptake.” As such, we edited our conceptual model to include the influence of nonbiomedical alternative knowledge on the uptake of information communicated (Figure 2).

Our ideas around alternative knowledge emerged from the pattern of “me-centric” responses from participants with low numeracy when asked to interpret the icon arrays. Here, participants drew from personal experiences in order to relate to the information. Additionally, 1 participant drew on alternative knowledge rather than the data because it did not reflect what he believed to be true based on his personal experience of living with COPD. Although a person may “understand” the data, as measured using knowledge questions, he/she may draw on a powerful lived experience, which may prevent the uptake of information when the data do not resonate with what he/she has seen/heard to be true (such as prognosis). The uptake of data may be necessary in order for patients to apply the data to their own decision making. In our adapted conceptual model, we make a distinction between “understanding” and “uptake” in which understanding is associated with skills linked to education and literacy (health, statistical, computer, etc.) that are necessary for basic comprehension and uptake is associated with both accepting the information and applying it to oneself. For uptake to occur, a person must trust the information being presented to him/her. However, alternative knowledge may still hinder uptake if it is at odds with biomedical knowledge and/or it leads to an emotional reaction to the information. This might be why more participants, across comprehension levels, had a difficult time providing a data-driven response when asked to apply the data to themselves (for predicted 1-year

survival) versus to a hypothetical group, despite stating that they trusted the data.

In our initial design, we tried to make the decision aid understandable to those with low literacy and numeracy levels, using plain language to define medical terminology and choosing to use icon arrays to present prognostic data and reduce problems associated with denominator neglect.⁴⁸ However, the findings from our usability testing showed that those with very limited numeracy and low education levels still had very low comprehension, specifically for the terminology and icon array questions. This reinforced our initial belief that the decision aid needs to first be introduced by a clinician who could explain the data presented and include audio descriptions of the data within the decision aid.

We saw that while most of the patients and surrogates in our study trusted the information, they stated that the estimates given could be incorrect. This could mean that while participants trusted the fact that they were not being misled deliberately, they also understood the uncertainty around the given estimates, which we intentionally tried to convey by using terms such as “on average” or “likely” alongside the estimates. Clinicians’ responses indicating that very few thought that these numbers could be wrong as opposed to the almost 100% of patients and surrogates may indicate more confidence in the data based on their clinician-centric knowledge of similar outcomes for their own COPD patients (their own lived experiences).

Finally, the fact that several people who had low comprehension also believed that they understood everything could have serious implications for informed decision making if some people mistakenly believe that they understand the information that they have received and use it to make an “informed decision.” Although we have learned that the content of our decision aid needs to be revised to increase comprehension, this will not address the discordance between users’ perceptions of comprehension and actual comprehension. We suggest that decision aids should parallel communication strategies in clinical encounters, in particular those in which complex information is being introduced, using an “ask-tell-ask” strategy.⁴⁹ This strategy not only starts with assessing patients’ baseline knowledge and allows for the understanding of alternative knowledge, which clinicians can use to tailor communication, but also asks the patient to describe in his/her own words what he/she has heard/understood from the medical information communicated by the clinician. This provides a rich opportunity for

the clinician to not only learn a patient’s perspective but also to immediately clarify any misunderstandings of the medical information. We propose that decision aids should similarly start with questions about baseline knowledge and experiences and incorporate measures of understanding, for example, using embedded knowledge testing questions.

Limitations

An important limitation of our study is that it was not tested within an actual clinical encounter. As such, the results may not accurately reflect the comprehension and acceptability of implementation for the setting in which it is intended to be used. In addition, it is clear that decision making in hypothetical scenarios differs from real-life situations. A second limitation is that we used a 9th grade readability level for the language of the decision aid. We believe that this may have contributed to the inability of some participants to fully understand the contents of the decision aid. Nevertheless, this early-stage and iterative usability testing allowed for early modifications to be made, which aimed to increase the likelihood that a real-life application would be feasible and acceptable.

Future Directions

Our next steps will be to embed questions that can elicit patients’ alternative knowledge within InformedTogether and questions to measure patients’ understanding of the biomedical knowledge presented. We hope that these modifications will enrich shared decision-making conversations and truly inform decision making about accepting life-sustaining treatments versus comfort measures alone. Additionally, we are undertaking feasibility testing in which we are observing clinicians using the decision aid with patients in an outpatient setting. We believe that due to the sensitive topic being covered, and supported by our interview and focus group responses, an in-person interaction between a clinician and a patient is important for a patient’s first encounter with the decision aid. Following the initial use of the decision aid in the clinic, we provide all patients with the ability to access the decision aid online as well as with a printout version of the decision aid to take home. To address physicians’ concerns regarding the lack of time to use the decision aid, we have included alternative strategies such as allowing nurse practitioners and respiratory therapists to use the decision

aid with patients. This strategy has thus far been successful in ongoing testing, allowing for the decision aid to be used within the context of shared decision making for which it was designed. Given changes in insurance reimbursements that now compensate clinicians for dedicated advance care planning discussions, we have also suggested scheduling patients for a designated advance care planning visit.

CONCLUSIONS

Decision aids that are intended to be used within the context of shared decision making should include assessments of patients' understanding of the biomedical data presented and their alternative knowledge frameworks in order to allow tailoring of communication and increased comprehension and uptake of the information. Knowledge assessments paralleling the ask-tell-ask model of communication, which first asks what patients' baseline knowledge and experiences are and then asks patients to explain in their own words what they have learned from the medical communication/decision aid, can assess overall comprehension/gist (particularly for those with lower level education) and provide opportunity for clarification. Further, attempts to elicit patients' knowledge frameworks and reactions to the data should be part of clinician training for using the decision aid.

Because alternative knowledge is rooted in the experiences of each individual, designing a tailored decision aid to address different alternative knowledge frameworks will be difficult. Instead, decision aids could help clinicians tailor conversations while using the decision aid based on the alternative knowledge elicited during shared decision-making conversations. Communicating within the context of a patient's alternative knowledge framework may be critical to patient uptake of information. Therefore, tools of knowledge clarification and information exchange can present fruitful opportunities for clinicians to address misunderstandings and opportunities for clinicians to understand the patient's perspective and that of his/her social network. One example is when patients apply anecdotal information that does not necessarily pertain to their own disease state. This exchange of information is at the core of the shared decision-making process, leading to a clearer understanding of goals and preferences and a collaborative approach to decision making. Shared decision making helps to achieve a "shared mind"⁵⁰ in which the clinician and patient/

patient's family understand each other's perspectives and goals, and decision aids should support the exchange of both biomedical and alternative knowledge necessary for achieving a shared mind and for preparing patients to make more informed, values-based medical decisions.

Finally, our research findings raise questions about whether decision aid effectiveness needs to be assessed with measures beyond those commonly used (e.g., change in knowledge and decisional conflict) to include the measurement of the uptake of data about the prognosis and risks and benefits of treatment choices presented within the decision aid.

REFERENCES

1. Christakis NA, Iwashyna TJ. Attitude and self-reported practice regarding prognostication in a national sample of internists. *Arch Intern Med.* 1998;158:2389–95.
2. Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ.* 2000;320:469–72.
3. Knauff E, Nielsen EL, Engelberg RA, Patrick DL, Curtis JR. Barriers and facilitators to end-of-life care communication for patients with COPD. *Chest.* 2005;127:2188–96.
4. Curtis JR, Patrick DL, Caldwell ES, Collier AC. Why don't patients and physicians talk about end-of-life care? Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. *Arch Intern Med.* 2000;160:1690–6.
5. Curtis JR. Palliative and end-of-life care for patients with severe COPD. *Eur Respir J.* 2008;32:796–803.
6. Barnato AE, Albert SM, Angus DC, Lave JR, Degenholtz HB. Disability among elderly survivors of mechanical ventilation. *Am J Respir Crit Care Med.* 2011;183:1037–42.
7. Hopkins RO, Jackson JC. Short- and long-term cognitive outcomes in intensive care unit survivors. *Clin Chest Med.* 2009;30:143–53, ix.
8. Connors AF, Dawson NV, Thomas C, et al. Outcomes following acute exacerbation of severe chronic obstructive lung disease: the SUPPORT investigators (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments). *Am J Respir Crit Care Med.* 1996;154:959–67.
9. International Patient Decision Aid Standards Collaboration. Criteria for judging the quality of patient decision aids. Available from: http://ipdas.ohri.ca/IPDAS_checklist.pdf.
10. Agency for Healthcare Research and Quality. The SHARE Approach. Available from: <http://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html>.
11. Hajizadeh N, Crothers K, Braithwaite RS. Using modeling to inform patient-centered care choices at the end of life. *J Comp Eff Res.* 2013;2:497–508.
12. Hajizadeh N, Goldfeld K. Burden of transitions after invasive mechanical ventilation for U.S. individuals with severe chronic obstructive pulmonary disease: opportunity to prepare for preference-congruent end-of-life care? *J Am Geriatr Soc.* 2016;64:434–5.

13. Hajizadeh N, Goldfeld K, Crothers K. What happens to patients with COPD with long-term oxygen treatment who receive mechanical ventilation for COPD exacerbation? A 1-year retrospective follow-up study. *Thorax*. 2015;70:294–6.
14. Taksler GB, Keshner M, Fagerlin A, Hajizadeh N, Braithwaite RS. Personalized estimates of benefit from preventive care guidelines: a proof of concept. *Ann Intern Med*. 2013;159:161–8.
15. Hajizadeh N, Crothers K, Braithwaite RS. Informing shared decisions about advance directives for patients with severe chronic obstructive pulmonary disease: a modeling approach. *Value Health*. 2012;15:357–66.
16. Hajizadeh N, Crothers K, Braithwaite RS. A theoretical decision model to help inform advance directive discussions for patients with COPD. *BMC Med Inform Decis Mak*. 2010;10:75.
17. Icon Array. Home page. Available from: www.iconarray.com.
18. Garcia-Retamero R, Cokely E. Communicating health risks with visual aids. *Curr Dir Psychol Sci*. 2013;22:392–9.
19. Galesic M, Garcia-Retamero R, Gigerenzer G. Using icon arrays to communicate medical risks: overcoming low numeracy. *Health Psychol*. 2009;28:210–6.
20. Fagerlin A, Zikmund-Fisher BJ, Ubel PA. Helping patients decide: ten steps to better risk communication. *J Natl Cancer Inst*. 2011;103:1436–43.
21. Plain Language. Home page. Available from: <http://www.plainlanguage.gov/>.
22. Uhler LM, Pérez Figueroa RE, Dickson M, et al. InformedTogether: usability evaluation of a web-based decision aid to facilitate shared advance care planning for severe chronic obstructive pulmonary disease. *JMIR Hum Factors*. 2015;2:e2.
23. Sepucha KR, Borkhoff CM, Lally J, et al. Establishing the effectiveness of patient decision aids: key constructs and measurement instruments. *BMC Med Inform Decis Mak*. 2013;13 Suppl 2:S12.
24. O'Connor AM, Bennett C, Stacey D, et al. Do patient decision aids meet effectiveness criteria of the International Patient Decision Aid Standards Collaboration? A systematic review and meta-analysis. *Med Decis Making*. 2007;27:554–74.
25. Bennett S, Barry C, Col M, et al. Decision aids for people facing health treatment or screening decisions (review). *Cochrane Database Syst Rev*. 2012;10:1–215.
26. O'Connor AM, Llewellyn-Thomas HA, Flood AB. Modifying unwarranted variations in health care: shared decision making using patient decision aids. *Health Aff (Millwood)*. 2004;Suppl Variation:VAR63–72.
27. Usability. Home page. Available from: www.usability.gov.
28. Kushniruk AW, Patel VL, Cimino JJ. Usability testing in medical informatics: cognitive approaches to evaluation of information systems and user interfaces. *Proc AMIA Annu Fall Symp*. 1997:218–22.
29. Reyna VF, Nelson WL, Han PK, Dieckmann NF. How numeracy influences risk comprehension and medical decision making. *Psychol Bull*. 2009;135:943–73.
30. Patton MQ. *Qualitative Research and Evaluation Methods*. London: Sage Publications; 2002.
31. Williams MV, Parker RM, Baker DW, et al. Inadequate functional health literacy among patients at two public hospitals. *JAMA*. 1995;274:1677–82.
32. David RA, Rhee M. The impact of language as a barrier to effective health care in an underserved urban Hispanic community. *Mt Sinai J Med*. 1998;65:393–7.
33. Lukoschek P, Fazzari M, Marantz P. Patient and physician factors predict patients' comprehension of health information. *Patient Educ Couns*. 2003;50:201–10.
34. Schapira MM, Davids SL, McAuliffe TL, Nattinger AB. Agreement between scales in the measurement of breast cancer risk perceptions. *Risk Anal*. 2004;24:665–73.
35. Schwartz LM, Woloshin S, Black WC, Welch HG. The role of numeracy in understanding the benefit of screening mammography. *Ann Intern Med*. 1997;127:966–72.
36. Galesic M, Garcia-Retamero R. Graph literacy: a cross-cultural comparison. *Med Decis Making*. 2011;31:444–57.
37. Hawley ST, Zikmund-Fisher B, Ubel P, Jancovic A, Lucas T, Fagerlin A. The impact of the format of graphical presentation on health-related knowledge and treatment choices. *Patient Educ Couns*. 2008;73:448–55.
38. REDCap. Home page. Available from: <https://projectredcap.org/>.
39. Viera AJ, Garrett JM. Understanding interobserver agreement: the kappa statistic. *Fam Med*. 2005;37:360–3.
40. QSR International. Run a coding comparison query. Available from: http://help-nv10.qsrinternational.com/desktop/procedures/run_a_coding_comparison_query.htm.
41. Readability Score. Home page. Available from: <https://readability-score.com/>.
42. Nutbeam D. The evolving concept of health literacy. *Soc Sci Med*. 2008;67:2072–8.
43. Gazmararian JA, Baker DW, Williams MV, et al. Health literacy among Medicare enrollees in a managed care organization. *JAMA*. 1999;281:545–51.
44. Browner CH, Press N. The production of authoritative knowledge in American prenatal care. *Med Anthropol Q*. 1996;10:141–56.
45. Clayman ML, Manganello JA, Viswanath K, Hesse BW, Arora NK. Providing health messages to Hispanics/Latinos: understanding the importance of language, trust in health information sources, and media use. *J Health Commun*. 2010;15 Suppl 3:252–63.
46. Alden DL, Friend J, Schapira M, Stiggelbout A. Cultural targeting and tailoring of shared decision making technology: a theoretical framework for improving the effectiveness of patient decision aids in culturally diverse groups. *Soc Sci Med*. 2014;105:1–8.
47. Myers RE, Sifri R, Hyslop T, et al. A randomized controlled trial of the impact of targeted and tailored interventions on colorectal cancer screening. *Cancer*. 2007;110:2083–91.
48. Garcia-Retamero R, Galesic M. Communicating treatment risk reduction to people with low numeracy skills: a cross-cultural comparison. *Am J Public Health*. 2009;99:2196–202.
49. French JC, Colbert CY, Pien LC, Dannefer EF, Taylor CA. Targeted feedback in the milestones era: utilization of the ask-tell-ask feedback model to promote reflection and self-assessment. *J Surg Educ*. 2015;72:e274–9.
50. Epstein RM, Street RL. Shared mind: communication, decision making, and autonomy in serious illness. *Ann Fam Med*. 2011;9:454–61.