Cover Page

The handle http://hdl.handle.net/1887/38221 holds various files of this Leiden University dissertation.

Author: Kunneman- van Unnik, Helena Josefina Antonia Maria (Marleen)
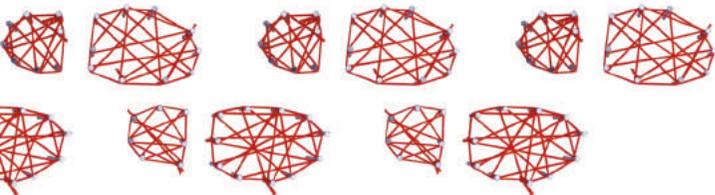**Title**: Shared decision making in adjuvant cancer treatment
Issue Date: 2016-02-25

Chapter 6

Do oncologists convey what they intend? Lay interpretation of verbal risk labels used in decision consultations

Marleen Kunneman, Anne M Stiggelbout, Arwen H Pieterse

Abstract

Background: Probabilities of benefits and harms of treatment may help patients making a treatment decision. Oncologists frequently use verbal labels only (non-numeric statements) to convey a probability. This study aimed to assess the numerical probability that patients associate with verbal labels and the influence of medical outcome, age, gender, educational level, health literacy and numeracy.

Materials and methods: Frequently-used verbal labels (N=11) were extracted from N=90 audiotaped decision consultations. A sample of the adult Dutch population (N=300), as proxies for newly-diagnosed cancer patients, assigned numerical probabilities to the labels and filled in a questionnaire on their socio-demographic characteristics, health literacy and numeracy.

Results: Considerable variation was seen in how individuals interpreted the verbal labels. Participants' probability estimates of verbal labels was lower in the context of cancer recurrence compared to nausea. Low numerate participants tended to differentiate less between the labels. The same tendency was found for educational level and health literacy, but not statistically significant. There was no association between participants' estimates and age or gender.

Discussion: Our results showed considerable variation in how individuals interpret verbal labels frequently-used, with medical outcome and numeracy as possible determinants. It is recommended to avoid the use of verbal labels only, to minimize misunderstandings.

Introduction

In medical consultations, oncologists frequently use verbal labels (non-numeric probability statements) to convey a probability of an event occurring.[1] Primary reasons to use verbal labels is lack of availability of numerical information, and uncertainty about the actual numerical probability for a specific patient.[2] Also, compared to numbers, verbal labels are easy and natural to use, and may better capture a person's emotions, intuitions, and directionality.[2-4] On the other hand, using verbal labels has the potential weakness of a high degree of variability in interpretation.[3] That is, the magnitude of the probability that an oncologist aims to convey using a verbal label may not be interpreted as such by a patient. This variability could especially be problematic when oncologists communicate probabilities that are relevant to treatment decision making. Probabilities often are the foundation of oncologists' treatment recommendations and they better enable patients to weigh the benefits and harms of different treatment strategies. We recently showed that in medical consultations with newly-diagnosed rectal cancer patients facing a treatment decision, in one-third of the cases, radiation oncologists only use verbal labels to convey a probability, in spite of the potential pitfall of variability in interpretation. Of note, in this clinical case numerical probabilities are available and known to most oncologists.[1]

The way in which probabilities are presented can have a significant effect on patients' interpretation and their readiness to undergo treatment.[5] More than with numerical probabilities, the interpretation of verbal labels can be influenced by the assumed frequency of an event occurring and by its severity, with people assigning higher numerical probabilities to verbal labels concerning high frequent or less severe events.[6-8] The influence of other determinants such as age, gender, educational level, health literacy and numeracy has been investigated to some extent, but is still equivocal.[2;9-11] To the best of our knowledge, no research has been conducted on the simultaneous influence of these determinants, nor on the interpretation of verbal labels that are frequently used in medical consultations with newly-diagnosed cancer patients facing a treatment decision.

This study aimed to assess the numerical probability that individuals associate with verbal labels used to convey probabilities of outcomes in cancer treatment decision consultations, and the association with type of treatment outcome and individuals' characteristics. Research questions to be answered were: 1) How do individuals from the general adult population (as proxies for newly-diagnosed cancer patients facing a treatment decision) interpret frequently-used verbal labels, in the context of two outcomes of cancer treatment? and 2) Is there an association between individuals' interpretation of verbal labels and the type of outcome, individuals' age, gender, educational level, health literacy, or numeracy?

Materials and methods

Design

An online questionnaire was offered to a sample representative for the adult Dutch population, in which participants were asked to rate verbal labels, regarding one of two outcomes of rectal cancer treatment. Verbal labels were offered in writing, excluding the influence of non-verbal factors as emphasis or stress.

Study population

The sample consisted of 300 adult Dutch participants, stratified to mirror the adult census population in terms of age, gender and educational level. For taking part in this study, participants received credits from a research agency, which they can exchange for gifts.

Procedure and measures

In preparation of the online questionnaire, we extracted utterances conveying a probability of a patient experiencing a treatment benefit or harm by use of a verbal label.[1;12] To this end, we used data collected during a large multicenter study on (risk) communication regarding short-course preoperative radiotherapy.[1] Consecutive consultations (N=90) between radiation oncologists and newly-diagnosed rectal cancer patients facing a treatment decision were audiotaped and coded. Verbal labels were selected for the current study from those most frequently used that covered a wide range in 1) wording of the labels and 2) probabilities conveyed with the verbal labels. Only verbal labels expressing an absolute risk were selected. Expressions containing a negation (e.g., not often) were excluded. This resulted in a list of 11 frequently-used verbal labels, which covered 71% of all verbal labels used during the 90 consultations.

The research agency invited members of their panel to participate by sending them a link to the questionnaire. Participants were given a short introduction stating that "to convey a probability that someone experiences for example a side-effect of treatment, clinicians may use probability words, such as often or sometimes". Next, they were asked to complete socio-demographic details. They were then either directed to the questionnaire or redirected back to the website of the research agency if the maximum number of participants with their characteristics had been reached. Participants directed to the questionnaire were randomized to one of two outcomes of rectal cancer treatment: 1) 'A patient will be treated with radiotherapy because of rectal cancer. A disadvantage of radiotherapy is that people can get nauseous'; or 2) 'A patient will undergo surgery because of rectal cancer. In spite of this surgery, the cancer could come back.' The situations were chosen such that they presented realistic outcomes of the treatment and that they differed in seriousness. To increase comparability and to best mimic current clinical practice, both were framed negatively. Characteristics of participants were comparable across the two groups (data not shown). Participants were offered the 11 verbal labels each as part of a short sentence (i.e., "sometimes people become nauseous") and in random order. They were asked to indicate how many people in their view will experience this outcome, by filling in a natural frequency (both the numerator and the denominator: "approximately … out of … people").

After rating the verbal labels, participants filled in a short questionnaire on health literacy and numeracy.[13;14]

Statistical analyses

Descriptive statistics were used to report the participants' characteristics and numerical estimate of each verbal label. Frequencies were converted to percentages. An overall numeracy score was calculated by averaging the ratings across all numeracy items. The classification of participants' health literacy and numeracy levels (inadequate/adequate and lower/higher, respectively) was based on recommendations of the questionnaire developers.[15;16]

We tested differences in the numerical probabilities that individuals associated with the verbal labels (within-subject levels) by medical outcome, age, and gender (between-subject factors) using repeated measure general linear models, adjusted using the Greenhouse-Geisser method. As we expected that individuals with a lower educational level, inadequate health literacy, or lower numeracy discriminate less between high and low probabilities and thus, assign lower probabilities to labels conveying a higher chance and higher probabilities to those conveying a lower chance,[10;17] we also tested whether there was a difference in the numerical probabilities individuals associated with the 'low' versus 'high' verbal labels depending on educational level, health literacy, and numeracy (between-subject factors).

Results

Participants

In total, 4902 people were invited to participate, and 994 (20%) began the survey. After filling in their socio-demographic details, 499/944 people were redirected from the questionnaire, because the maximum of participants with their characteristics had already been reached. All other participants (N=495) were directed to the questionnaire. Thirteen of them were excluded from the

analyses, because they filled in the same numbers for all verbal labels. A total of 300/482 (62%) participants completed the questionnaire, in a median time of 4.9 minutes (Table 1).

Table 1. Participants' characteristics (N=300)

	N (%)
Age	
20-39 years	99 (33)
40-64 years	145 (48)
65-80 years	56 (19)
Male gender	151 (50)
Educational level[a]	
Low	47 (16)
Intermediate	168 (56)
High	84 (28)
Health literacy	
Inadequate	110 (37)
Adequate	190 (63)
Subjective numeracy	
Low, median score on 1-6 scale (range)	3.3 (1-4)
High, median score on 1-6 scale (range)	5.1 (4.3-6)

[a] Educational levels included low = completed no/primary school; intermediate = completed lower general secondary education/vocational training; or high = completed pre-university education/high vocational training/university. One participant (0.3%) filled in 'other', without specifying level of education.

Interpretation of verbal labels

Figure 1 shows how verbal labels were interpreted for the two medical outcomes. There was a significant effect of outcome on the estimated numerical probabilities of verbal labels, that is, participants' estimates of verbal labels were lower for cancer recurrence compared to nausea ($F_{(3.4, 1025.5)}=5.21$, $p=0.001$). On average, participants' estimates of verbal labels were an absolute 11% lower for cancer recurrence compared to nausea (range, 2-20).
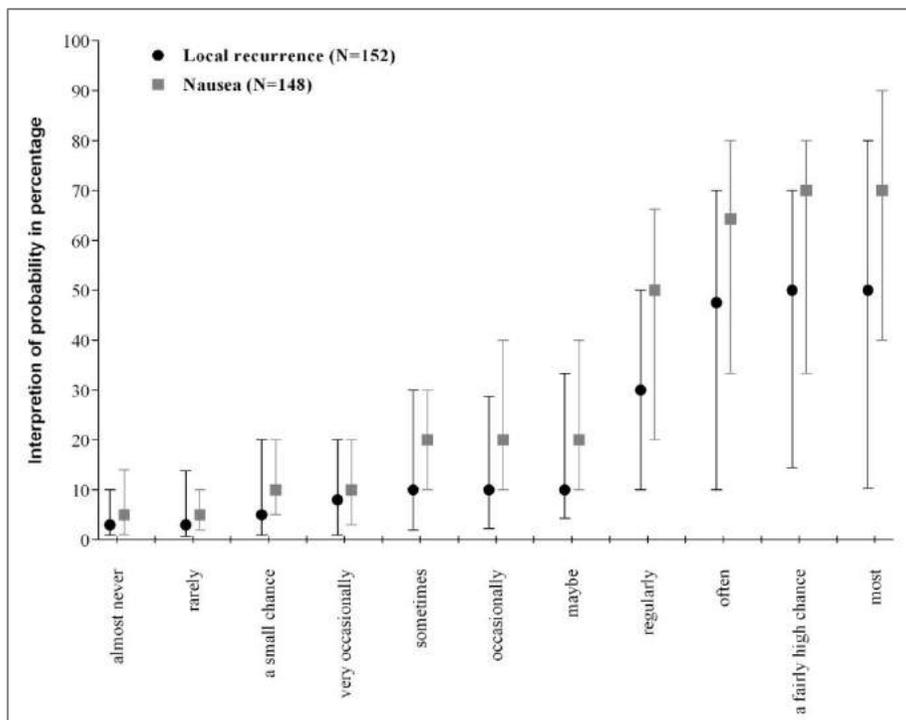
Figure 1. Interpretation in percentages of each verbal label (median (1st and 3rd quartile))

Based on our data, we identified those labels that the participants considered to reflect a low versus high probability (N=7 vs N=3, respectively; see Figure 1). The verbal label 'regularly' was excluded as it represented an intermediate probability. Low numerate participants tended to estimate higher probabilities than high numerate participants for verbal labels indicating a low probability, and significantly lower probabilities for verbal labels indicating a high probability ($F_{(1.9, 590.6)}$=7.34, p=0.001). Thus, lower numerate participants discriminated less between verbal labels than higher numerate participants. The same tendency was seen for educational level and health literacy, but the results were not statistically significant (data not shown). There was no significant association between participants' estimates and participants' age or gender.

Discussion

Our study showed considerable variation in how individuals interpret verbal labels that are frequently-used in cancer consultations in which a treatment decision needs to be made. Communicating probabilities that are relevant to the treatment decision is complex but essential, as probabilities help to weigh the potential benefits and harms of treatment. Most people prefer to receive probabilistic information numerically, but to use verbal labels to convey a probability,[18;19] despite recommendations from the literature to avoid the use of verbal labels only.[20;21] Indeed, in daily clinical practice, radiation oncologists frequently use verbal labels only to convey probabilities to patients facing a treatment decision.[1] Patients' satisfaction has been shown to be lower when receiving probabilistic information verbally, and their interpretation to be less accurate.[5;22] That is, the magnitude of the probability that an oncologist aims to present using a verbal label may not be interpreted as such by the patient. Probabilities of common side-effects might be known to clinicians, but clinicians should not assume that patients interpret probabilities for different outcomes in the same way clinicians do. In fact, in earlier research, we found that patient tend to underestimate the probability of a side effect occurring.[1]

In line with previous research, we found that the interpretation of verbal labels was influenced by the medical outcome, which is likely due to the perceived severity and/or the assumed frequency of occurrence of the outcomes.[6-8] We cannot disentangle the individual effect of perceived severity and assumed frequency of occurrence as the outcomes we presented differed on both, as is usually the case in actual clinical cases. We further found that less numerate individuals estimated numerical probabilities of verbal labels closer to 50% than more numerate individuals, that is, less numerate individuals tended to differentiate less between the verbal labels. This finding is consistent with research outside of the medical field,[10] and might reflect an "I don't know" response. However, since we do not have a 'golden standard' for the interpretation of verbal labels, we cannot make any statements on whether the high versus low numerate group has more accurate estimates of verbal labels. We found a similar effect in differentiation between labels for individuals' educational level and health literacy, although not statistically significant.

A strength of our study is that we offered participants a list of verbal labels that are most frequently used during cancer decision consultations. This enabled us to gain insight in how they interpret non-numerical probability statements used in daily clinical practice. Furthermore, we were able to assess the influence of multiple determinants in a large sample of the adult census population, as proxies for newly-diagnosed patients facing a treatment decision. A possible limitation is that our participants did not experience the emotions that patients do when they are diagnosed with cancer and face treatment. In general, patients seem to underestimate the probability of an adverse effect occurring (1). We expect that the variation in interpretation will be similar for newly-diagnosed cancer patients and the general adult population.

In conclusion, our results show considerable variation in how individuals interpret frequently-used verbal labels, with medical outcome and individuals' numeracy as possible determinants. By using verbal labels, oncologists attempt to convey a magnitude of the probability that a patient will experience a benefit or harm. The large variation in interpretation of verbal labels shows that the magnitude that an oncologist aims to present using a verbal label will likely not be interpreted as such by individual patients. It is recommended to avoid the use of verbal labels only, to minimize misunderstandings and to prevent patients from consenting to treatments that go against their informed values and preferences.

References

(1) Kunneman M, Stiggelbout AM, Marijnen CAM, Pieterse AH. Probabilities of benefit and harms of preoperative radiotherapy for rectal cancer: What do radiation oncologists tell and what do patients understand? *Patient Educ Couns* 2015;98:1092-1098.
(2) Timmermans D. The roles of experience and domain of expertise in using numerical and verbal probability terms in medical decisions. *Med Decis Making* 1994;14:146-156.
(3) Lipkus IM. Numeric, verbal, and visual formats of conveying health risks: suggested best practices and future recommendations. *Med Decis Making* 2007;27:696-713.
(4) Budescu DV, Karelitz T, Wallsten TS. Predicting the directionality of probability words from their membership functions. *J Behav Dec Making* 2003;16:159-180.

(5)   Man-Son-Hing M, O'Connor AM, Drake E, Biggs J, Hum V, Laupacis A. The effect of qualitative vs. quantitative presentation of probability estimates on patient decision-making: a randomized trial. *Health Expect* 2002;5:246-255.
(6)   Wallsten TS, Fillenbaum S, Cox J. Base rate effects on the interpretations of probability and frequency expressions. *J Mem Lang* 1986;25:571-587.
(7)   Merz JF, Druzdzel MJ, Mazur DJ. Verbal expressions of probability in informed consent litigation. *Med Decis Making* 1991;11:273-281.
(8)   Weber EU, Hilton DJ. Contextual effects in the interpretations of probability words: Perceived base rate and severity of events. *Journal of Experimental Psychology: Human Perception and Performance* 1990;16:781-789.
(9)   Brewer NT, Tzeng JP, Lillie SE, Edwards AS, Peppercorn JM, Rimer BK. Health literacy and cancer risk perception: implications for genomic risk communication. *Med Decis Making* 2009;29:157-166.
(10) Budescu DV, Por HH, Broomell SB, Smithson M. The interpretation of IPCC probabilistic statements around the world. *Nature Climate Change* 2014.
(11) Mazur DJ, Merz JF. How age, outcome severity, and scale influence general medicine clinic patients' interpretations of verbal probability terms. *J Gen Intern Med* 1994;9:268-271.
(12) Shepherd HL, Barratt A, Trevena LJ et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: a cross-over trial. *Patient Educ Couns* 2011;84:379-385.
(13) Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *Fam Med* 2004;36:588-594.
(14) Fagerlin A, Zikmund-Fisher BJ, Ubel PA, Jankovic A, Derry HA, Smith DM. Measuring numeracy without a math test: development of the Subjective Numeracy Scale. *Med Decis Making* 2007;27:672-680.
(15) Chew LD, Griffin JM, Partin MR et al. Validation of screening questions for limited health literacy in a large VA outpatient population. *J Gen Intern Med* 2008;23:561-566.
(16) Zikmund-Fisher BJ, Smith DM, Ubel PA, Fagerlin A. Validation of the Subjective Numeracy Scale: effects of low numeracy on comprehension of risk communications and utility elicitations. *Med Decis Making* 2007;27:663-671.
(17) de Bruin WB, Fischhoff B, Millstein SG, Halpern-Felsher BL. Verbal and Numerical Expressions of Probability: "It's a Fifty-Fifty Chance". *Organ Behav Hum Decis Process* 2000;81:115-131.
(18) Erev I, Cohen BL. Verbal versus Numerical Probabilities: Efficiency, Biases, and the Preference Paradox. *Organ Behav Hum Decis Process* 1990;45:1-18.
(19) Wallsten TS, Budescu DV, Zwick R, Kemp SM. Preferences and reasons for communicating probabilistic information in verbal or numerical terms. *Bulletin of the Psychonomic Society* 1993;31:135-138.
(20) Zipkin DA, Umscheid CA, Keating NL et al. Evidence-based risk communication: a systematic review. *Ann Intern Med* 2014;161:270-280.
(21) Fagerlin A, Zikmund-Fisher BJ, Ubel PA. Helping patients decide: ten steps to better risk communication. *J Natl Cancer Inst* 2011;103:1436-1443.
(22) Marteau TM, Saidi G, Goodburn S, Lawton J, Michie S, Bobrow M. Numbers or words? A randomized controlled trial of presenting screen negative results to pregnant women. *Prenat Diagn* 2000;20:714-718.