Patients' Understanding of Medical Risks: Implications for Genetic Counseling

DAVID A. GRIMES, MD, AND GILLIAN R. SNIVELY

Objective: **To assess patients' ability to compare magnitudes of Down syndrome risk at maternal ages of 35 and 40 years, expressed as rates or as proportions.**

Methods: **We used a self-administered, anonymous questionnaire that posed the same comparison in two different formats: 2.6 versus 8.9 per 1000 women (rates) and one in 384 versus one in 112 women (proportions). The study setting included several university-affiliated obstetrics and gynecology outpatient clinics in San Francisco, California. A total of 633 women, whose primary languages were English, Spanish, or Chinese, participated. The main outcome measure was correct identification of the larger of two risks.**

Results: **Women were more successful with rates (463 of 633 respondents, 73%) than with proportions (353 of 633 respondents, 56%). A paired analysis, in which each woman served as her own control, found risk assessment to be significantly better with rates than with proportions ($P < .001$). Women with little formal education had difficulty understanding risks framed either way.**

Conclusion: **The traditional use of proportions to express risk in genetic counseling lacks scientific basis. Rates were easier to understand than proportions, regardless of respondents' age, language, and education. (Obstet Gynecol 1999; 93:910–4. © 1999 by The American College of Obstetricians and Gynecologists.)**

"Every definition of genetic counseling includes mention of the need to give parents an accurate recurrence rate for the condition of concern: imparting such information is a sine qua non of counseling."[1] Conveying probabilities of genetic abnormalities and other birth defects, however, is often difficult. Many patients have a binary view of risk: a bad outcome either will occur, or it will not. Additional hurdles to understanding probability include emotional shock,[2,3] low social class,[4] low educational attainment, and limited knowledge of biology.[5] Differences in language and culture pose other barriers.[6] With a few exceptions,[7] genetic counseling literature shows that patients' understanding of risk is limited.[2,4,6,8–11] We need to improve how we convey the concept of risk.

Landmark epidemiologic studies[12] described the risk of genetic abnormalities in scientific format: rates of disease per unit of population exposed to the risk (commonly per 1000 persons). Genetic counselors attempting to make those risks more understandable (Hook EB, written communication, July 8, 1997) transformed those rates into proportions with a numerator of one and shifting denominators (eg, three per 1000 becomes one in 333). However, proportions with large denominators are confusing. As noted by Walker,[6] "To many, 1/400 sounds higher than 1/200 because the denominator is bigger. To any of us, 1 in 20 may sound higher than 5%, or vice versa." Because effective communication of risk is important and little is known about the effectiveness of different strategies, we conducted this study. Our a priori hypothesis was that women would understand rates better than proportions.

Materials and Methods

We designed a self-administered questionnaire to compare women's understanding of risk expressed in two different ways: rates per 1000 women or proportions with a numerator of one. To avoid the potential effect of anxiety related to serious risks[2,3] such as Down syndrome, we chose bladder infection as our clinical event. Without individual counseling, many respondents would not have understood the term Down syndrome. The anonymous questionnaire began with a simple example, showing respondents how to identify and circle the larger of two choices (the height of two buildings). We then used rates of trisomy 21 at birth at maternal ages of 35 years (one in 384) and 40 years (one in 112) cited by the California Department of Health

From the Department of Obstetrics, Gynecology and Reproductive Sciences, University of California, San Francisco, San Francisco, California, and Family Health International, Research Triangle Park, North Carolina.

The Dean's Office, University of California, San Francisco, provided research support to Ms. Snively.

PII S0029-7844(98)00567-5

Table 1. Selected Characteristics of Respondents by Primary Language

Characteristic	Primary language					
	English		Spanish		Chinese	
	n	%	*n*	%	*n*	%
Age (y)						
≤ 19	37	10	22	11	0	0
20–29	151	41	121	58	14	25
30–39	112	31	52	25	20	36
≥ 40	66	18	14	7	21	38
Total	366	100	209	100	55	100
Education (y)						
≤ 9	18	5	87	43	30	55
10–12	111	30	79	39	10	18
≥ 13	236	65	37	18	15	27
Total	365	100	203	100	55	100

Services, Genetic Diseases Branch,[13] for the cystitis questions. The first question asked respondents to identify which rate of bladder infection was higher: 1 in 384 or 1 in 112 persons. In the next question, we posed the same comparison, this time using rates: 2.6 or 8.9 per 1000 women (the same proportions converted into rates). We also asked women to give their ages and educational attainments. To avoid bias in responses to the second question from experience gained by answering the first question, we randomly varied the sequence of the two questions. We used a table of random numbers to generate the sequence of questions.

After approval of the project by the Committee on Human Research of the University of California, San Francisco and San Francisco General Hospital, we had clinic staff translate the questionnaire into Spanish and Chinese. We field-tested the translations to ensure accuracy. We then distributed questionnaires in all three languages to the waiting rooms of three obstetric and gynecologic clinics affiliated with University of California, San Francisco. Code numbers on the questionnaires identified clinical sites. The first site, San Francisco General Hospital, serves a large immigrant population; many of the women in this population speak Spanish or the Chinese dialects of Cantonese or Mandarin. We also distributed questionnaires in the obstetrics and gynecology resident continuity clinic at Moffitt Hospital of University of California, San Francisco and in the faculty private practice at that hospital. Women in the continuity clinic population tend to be English-speaking but less educated, whereas the private practice patients are largely English-speaking and highly educated. At each site, we asked the clinic staff to encourage women to complete the four-question form while waiting for their appointments. For the two main questions, respondents could choose either of the risk expressions or "don't know." Our analysis focused on correct responses, and we grouped nonresponses with "don't know" and incorrect answers. We excluded from the survey women whose primary language was other than English, Spanish, or Chinese and those who were illiterate or previously had completed a questionnaire for the study.

We analyzed the results using public-domain software (Epi Info 6, USD, Inc., Stone Mountain, GA). The sample size was one of convenience; the total number of questionnaires completed from June through August of 1997 was 633. The primary outcome measure was the ability of respondents to identify the higher of two risks (probability of Down syndrome at maternal age 35 years versus 40 years) portrayed as a proportion or rate. We calculated 95% confidence intervals (CIs) for correct response rates and compared proportions using χ^2 tests. We also examined the potential effect of age (in 10-year intervals), primary language, and educational attainment on the outcome measure. We calculated crude and adjusted relative risks of correct answers using the Mantel-Haenszel procedure. In addition, we did a paired analysis with the McNemar test.

Results

The clinical sites provided a heterogeneous group of women. The largest number of respondents came from San Francisco General Hospital (442), followed by the faculty practice at Moffitt Hospital (137) and the resident continuity clinic at Moffitt Hospital (54). Most women (367 of 633, 58%) used English as their primary language; 211 (33%) returned Spanish questionnaires, and 55 (9%) chose Chinese (Table 1). Most respondents were of reproductive age, although the Chinese-speaking women were older on average. In general, English-speaking women were more educated than the other women. Nearly two-thirds of English-speaking

Table 2. Ability of Respondents to Identify the Larger of Two Risks

	Format			
	Rate per 1000		Fraction	
Response	*n*	%	*n*	%
Correct	463	73	353	56
Incorrect	44	7	160	25
Don't know*	126	20	120	19
Total	633	100	633	100

* Includes questions left blank (15 for rates and 12 for fractions).

respondents had completed at least some college. In contrast, only 18% of Spanish-speaking women and 27% of Chinese-speaking women had education beyond high school. Three women did not supply their age, and ten did not disclose their educational attainment.

Women understood rates better than proportions (Table 2). Overall, 73% (95% CI 70, 77) correctly identified the higher risk in rate format, in contrast with 56% (95% CI 52, 60) who correctly answered the same question framed as proportions. The crude relative risk (RR) of correct assessment with the rate format was 1.3 times (95% CI 1.2, 1.4; $P < .001$) that of proportion format.

Superiority of the rate format was consistent across all age groups, primary languages, and educational levels (data not shown). Controlling singly for the effect of age, language, and education did not alter the RR estimate for the rate format, which remained 1.3. As shown in Figure 1, the likelihood of correctly judging the larger of two risks was related directly to educational attainment ($P < .001$). However, at each educational level the 95% CI around the percent correct responses for rates and proportions did not overlap. Among women with 9 or fewer years of school, only half could evaluate the rates correctly, and less than a third could assess the proportions.

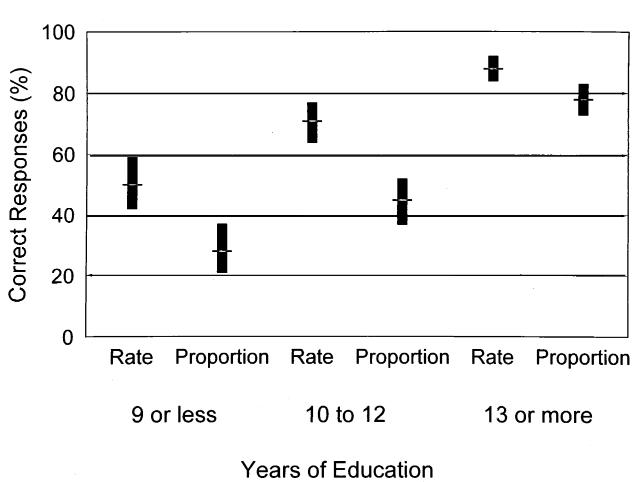

Figure 1. Correct identification of the higher of two risks by format and level of education. *Bars* indicate 95% confidence intervals.

The paired analysis confirmed the superiority of the rate format. In Figure 2, cell a includes those women who correctly identified the larger of two risks with both formats. Cell d contains those who failed with both formats. If the rate and proportion formats were equally easy to understand, then the number of women who answered correctly in one format but not in the other should have been equal in cells b and c. The χ^2 value for these discordant cells was 64.17, indicating $P < .001$.

Discussion

Our evidence contradicts conventional wisdom of genetic counselors[5,13–15] and physicians[16] that women understand proportions better than rates. Given the national scope of genetic counseling and antenatal screening and the critical decisions based on them, that discrepancy is troubling. By using a suboptimal format for expressing risk, counselors and clinicians might be causing unnecessary confusion.

Our survey had several strengths. We attempted to improve the generalizability of the study by using the three most common languages spoken by our patients. Respondents ranged from recent immigrants with little education to highly educated professionals in a university community. We tried to avoid ascertainment bias

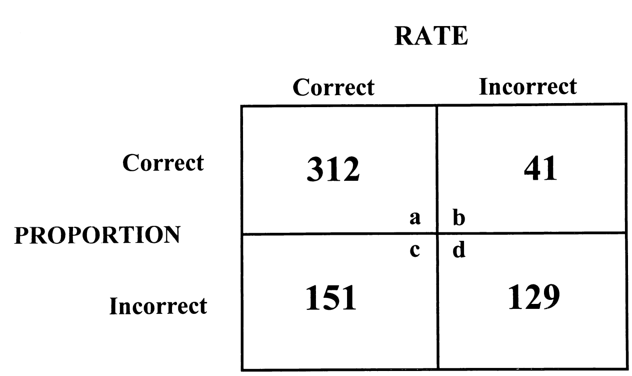

Figure 2. Distribution of answers by format.

by randomly varying the sequence of the two principal questions.

How counselors frame the expression of risk and design individual counseling[15] might influence women's comprehension. According to one report,[15] "The mode in which this type of information is explained to counsellees is also of the utmost importance. Many individuals seen for counselling have little or no concept of probability theory." Hence, we framed the comparison in an objective, written questionnaire to avoid that potential influence.

The paired analysis provided the most robust comparison of the formats. Many women (129) did not understand either format. However, if the two formats were equally understandable, we expected equal numbers of women in cells b and c of Figure 2 (those who were correct with only one of the two formats). However, more than three times as many women (151) judged risks correctly with rates alone, compared with only proportions (41). Each woman served as her own control in this analysis, so bias could not account for that difference. The likelihood that those results were due to chance is less than one in a quadrillion. Neither bias nor chance can account for our results, so we conclude that the observed differences are real.

Our survey had several weaknesses as well. The voluntary, unsupervised nature of the survey probably led to selection bias in responses. Those who thought they were unable to answer the questions were probably less likely to turn in their forms than were other women. Thus, the proportion of correct responses here is probably spuriously high. All respondents came from a single city, so replication of our research in other locales should be a priority. The questionnaire was written, so the results cannot be extrapolated to women who cannot read. The number of Chinese respondents was small, limiting the precision of estimates for that population. We gathered little demographic information on respondents. Exposure to courses in mathematics or probability, experience with mathematics in employment, duration of residence in the United States, and other information might have refined our evaluation. We intentionally limited the survey instrument to four questions, hoping its brevity would encourage voluntary participation.

We intentionally chose a nonthreatening hypothetical example for the study instead of Down syndrome. Emotions can impair understanding[2,3]; therefore we believe comprehension might be poorer in actual genetic counseling practice, so our results might be optimistic. Women at risk also might pay more attention to counseling, resulting in better understanding.

Illiteracy poses a major problem in health care.[17–19] For example, a quarter of the adult population cannot read simple written materials, and the average reading ability of the nation is at the eighth-grade level.[18] Innumeracy, the mathematical equivalent of illiteracy, is also endemic—and problematic in health care.[20] A large portion of the public lacks functional knowledge of fractions, large numbers, or percentages.[21] Facility with percentages is limited, despite universal exposure to these terms during school. Students have difficulty learning percentages, and their comprehension does not grow as they progress in school.[22] Both school children and adults have difficulty transforming data into percentages. Indeed, in one study[22] a third of adult women with less than a college education did not recognize that 1/1000 is less than 1%. Most respondents in our study were younger than 40 years. Mathematical ability is better among younger women,[23] so women's understanding in this study might be higher than that of the general population of women.

Against that background, our finding that women struggle even more with proportions is not surprising.[6] Confusion between proportions and odds complicates the issue further. For example, "one in two" is not equivalent to the odds of "one to two," which is one in three (33%). Fortunately, the error from confusing odds and proportions becomes large only when risk is very high.[14]

Although using proportions for genetic counseling[5,13–16] has been standard for decades, we can find no scientific evidence to support that convention. Recipients of genetic counseling prefer numeric to nonnumeric information.[24] Our responsibility is to provide this numeric information in an understandable manner. Alternative means of conveying risk, such as use of pictograms, risk ladders, or pie charts, might be more useful for women with limited facility with numbers.[23] However, given the choice of conveying risk as rates or as proportions, physicians and counselors should choose rates because they are much better understood.

References

1. Lippman-Hand A, Fraser FC. Genetic counseling: Provision and reception of information. Am J Medical Genet 1979;3:113–27.
2. Leonard CO, Chase GA, Childs B. Genetic counseling: A consumers' view. N Engl J Med 1972;287:433–9.
3. Antley RM, Bringle RG, Kinney KL. Down's syndrome. In: Emery AE, Pullen IM, eds. Psychological aspects of genetic counselling. London, United Kingdom: Academic Press, 1984:75.
4. Evers-Kiebooms G, van den Berghe H. Impact of genetic counseling: A review of published follow-up studies. Clin Genet 1979;15: 465–74.
5. Murphy EA, Chase GA. Principles of genetic counseling. Chicago: Year Book Medical Publishers, Inc., 1975.
6. Walker AP. Genetic counseling. In: Rimoin DL, Connor JM, Pyeritz RE, eds. Emery and Rimoin's principles and practice of medical genetics. 3rd ed. New York: Churchill Livingstone, 1997:595–618.

7. Whitten CF, Thomas JT, Nishiura EN. Sickle cell trait counseling—evaluation of counselors and counselees. Am J Hum Genet 1981; 33:802–16.
8. Sprung CL, Winick BJ. Informed consent in theory and practice: Legal and medical perspectives on the informed consent doctrine and a proposed reconceptualization. Crit Care Med 1989;17:1346–53.
9. Parsons EP, Clarke AJ. Genetic risk: Women's understanding of carrier risks in Duchenne muscular dystrophy. J Med Genet 1993;30:562–6.
10. Sorenson JR, Swazey JP, Scotch NA. Reproductive pasts. Reproductive futures. Genetic counseling and its effectiveness. Birth defects: Original article series XVII. New York: Alan R. Liss, Inc., 1981:84–8.
11. Faden RR, Chwalow AJ, Orel-Crosby E, Holtzman NA, Chase GA, Leonard CO. What participants understand about a maternal serum alpha-fetoprotein screening program. Am J Public Health 1985;75:1381–4.
12. Hook EB. Rates of chromosome abnormalities at different maternal ages. Obstet Gynecol 1981;58:282–5.
13. Genetic Disease Branch, California Department of Health Services. Prenatal testing choices for women 35 years and older. Berkeley, California: California Department of Health Services, 1995.
14. Harper PS. Practical genetic counseling. 4th ed. New York: Butterworth Heinemann, 1993:9–11.
15. Skinner R. Genetic counselling. In: Emery AEH, Rimoin DL, eds. Principles and practice of medical genetics, vol. 2. Edinburgh, United Kingdom: Churchill Livingstone, 1983:1427–36.
16. American Academy of Pediatrics and American College of Obstetricians and Gynecologists. Guidelines for perinatal care. 4th ed. Washington, DC: American College of Obstetricians and Gynecologists, 1997:65–92.
17. Williams MV, Parker RM, Baker DW, Parikh NS, Pitkin K, Coates WC. Inadequate functional health literacy among patients at two public hospitals. JAMA 1995;274:1677–82.
18. Weiss BD, Coyne C. Communicating with patients who cannot read. N Engl J Med 1997;337:272–3.
19. Jackson RH, Davis TC, Bairnsfather LE, George RB, Crouch MA, Gault H. Patient reading ability: An overlooked problem in health care. South Med J 1991;84:1172–5.
20. Paulos JA. Innumeracy: Mathematical illiteracy and its consequences. New York: Vintage Books, 1990.
21. Dewdney AK. 200% of nothing. New York: John Wiley & Sons, Inc, 1993.
22. Chase GA, Faden RR, Holtzman NA, Chwalow AJ, Leonard CO, Lopes C, et al. Assessment of risk by pregnant women: Implications for genetic counseling and education. Soc Biol 1986;33:57–64.
23. 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.
24. Bloch EV, DeSalvo M, Hall BD, Epstein CJ. Alternative ways of presenting empiric risks in birth defects. Birth defects: Original article series XV(5c). New York: Alan R. Liss, Inc., 1979:233–44.

Address reprint requests to:
David A. Grimes, MD
Family Health International
PO Box 13950
Research Triangle Park, NC 27709
E-mail: dgrimes@fhi.org

Received September 21, 1998.
Received in revised form November 19, 1998.
Accepted December 10, 1998.