

Genetic testing and lifetime risk: How do women interpret lifetime risk results?

Yaniv Hanoch & Talya Miron-Shatz


University of Plymouth and Princeton University

yaniv.hanoch@plymouth.ac.uk

Deborah Lindner, MD



“I have the amazing gift of *knowing my risk* ... How can I not do anything about that?” (NYT, 2007)



Women might know their lifetime risk,
but it is less clear how they interpret it.



Genetic testing: Risk information

- Genetic counselling provide a personal lifetime risk information
- Women use this information for both treatment and family planning decision.



Genetic testing: Risk information

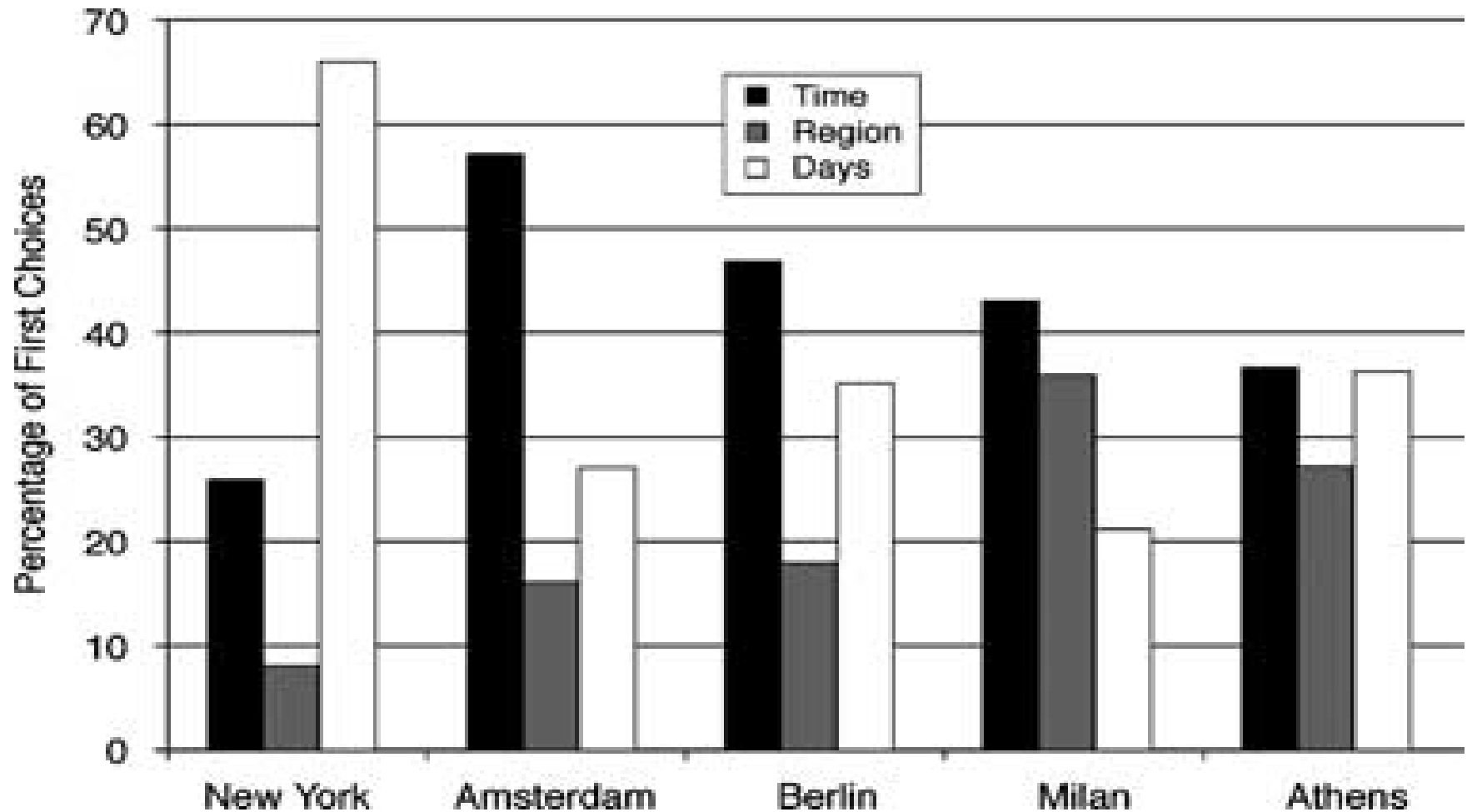
- Studies show that women tend to both over-and-under estimate their lifetime risk for developing breast cancer
- How do women interpret lifetime risk information.




There is a 30% chance of rain tomorrow

- It will rain tomorrow in 30% of the region.
- It will rain tomorrow for 30% of the time.
- It will rain on 30% of days like tomorrow.

Participants' response





If people have difficulties interpreting the meaning of weather forecast, how well will they do in interpreting lifetime risk of developing cancer?



Numeracy and medical decision making

- Understanding benefits of mammography screening , prenatal screening results, and is associated with reduced health knowledge and poor outcomes



Hypotheses

- NCI statement about lifetime risk of developing cancer would evoke various interpretations.
- High numeracy individuals will have a better understanding of lifetime risk information.

Participants: 277 women

| | |
|-----------------|------------------------|
| Age | M= 40.68 (SD=13.63) |
| Income | |
| < 19,999 | 8.2% |
| 20,000 – 49,999 | 28.4% |
| > 55,000 | 63.4% |
| Education | |
| High School | 99.1% |
| College | 80.5% |



Procedure

- We placed an ad in facebook.
- Possibility of winning \$50 gift certificate to Amazon.com



National Cancer Institute message

According to estimates of lifetime risk, about 13.2% (132 out of 1,000 individuals) of women in the general population will develop breast cancer, compared with estimates of 36 to 85% (360-850 out of 1000) of women with an altered BRCA1 or BRCA2 gene. In other words, women with an altered BRCA1 or BRCA2 gene are 3 to 7 times more likely to develop breast cancer than women with-out alterations in those genes

The most appropriate interpretation

1. “Breast cancer will develop in 36 to 85% of women who are found to have BRCA1 and BRCA2 gene alterations.”
2. “Breast cancer will develop in all women aged 36 to 85.”
3. “Women who have BRCA1 and BRCA2 gene alterations will exhibit 36 to 85% of the symptoms associated with breast cancer.”
4. “Women who are found to have alterations in the genes called BRCA1 and BRCA2 have 36% to 85% higher chance of developing breast cancer.”



Numeracy

Completed an 11 item numeracy scale (Lipkus et al., 2001).

Results: Interpretation

- 47.5% ($n = 128$) chose the correct interpretation.
- 46.1% ($n = 120$) believe the correct interpretation was “36-85% higher chance”
- An additional 6.3% ($n = 15$) chose the other two options.

Results: Numeracy

- High numeracy was significantly positively correlated with correct interpretation, $r(239) = .28, p < .001$.



Conclusion

- About 50% of women misinterpreted the NCI message
- Our sample is better educated and has higher income than the general female population.
- Numeracy plays an important role in patients understanding medical information.