User Manual - Realistic Expectations

Definition

'Expectations' refers to a person's perceptions of the likelihood or probability of outcomes for each option, which may also include 'watchful waiting'.
Expectations are 'realistic' when they correspond to known evidence of the probabilities of outcomes for a person's health profile.

Sample Tools (larger, smaller, very small outcome probabilities)

    A. Larger Outcome Probabilities (Osteoporosis example)
    B. Smaller Outcome Probabilities (Tamoxifen example)
    C. Very Small Outcome Probabilities (Transfusion example)

A. Larger Outcome Probabilities (Osteoporosis example)

My chances of fractures without treatment for osteoporosis

Now we are interested in your opinion about your chances of hip fractures some time in your lifetime **without** the use of therapy for osteoporosis.

Broken Hips from Osteoporosis

Out of **100** women <u>like you</u>, how many will have broken hips from osteoporosis some time in their life? Check (☑) <u>one</u>:

☐ **100** out of **100** women will have broken hips from osteoporosis some time in their life

☐ **81-99** women out of **100** women will have broken hips

☐ **61-80** women out of **100** women will have broken hips

☐ **41-60** women out of **100** women will have broken hips

☐ **21-40** women out of **100** will have broken hips

☐ **1-20** women out of **100** will have broken hips

☐ **0** women out of **100** will have broken hips

☐ Don't know

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User Manual - Realistic Expectations

B. Smaller Outcome Probabilities (Tamoxifen example)

My chances of disease if I take Tamoxifen

Now we are interested in your opinion on how much tamoxifen will affect your chances of developing breast cancer, cancer of the uterus, and blood clots.

Breast Cancer

For women at the same risk as you (your age, your risk factors) who take tamoxifen for 5 years, how many women out of 1000 will have breast cancer in the next 5 years?

- ☐ I don't know
- ☐ 0 out of 1000;   Nobody like me will have breast cancer.
- ☐ 1 to 10 out of 1000
- ☐ 11 to 19 out of 1000
- ☐ 20 to 29 out of 1000
- ☐ 30 to 39 out of 1000
- ☐ 40 to 49 out of 1000
- ☐ 50 to 99 out of 1000
- ☐ 100 to 149 out of 1000
- ☐ 150 to 199 out of 1000
- ☐ 200 to 249 out of 1000
- ☐ 250 to 299 out of 1000;   One quarter of the women like me will have breast cancer.
- ☐ 300 to 399 out of 1000
- ☐ 400 to 499 out of 1000
- ☐ 500 to 599 out of 1000;   Half of the women like me will have breast cancer.
- ☐ 600 to 699 out of 1000
- ☐ 700 to 799 out of 1000;   Three quarters of women like me will have breast cancer.
- ☐ 800 to 899 out of 1000
- ☐ 900 to 9999 out of 1000
- ☐ 1000 out of 1000;   Everybody like me will have breast cancer.

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User Manual - Realistic Expectations

C. <u>Very Small</u> Outcome Probabilities (Transfusion example)

Thinking About Chances: What do the Numbers Mean?

In the following questions, you will be asked to give your opinion about the chances of complications from transfusion in patients having heart surgery. We are considering the chance of a complication happening out of a specific number of patients having heart surgery.

For example:

Chance of complications	**For comparison, this is like one patient in a place the size of:**
One in ten million patients	Ontario **(extremely small chance)**
One in a million patients	Ottawa-Hull
One in five hundred thousand	Ottawa plus Kanata and Nepean
One in a hundred thousand patients	A large city such as Nepean
One in fifty thousand patients	A city such as Kanata
One in twenty-five thousand patients	A large sports stadium
One in ten thousand patients	A town such as Hawkesbury
One in a thousand patients	A village such as Chalk River
One in a hundred patients	A movie theatre crowd
One in ten	A sports team (**very large chance**)

In other words:

"**one in a million**" is a very **low chance** (it is not very likely to happen)

    and

"**one in ten**" is a very **high** chance (it is very likely to happen)

User Manual - Realistic Expectations

Considering the examples listed on the previous page, please **write in your answer** and **place a check ☑** in the box next to the closest category.

1. If I choose **volunteer-donated blood,** if it is needed for heart surgery, my chance of contracting **Acquired Immune Deficiency Syndrome (AIDS)** is:
_____ (Please fill in.)

2. This is closest to:

   ☐ one in ten million   (Extremely small chance)

   ☐ one in a million

   ☐ one in five hundred thousand

   ☐ one in a hundred thousand

   ☐ one in fifty thousand

   ☐ one in twenty-five thousand

   ☐ one in ten thousand

   ☐ one in a thousand

   ☐ one in a hundred

   ☐ one in ten   (Very large chance)

   ☐ I have no idea of the chance

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Directions for Adaptation and Use

In a short introductory statement, respondents are asked to identify the number of individuals who might experience an outcome (benefits, harms) in a group of people like them under different circumstances (e.g. watchful waiting with no treatment, Treatment A, Treatment B). Probabilities are elicited as numbers and words. The range of probabilities depends on the evidence on likelihoods of events (e.g. scales ranging from 0 to 100; 0 to 1000, or 0 to a million). The intervals used in the scales (e.g. 10-19 or 10-14) depend on the degree of precision required for particular decision outcomes. One should be able to discriminate between those with accurate expectations and those who are inaccurate on all outcomes of interest (e.g. cancer may have a different level of risk than fractures but the scale should work for both of them).
Scales can be elicited over time and before/after interventions.

User Manual - Realistic Expectations

Scoring and Interpretation

For each item, a response is classified as realistic or accurate, if it falls in the range of known probabilities that correspond to a person's health profile. The known range of probabilities is determined from published evidence or risk appraisal tools.

A score can be calculated as the percentage of items that are realistic, ranging from 0% (none of the expectations are realistic) to 100% (all of the expectations are realistic). For example, if there are 6 questions and a person has 3 realistic/accurate responses, the score would be 50%.

Psychometric Properties

Test-retest coefficients > 0.80; Alpha coefficient > 0.70 [1]
Content validity based on scientific evidence
Sensitive to change following decision aid (effect size =1.0) [1,4,5,8,9,10]
Discriminates between patients in different clinical risk categories [7]
Discriminates between decision aid and controls [2,3,11]

Clinical Applications Using this Tool

Hormone therapy [1,2,3,12]
Atrial fibrillation [4]
Osteoporosis [5]
High risk breast cancer [6]
Influenza vaccine [7]
Hepatitis B vaccine [8]
Lung cancer [9]
Prenatal genetic testing [10]
Blood transfusions [11]

Availability

You may use any of these scales at no cost without permission.

These tools are protected by copyright but are freely available for you to use, provided you cite the reference in any questionnaires or publications.

Suggested Citation

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User Manual - Realistic Expectations

References

1. O'Connor A, Tugwell P, Wells G. (1994) Testing a portable, self-administered decision aid for post menopausal women considering long-term hormone replacement therapy to prevent osteoporosis and heart disease. Medical Decision Making, 14(4);438 (Abstract).

2. O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, McPherson R, Bunn H, Graham I, Drake E. A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. Patient Education and Counseling 1998; 33: 267-279.

3. O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, McPherson R, Drake E, Hopman W, MacKenzie T. Randomized Trial of a Portable, Self-administered Decision Aid for Postmenopausal Women Considering Long-term Preventive Hormone Therapy. Medical Decision Making 1998; 18: 295-303.

4. Man-Son-Hing M, Laupacis A, O'Connor AM, Biggs J, Drake E, Yetisir E, Hart RG. A patient decision aid regarding antithrombotic therapy for stroke prevention in atrial fibrillation. Journal of the American Medical Association 1999; 282: 737-743.

5. Cranney A, O'Connor AM, Jacobsen MJ, Tugwell P, Adachi JD, Ooi DS, Waldegger L, Goldstein R, Wells GA. Development and pilot testing of a decision aid for postmenopausal women with osteoporosis. Patient Education and Counseling 2002; 47: 245-255.

6. Stacey D, O'Connor A, DeGrasse C, Verma S. Development and evaluation of a breast cancer prevention decision aid for higher risk women. Health Expectations . 6:3-18, 2003.

7. O'Connor AM, Pennie R, Dales R. Framing effects on expectations, decisions, and side effects experienced: The case of Influenza immunization. Journal of Clinical Epidemiology 1996; 49: 1271-1276.

8. O'Connor A, Pennie R. Reliability and validity of measures used to elicit health expectations, values, tradeoffs and intentions to be immunized for Hepatitis B. Journal of Clinical Epidemiology 1995; 48 (2): 255-262.

9. Fiset V, O'Connor A, Evans W, Graham I, DeGrasse C, Logan J. Development and evaluation of a decision aid for patients with stage IV non-small cell lung cancer. Health Expectations 2000; 3:125-136.

10. Drake ER, Engler-Todd L, O'Connor AM, Surh L, Hunter A. Development and evaluation of a decision aid about prenatal testing for women of advanced maternal age. Journal of Genetic Counseling 1999;8(4):217-33.

11. Grant FC, Laupacis A, O'Connor A, Rubens F, Robblee J. Evaluation of a decision aid for patients considering autologous donation of blood before open-heart surgery. CMAJ 2001;164(8):1139-44.

12. Rostom A, O'Connor A, Tugwell P. A Randomized Trial of a Computerized versus an Audio-booklet Decision Aid for Women Considering Post-menopausal Hormone Replacement Therapy. Patient Education and Counseling. 46:67-74, 2002.