Are people naively optimistic?

A systematic review of expectations of the benefits and harms of treatments, screening, and tests

Professor Tammy Hoffmann

Centre for Research in Evidence-Based Practice
Bond University

@Tammy_Hoffmann
• Our expectations can influence our decisions and behaviours

Lessons from this story?
• Making assumptions without checking the facts first can be dangerous!

• The chicken assumed the worst…

What expectations do patients have about medical interventions?
Patients’ Expectations of the Benefits and Harms of Treatments, Screening, and Tests: A Systematic Review

Tammy C. Hoffmann, PhD, Chris Del Mar, MD, FRACGP

IMPORTANCE Unrealistic patient expectations of the benefits and harms of interventions can influence decision making and may be contributing to increasing intervention uptake and healthcare costs.

OBJECTIVE To systematically review all studies that have quantitatively assessed patients’ expectations of the benefits and/or harms of any treatment, test, or screening test.

EVIDENCE REVIEW A comprehensive search strategy was used in 4 databases (MEDLINE, Embase, Cumulative Index to Nursing and Allied Health Literature, PsycINFO) up to June 2015, with no language or study type restriction. We also ran cited reference searches of included studies and contacted experts and study authors. Two researchers independently evaluated methodological quality and extracted participants’ estimates of benefit and harms and authors’ contemporaneous estimates.

FINDINGS Of the 15,343 records screened, 36 articles (from 35 studies) involving a total of 27,323 patients were eligible. Thirteen studies focused on a screen, 15 on treatment, 3 on a test, and 3 on treatment and screening. More studies assessed only benefit expectations (22 [63%]) than benefit and harm expectations (10 [29%]) or only harm (3 [9%]). Fifty-four outcomes (across 32 studies) assessed benefit expectations; of the 34 outcomes with overestimation data available, the majority of participants overestimated benefit for 22 (65%) of them. For 17 benefit expectation outcomes, we could not calculate the proportion of participants who overestimated or underestimated, although for 15 (88%) of these, study authors concluded that participants overestimated benefits. Expectations of harm were assessed by 27 outcomes (across 13 studies); underestimation data were available for 15 outcomes and the majority of participants underestimated harm for 10 (67%) of these. A correct estimation by at least 50% of participants only occurred for 2 outcomes about benefit expectations and 3 outcomes about harm expectations.

CONCLUSIONS AND RELEVANCE The majority of participants overestimated intervention benefit and underestimated harm. Clinicians should discuss accurate and balanced information about intervention benefits and harms with patients, providing the opportunity to develop realistic expectations and make informed decisions.

Author Affiliations: Center for Research in Evidence-Based Practice, Faculty of Health Sciences and Medicine, Bond University, Queensland, Australia (Hoffmann), Del Mar, School of Health and Rehabilitation Sciences, University of Queensland, Brisbane, Australia (Hoffmann)

Corresponding Author: Tammy C. Hoffmann, PhD, Centre for Research in Evidence-Based Practice, Faculty of Health Sciences and Medicine, Bond University, Gold Coast, Queensland, Australia 4229, hoffmann@bond.edu.au
Background

• Increasing costs of health interventions and overuse of many

• Multiple possible causes
  ▫ Patient assumptions about intervention benefit and “more is better” likely plays a role

Existing studies of individuals’ expectations of benefit and harm fragmented across the literature
Inclusion criteria

• All studies …in which participants were asked to provide a quantitative estimate of the expected benefits and/or harms of a treatment, test, or screen

• Outcomes were eligible if they asked about the chance of the benefit or harm occurring and/or the size of it.

Not eligible:
• Descriptive estimates (e.g. “much better”)
• Expectations about the risk of developing a disease
Methods

- Databases (MEDLINE, Embase, CINAHL, PsycINFO) up to June 2013
  - with no language or study type restriction
- Cited reference searches of included studies
- Contacted experts and study authors
- 2 researchers evaluated methodological quality and extracted data
  - where provided, a ‘correct’ contemporaneous answer about an intervention’s benefits or harms
Provided ‘correct’ answer
  + % correct
  % overestimated
  &/or
  % underestimated

Provided ‘correct’ answer
  + only % correct

Did not provide ‘correct’ answer numerically; narratively expressed

ANS: 15 of 100 people
65% overestimated
20% correct
15% underestimated

“nearly all overestimated the benefit of...”
Flowchart of searching

14859 Records identified through database searching
484 Additional records identified through other sources

15343 Records screened

15252 Records excluded by title and abstract

91 Full-text articles assessed for eligibility

55 Full-text articles excluded
30 Benefit/harm responses not quantitative
15 Studied effect of giving benefit and/or harm information and no usable control group or baseline data provided
6 Not original research (e.g., commentary)
4 Measured risk of developing disease

36 Articles analyzed

36 articles (from 35 studies)
Total of 27 323 patients
About the 35 studies

Earliest: 1994
Most recent: 2013

16 countries
50% from USA

- 69% - used multiple choice Qs
- 31% - asked to provide a quantitative estimate e.g. “out of 1000 people, how many…”

- 40% - screening
- 43% - treatment
- 9% - test
- 9% - treatment and screening
About the 35 studies

• Of the screening & test studies, 75% were about cancer:
  ▫ Breast, prostate
  ▫ Bowel, cervical

• Of the 16 studies of treatments:
  - 18 different treatments
    - Medication e.g. statins, IBD, osteoporosis, HRT
    - Surgery e.g. hip/knee replacement, back surgery
    - Cancer treatment e.g. mastectomy
    - Other e.g. CPR, trial of labour after C-section
More focus on assessment of **benefit** than **harm** expectations

<table>
<thead>
<tr>
<th>Broad intervention topic</th>
<th>Harm expectations (N = 27 outcomes)</th>
<th>Benefit expectations (N = 54 outcomes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication – other (4)</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Cardiovascular disease prevention &amp; management (6)</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Maternal &amp; fetal medicine (3)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Surgery - other (3)</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Diagnostic radiology (2)</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Cancer – screening (15)</td>
<td>6</td>
<td>23</td>
</tr>
<tr>
<td>Cancer – management &amp; risk-reducing surgery (4)</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>CPR (2)</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>
Expectations of benefit

54 outcomes, across 32 studies

Of the 34 outcomes with overestimation data available:
- the majority of participants overestimated benefit for 22 (65%) of them

Majority provided correct answers for 2 outcomes (cataract surgery; cervical smear test)

Majority underestimated benefit for 1 outcome (surgery for low back pain)
Cancer screening
Barratt et al., 1999, mammography sensitivity
Chamot and Perhaerger, 2001, decreased breast Ca death by mammography
Domenighetti et al., 2003, decreased breast Ca death by mammography
Domenighetti et al., 2003, deaths prevented by mammography screening
Gigerenzer et al., 2005, decreased breast Ca death by mammography
Gigerenzer et al., 2005, decreased prostate Ca death by PSA screening
Haakenson et al., 2006, decreased breast Ca death by mammography
Haggstrom and Schapira, 2006, increased death risk from breast Ca by mammography
Hoffman et al., 2010, Ca diagnosis from positive mammogram
Hoffman et al., 2010, Ca diagnosis from high PSA
Hudson et al., 2012, decreased bowel Ca death by screening
Hudson et al., 2012, decreased breast Ca death by screening
Phillips et al., 2003, accuracy of cervical smear test
Phillips et al., 2003, cervical Ca prevented by screening
Phillips et al., 2005, accuracy of cervical smear test
Phillips et al., 2005, cervical Ca prevented by screening
Schwartz et al., 2000, decreased breast Ca death by mammography

Medication
Baars et al., 2009, IBD remission 1 y from infliximab
Baars et al., 2009, IBD remission 2 y from infliximab
Coo et al., 2001, decreased heart disease from HT in healthy women
Coo et al., 2001, decreased heart disease from HT in women at high risk
Coo et al., 2001, decreased hip fracture risk from HT in healthy women
Coo et al., 2001, decreased hip fracture risk from HT in women at higher risk
Hudson et al., 2012, hip fractures prevented by medication
Siegel et al., 2008, IBD improvement with 2 y of infliximab
Siegel et al., 2008, IBD remission after 1 y of infliximab (adults)
Siegel et al., 2008, IBD remission rate after 1 y of infliximab (parents)

Surgery
Fagerlin et al., 2010, pain relief after hip or knee replacement
Fagerlin et al., 2010, improved vision after cataract surgery
Fagerlin et al., 2010, benefit from back surgery

Cancer treatment and risk-reducing surgery
Lewis et al., 2003, live longer from mammography
Mancini et al., 2006, ovarian Ca prevented by oophorectomy in genetic risk women
Mancini et al., 2006, breast Ca prevented by mastectomy in genetic risk women

Fetal and maternal medicine
Babak et al., 2004, % fetal abnormalities detected by scan
Bernstein et al., 2012, success of labor trial after cesarean delivery

Cardiovascular disease
Hudson et al., 2012, decreased death from cardiovascular disease from medication
Weymiller et al., 2007, decreased death from cardiovascular disease from statin use
17 outcomes with no ‘correct’ numerical answer provided:
- in 15 (88%), study authors concluded that participants overestimated benefits
Expectations of harm

27 outcomes, across 13 studies

Of the 15 outcomes with underestimation data available:
- the majority of participants underestimated harm for 10 (67%) of them

Majority provided correct answers for 2 outcomes (need glasses after cataract surgery; miscarriage risk from amniocentesis)

Majority underestimated harm for 1 outcome (breast cancer risk from HRT)
Cancer screening
Lewis et al., 2003, chance of false positive from mammography
Lewis et al., 2003, upset by false positive from mammography
Haakenson et al., 2006, need biopsies after extra mammogram
Haakenson et al., 2006, need to return for additional mammogram
Haakenson et al., 2006, noncancerous abnormalities after biopsy

Medication
Baars et al., 2009, death risk from infliximab adverse effect
Baars et al., 2009, lymphoma risk from infliximab
Coo et al., 2001, breast Ca risk from HT in higher risk women
Coo et al., 2001, increased breast Ca risk from HT in healthy women
Siegel et al., 2008, death from infliximab adverse effect
Siegel et al., 2008, lymphoma risk from infliximab (adults)
Siegel et al., 2008, lymphoma risk from infliximab (parents)

Surgery
Fagerlin et al., 2010, complications from hip or knee replacement
Fagerlin et al., 2010, need second procedure after cataract surgery
Fagerlin et al., 2010, not better after back surgery
Fagerlin et al., 2010, complications from back surgery
Fagerlin et al., 2010, need glasses after cataract surgery

Diagnostic radiology
Neptune et al., 1994, risk of death from contrast material
Neptune et al., 1994, risk of minor reaction to contrast material
Neptune et al., 1994, risk of severe reaction to contrast material
Sin et al., 2013, No. of chest radiographs to equal dose from CT
Sin et al., 2013, risk of fatal Ca from CT scan

Fetal and maternal medicine
Bernstein et al., 2012, risk of uterine rupture during vaginal delivery
Gekas et al., 1999, % miscarriage induced by amniocentesis

Cardiovascular disease
Kee et al., 1997, rate of major complications from angiography
Conclusions

The majority of participants
- overestimated intervention benefit
- underestimated harm
• Requests

• Heavy impact of patient expectations on clinicians
Patient expectations

Assumptions about intervention benefit

Clinicians’ decisions
Missed opportunities?

Expectations:
- Not detected
- Actively avoided
Clinicians’ contributions…

- Best of intentions & desire to ‘do something’
- Unaware of true effectiveness & benefit-harm trade-off
- Lack of incentive for discouraging an intervention
- Pecuniary interests
Shared decision making!
Part of the solution…

**Shared Decision Making**

- Elicit expectations
- Accurate and balanced information about benefits and harms
- The opportunity to develop realistic expectations and make informed decisions
Thank you

thoffmann@bond.edu.au  @Tammy_Hoffmann
The truth about medicine: we usually overestimate the benefits and underestimate the harms.

If Patients Only Knew How Often Treatments Could Harm Them

March 2, 2015

The New York Times

THE NEW HEALTH CARE

THE AUSTRALIAN

Great expectations: our naive optimism about medical care

December 23, 2014

The Conversation

The Overselling of Spine Care—Is It Time to Scale Down Expectations and Emphasize Risk?

PATIENT EXPECTATION: BENEFIT AND HARMs

A recent study by Bond University found most patients overestimate the benefits of MRI and underestimate the harms. AMA Queensland Council of General Practice recommends on the need to proper manage patient’s expectations when it comes to tests.