Introduction and Objectives

The term overdiagnosis describes a situation in which a condition is diagnosed that would otherwise not go on to cause symptoms or death. The concept of overdiagnosis may be controversial (Welch and Black, 2010; Kopans, 2012) but it may also simply be poorly understood, whether by clinicians, health researchers, or the general public. This may be particularly true of cancer overdiagnosis, as it goes against the common assumption that cancer is inevitably fatal if left untreated. Although we are left with the conundrum (with present scientific knowledge) of not knowing which diagnosed lesions will cause harm and which will not, better understanding of the concept could lead to better communication about the harms and benefits of cancer screening, as well as other conditions prone to overdiagnosis.

To get a sense of current understanding of overdiagnosis, we performed a preliminary, open-ended survey of health professionals and the educated lay public.

Methods

Preliminary survey

- Convenience sample of 45 voluntary respondents to survey request distributed to Facebook contacts of authors
- Questionnaire administered using surveymonkey.com
- All responses were anonymous

Survey questions:

1. Prior today, had you ever heard the word ‘overdiagnosis’ used in the context of medical care or medical research?
2. What is the definition of overdiagnosis? If you’ve never heard the word or are unsure, please write ‘can’t answer’. Otherwise, write your definition. Try to limit your answer to a sentence or two.
3. Do you now or have you ever worked in medical care, biomedical research, or health services research?

Our approach to qualitative analysis of the survey results was to attempt to group responses into common thematic categories.

Results

Table 1. Sample description (45 total respondents)

<table>
<thead>
<tr>
<th></th>
<th>Non-health professionals (n=24)</th>
<th>Health professionals (n=21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Answered main question</td>
<td>9 (38%)</td>
<td>19 (90%)</td>
</tr>
<tr>
<td>Not answering</td>
<td>15 (62%)</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>N</td>
<td>24</td>
<td>21</td>
</tr>
</tbody>
</table>

Table 2. Definitions of overdiagnosis proposed by respondents

<table>
<thead>
<tr>
<th>Paraphrased definition</th>
<th>Non-health professionals (n=24)</th>
<th>Health professionals (n=21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis of condition never leading to symptoms</td>
<td>1 (4%)</td>
<td>9 (43%)</td>
</tr>
<tr>
<td>Misdiagnosis or false positive</td>
<td>1 (4%)</td>
<td>4 (19%)</td>
</tr>
<tr>
<td>Inadequate, misapplied, or subjective diagnostic criteria</td>
<td>4 (17%)</td>
<td>6 (29%)</td>
</tr>
<tr>
<td>Ad- or media-driven diagnosis</td>
<td>2 (8%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Profit-driven diagnosis</td>
<td>1 (4%)</td>
<td>0</td>
</tr>
<tr>
<td>Inappropriate diagnosis</td>
<td>0</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Not definition given</td>
<td>15 (63%)</td>
<td>2 (10%)</td>
</tr>
</tbody>
</table>

Discussion and Conclusions

Awareness of the concept of cancer overdiagnosis, while controversial, existed in the early 1990s in the field of diagnostic radiology (Black and Welch 1993). Since then, evidence for the occurrence of overdiagnosis has accumulated in the scientific literature for lung cancer, breast cancer and other sites (Marcus et al. 2006; Gotzsche 2009) and H. Gilbert Welch published a book for non-health professionals encouraging a more thoughtful approach to cancer screening. Overdiagnosis is a concern in other areas of health as well - in mental health, for example - and accepted definitions of the term may appropriately vary across different fields. The idea of diagnosing a condition in that will never produce symptoms in an otherwise well individual, and concerns about the cascade of treatment, stigma, and other effects on a person’s life, are not limited to cancer.

In this preliminary investigation of the public’s understanding of the concept of overdiagnosis, we received 45 anonymous responses based on posts from the authors’ Facebook pages. Slightly over half of respondents were non-health professionals. Fifteen of the 24 non-health-professional respondents declined to guess at the meaning of the term ‘overdiagnosis’; of those that did answer, while only one gave an answer that was quite close to what we considered the accepted definition, most of the other definitions suggested were in line with those proposed by the health professionals in the sample. Nine of the health professionals gave the correct definition and six posited definitions related to diagnostic criteria, while four equated overdiagnosis with misdiagnosis or false positive; somewhat surprisingly, two declined to answer.

This non-scientific survey was a useful first look at areas of understanding and misunderstanding of the concept of overdiagnosis, In a concise survey format designed to encourage candid response. It is possible that, because of the research interests of the authors, close contacts responding to the survey were more likely than the general population (of health professionals or non-professionals) to be familiar with the concept of overdiagnosis.

Proposed next steps:

- Disseminate the question to a larger sample of non-health professionals, health communicators, and health professionals personally unknown to the authors
- Refine the questions and add a multiple-choice component
- Incorporate questions regarding the implications of overdiagnosis.
- Examine whether responses differ by country or type of health system
- Examine the use of the term ‘overdiagnosis’ in popular media, with regard to cancer as well as other conditions.

References


Contacts

Emily DeVoto, PhD, Norwich UK  emily.devoto@gmail.com
Pamela Marcus, PhD, Rockville MD marcusmp@mail.nih.gov