Words do matter: a systematic review on how different terminology for the same condition influences treatment preferences

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BACKGROUND

Panel: Consensus of the working group recommendations regarding overdiagnosis and overtreatment presented to the National Cancer Institute

1. Recognise that overdiagnosis occurs and is common
2. Embrace the development of new terminology to replace the word cancer when appropriate, when data or companion diagnostics support the classification of low-risk lesions as indolent lesions of epithelial origin (IDLEs)
3. Create observational registries for IDLEs and disorders with low or uncertain risk of progression to cancer
4. Mitigate overdiagnosis by testing strategies that lower the chance of detecting unimportant lesions
5. Embrace new concepts for how to approach cancer progression and prevention

Ductal carcinoma in situ of the breast, or DCIS, represents a spectrum of abnormal cells confined to the breast duct and is a risk factor for invasive breast cancer development. Unlike invasive breast cancer, DCIS either has not yet invaded beyond its intraductal origin or may never invade neighboring tissues. DCIS is most often diagnosed as a consequence of screening for invasive breast cancer because DCIS has no specific screening modality. The etiology of DCIS is presumably heterogeneous, making

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REVIEW QUESTION

How do different terminologies given to the same condition influence treatment decision making?
METHODS

• A comprehensive list of search terms was developed

• *Medline, Pre-Medline, Embase, PsycINFO, Cinhal, and PubMed* searches were conducted from inception to Feb 2016

• Search results were screened by title and abstract and then assessed for eligibility independently by two researchers

• All included studies were appraised by study quality
  
  • Quantitative studies – modified version of the Cochrane Collaboration’s tool for assessing risk of bias
  
  • Qualitative study – criteria adapted from the Consolidated Criteria for Reporting Qualitative studies (COREQ) framework

• Data from the studies were extracted and results were synthesised in a narrative form as the heterogeneity of the studies and their respective outcome measures did not support pooling of results
Search results (n=1142)

Duplicates removed (n=231)

Review title and abstract (n=911)

Excluded irrelevant studies (n=892)

Review full text (n=19)

Excluded, did not meet eligibility criteria (n=14)
  - No manipulation of conditions' terminology (n=11)
  - No treatment decision outcome assessed (n=3)

Studies identified through reference lists (n=1)

Included in final review (n=6)
RESULTS

• 3 studies reported on ductal carcinoma in situ (DCIS), 2 on common childhood conditions (gastroesophageal reflux disease (GERD), conjunctivitis) and 1 on a bony fracture

• 5 studies reported quantitative findings and 1 reported qualitative findings
  • 4 involved a randomised experimental design – 2 using a paired sample design and 2 using an independent sample design
  • Qualitative study was linked to one of the quantitative studies

• All studies were hypothetical and involved various samples of community members who were not currently and/or previous diagnosed with the condition assessed
# RESULTS: risk of bias

<table>
<thead>
<tr>
<th>Study</th>
<th>Study design</th>
<th>Study setting</th>
<th>Selection bias</th>
<th>Performance bias</th>
<th>Attrition bias</th>
<th>Reporting bias</th>
<th>Measurement Bias</th>
<th>Analysis</th>
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</thead>
<tbody>
<tr>
<td>McCaffery 2015</td>
<td>+</td>
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<tr>
<td>Omer 2013</td>
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<td>?</td>
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<td>?</td>
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<td>Scherer 2013</td>
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<td>Scherer 2015</td>
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<td>Azam 2010</td>
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</tbody>
</table>
RESULTS: McCaffery et al. 2015 (Ductal carcinoma in situ)

Aim:
Impact of DCIS terminology on treatment preferences (immediate treatment vs watchful waiting) and women’s level of concern

Terminology:
‘pre-invasive breast cancer cells’ vs. ‘abnormal cells’

Primary outcome:
No significant differences in initial treatment preference, $p=0.23$. However, 18% of women who were initially given the ‘abnormal cells’ terminology changed their preference to treatment when the terminology was switched to ‘pre-invasive breast cancer cells’ while only 6% changed to watchful waiting ($p=0.008$).
RESULTS: Nickel et al. 2015 (Ductal carcinoma in situ)

Aim:
Impact of DCIS terminology on treatment preferences (immediate treatment vs watchful waiting) and women’s level of concern

Terminology:
‘pre-invasive breast cancer cells’ vs. ‘abnormal cells’

Primary outcome:
Overall, women preferred a diagnosis of DCIS to be communicated using terminology that did not include the term cancer, as women generally exhibited stronger preferences for immediate treatment when the cancer term was used to describe DCIS.
RESULTS: Omer et al. 2013 (Ductal carcinoma in situ)

Aim:
Impact of DCIS terminology on treatment preferences (surgery, medication, active surveillance)

Terminology:
‘non-invasive breast cancer cells’, ‘breast lesion’, ‘abnormal cells’

Primary outcome:
When DCIS was described as a non-invasive cancer 53% of participants preferred non-surgical options, whereas 66% chose non-surgical options when it was described as breast lesion and 69% chose non-surgical options when it was described as abnormal cells (p= <.001).
RESULTS: Scherer et al. 2013 (Gastroesophageal reflux disease)

Aim:
Influence of the term GERD (versus no term or label) on parents preferences for medication for their infant

Terminology:
‘GERD’ vs. no specific term/label (“this problem”)

Primary outcome:
Parents who received the term GERD in the scenario were more interested in medication than parents who did not receive that term, $F(1,165) = 6.95, p<.01$. 
RESULTS: Scherer et al. 2015 (Conjunctivitis)

Aim:
Influence of the term ‘pink-eye’ (versus the term ‘eye-infection’) on parents preferences for antibiotics for their infant

Terminology:
‘pink-eye’ vs. ‘eye-infection’

Primary outcome:
There was no initial difference between the term ‘pink-eye’ and ‘eye-infection’ on parents’ preference to medicate their infant. However, when symptoms were referred to as an 'eye infection', information about antibiotic ineffectiveness significantly reduced interest in using medication $F(1, 62) = 14.67$, $p=<.001$. 
RESULTS: Azam et al. 2010 (Bony Fracture)

Aim:
To assess the way different terms used to describe a bony fracture affect how the patient expects to be treated (heals on own, sling, cast, operation)

Terminology:

Primary outcome:
Patients expected more invasive treatments (operation or cast) when a more medicalised term was used to describe the injury, p<0.025.
# RESULTS: treatment preferences

<table>
<thead>
<tr>
<th>Study</th>
<th>More medicalised term/s (%)</th>
<th>Less/non-medicalised term/s (%)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>McCaffery 2015</strong></td>
<td>40</td>
<td>33</td>
<td>0.23</td>
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<tr>
<td><strong>Omer 2013</strong></td>
<td>47</td>
<td>32.5</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Scherer 2013</strong></td>
<td>74</td>
<td>67</td>
<td>0.346†</td>
</tr>
<tr>
<td><strong>Scherer 2015</strong></td>
<td>60</td>
<td>58</td>
<td>0.812†</td>
</tr>
<tr>
<td><strong>Azam 2010</strong></td>
<td>42</td>
<td>22</td>
<td>&lt;0.025†</td>
</tr>
</tbody>
</table>

*Summary of preferences for more invasive treatment option by type of terminology*

*Combined data where applicable and mean percentages reported

**Data from Likert scale with anchored end-points (0=No, definitely not; 5=Yes, definitely), assumed 1=No, 2=Maybe not, 3=Maybe, 4=Yes; therefore 0-1=non-invasive treatment preference, 2-5=invasive treatment preference

†Calculated significance using raw (Scherer) and published (Azam) data based on our classification of which terms were more medicalised
DISCUSSION

• First systematic review which synthesises the evidence on how different terminology given for the same condition impacts treatment preferences

• Findings indicated that when a more medicalised term is used to describe a condition, people seem to have stronger preferences for more invasive treatment options
LIMITATIONS

• Small number of included studies in the review

• Due to the variability of terms and outcomes assessed, we were unable to conduct a meta-analysis and pool the effects of the data

• Explicit judgements on which terms were deemed more medicalised, and which treatments were considered more invasive and less or non-invasive
  • However, decisions were guided from aims and outcomes of the studies

• Importantly, all studies were hypothetical – what would happen in clinical practice is still unknown
IMPLICATIONS

• Different terminology or labels used to describe the same condition can influence treatment preferences

• Supports the calls for changing the terminology of conditions where the risk of progression is low

• Potential communication strategy for indolent or low-risk conditions to help shift assumptions that immediate invasive treatments are always needed, allow for better shared decision making between clinicians and patients, and the consideration of more conservative treatment options
ACKNOWLEDGEMENTS

Kirsten McCaffery, Alex Barratt, Ray Moynihan
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Wiser Healthcare

Sydney Catalyst

PROSPERO trial registration number: CRD42016035643
Thank you

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