

Becoming Diseased Before Becoming Ill: A Systematic Review of the Negative Psychological Effects of Labeling

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Background

Although many people think of the harm of overdiagnosis as due exclusively to the physical effects of overtreatment, there are also psychological effects on an individual simply by being told she has a “disease”, a phenomenon known as “labeling”. We are aware of a 1978 study of labeling of male workers with the diagnosis “hypertension”, leading to increased absenteeism.¹ We asked whether there have been further studies that could help us determine both the frequency and burden (i.e., magnitude) of labeling among people newly diagnosed with both cancer and non-cancer diseases.

1. Haynes RB, Sackett DL, Taylor DW, Gibson ES, Johnson AL. Increased absenteeism from work after detection and labeling of hypertensive patients. *NEJM* 1978; 299(14):741-44.

Results

We examined 8,843 abstracts for BC, 1,507 for lung cancer, 165 for AAA, and 8,504 for DM. We included 49 studies for BC, 25 for LC, 4 for AAA, and 13 for DM. We found no consistent definition or conceptual framework for the construct of labeling; studies used an array of instruments to measure an equally wide variety of psychological outcomes (see Table 1). The terms labeling and overdiagnosis were not used by any study. In almost every study, however, we found clear evidence for at least a moderate negative effect on those diagnosed. The effects were more severe and affected a larger percentage of people diagnosed with BC and LC than with AAA or DM.

Methods

We used standard systematic review methods to find research studies of any design published between January 2002 and December 2013 that examined psychological effects within 3 months of diagnosis of breast cancer (BC), lung cancer (LC), abdominal aortic aneurysm (AAA), and Type 2 diabetes mellitus (DM).

Discussion

We had 2 major findings:

(1) Over the past 12 years, some studies – more for breast and lung cancers than abdominal aortic aneurysm or diabetes - have assessed aspects of the psychological status of recently-diagnosed individuals. Few studies examined changes in psychological status from before to after diagnosis, or followed individuals longitudinally after diagnosis to determine changes in psychological status for the months or years. No study systematically examined both the frequency of psychological effects from diagnosis of a representative sample of people and the degree of burden caused by psychological problems.

(2) Studies measured psychological status after diagnosis in many different ways, examining multiple different constructs. There is no agreed-upon classification of the psychological harms of labeling. Because there is no agreement on the construct(s) we are trying to measure, there is also no agreed-upon measurement instrument.

To determine the psychological consequences of overdiagnosis, we need a classification of these harms and agreed-upon measurement instruments to assess their frequency and burden.

Table 1. Partial list of outcomes and instruments

Outcome	Instrument(s)
Acute stress disorder/reaction	Acute Stress Disorder Interview (ASDI); Stanford Acute Stress Reaction Questionnaire
Anxiety	Hospital Anxiety and Depression Scale (HADS); State-Trait Anxiety Inventory (STAI)
Body image distress	Body Image Scale (BIS)
Cancer-specific beliefs and concerns	Consequences of Screening in Breast Cancer questionnaire
Cancer-related quality of life	EORTC QLQ-C30; EORTC Lung Cancer Questionnaire
Depression	Beck Depression Inventory (BDI); Centre for Epidemiological Studies Depression Scale (CES-D); Composite International Diagnostic Interview; Hospital Anxiety and Depression Scale (HADS)
Health-related concerns	Illness Attitudes Scale (IAS); Revised Illness Perception Questionnaire
Health-related quality of life	World Health Organization Quality of Life scale (WHOQOL-100); Short-Form 36 (SF-36)
Negative emotional suppression	Courtauld Emotional Control Scale
Post-traumatic stress disorder	Harvard Trauma Questionnaire (HTQ); Trauma Symptom Checklist (TSC)
Psychosocial or psychological distress	Distress thermometer (DT); Profile of Mood Status (POMS); Psychological Consequences Questionnaire (PCQ); Psychosocial Distress Questionnaire-Breast Cancer (PDQ-BC)
Uncertainty	Uncertainty in Illness Scale (UIS)
Worry	Penn State Worry Questionnaire (PSWQ)