Research Paper

Searching for disability in electronic databases of published literature

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Abstract

Background: As researchers in disability and health conduct systematic reviews with greater frequency, the definition of disability used in these reviews gains importance. Translating a comprehensive conceptual definition of ''disability'' into an operational definition that utilizes electronic databases in the health sciences is a difficult step necessary for performing systematic literature reviews in the field. Consistency of definition across studies will help build a body of evidence that is comparable and amenable to synthesis.

Objective: To illustrate a process for operationalizing the World Health Organization's International Classification of Disability, Functioning, and Health concept of disability for MEDLINE, PsycINFO, and CINAHL databases.

Methods: We created an electronic search strategy in conjunction with a reference librarian and an expert panel. Quality control steps included comparison of search results to results of a search for a specific disabling condition and to articles nominated by the expert panel.

Results: The complete search strategy is presented. Results of the quality control steps indicated that our strategy was sufficiently sensitive and specific.

Conclusions: Our search strategy will be valuable to researchers conducting literature reviews on broad populations with disabilities. © 2014 Elsevier Inc. All rights reserved.

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In the field of disability and health research and surveillance, definitional dilemmas surround the issue of framing relevant concepts and questions. Multiple definitions of disability are used in the field, and these definitions result in different prevalence estimates and produce results about somewhat different populations of people with disabilities. For example, the definition of disability used in the Behavioral Risk Factor Surveillance System (BRFSS) (any activity limitation or use of assistive equipment) results in a prevalence of nearly 23% of the U.S. adult population.[1] This represents a larger and broader disability population than the 14.5% prevalence for adults 18 years and older that results from the American Community Survey (ACS) definition based on specific activity limitations.[2] Definitional dilemmas in electronic searches echo definitional dilemmas in disability research and surveillance. In research studies, the definition of disability and how that definition is operationalized have implications for the study results; therefore, it is important to carefully and purposefully set definitions for disability for any research effort.

In an on-going project to identify factors related to health outcomes and health care utilization among diverse populations of individuals with disabilities, we enrolled an Expert Panel and charged them with determining working definitions for multiple systematic scoping reviews on topics related to health and health care disparities among people with disabilities (e.g., Andresen et al, 2013[3]). These reviews required conceptual and operational definitions for disability that were broad enough to capture people with disabilities across etiologies and categories. The Expert Panel chose the World Health Organization (WHO)

definition of disability from the International Classification of Functioning, Disability and Health (ICF) as our conceptual definition, and then set out to create a search strategy for the purpose of a systematic review based on this definition.[4] The authors have conducted numerous systematic and scoping reviews on the health and wellness of individuals with disabilities. In our experience, the issue of translating a comprehensive conceptual definition of "disability" into an operational definition that applies to existing electronic resources in the health sciences has been a repeated difficulty for us and for others in the field. Therefore, we dedicated resources specifically to careful creation and testing of such a strategy.

The purpose of this report is to describe our process of operationalizing the ICF concept of disability for conducting systematic literature searches using the MEDLINE, PsycINFO, and CINAHL databases. While our discussion is limited to these databases, our methods for locating literature about people with disabilities should be relevant to researchers utilizing diverse electronic databases of published literature.

Methods

Defining disability conceptually

In early meetings of the project's Expert Panel, we decided to define "disability" for the purposes of the project's scoping reviews based on the conceptual domains of the ICF. The panel reached consensus on a definition based on the ICF for three reasons. First, the 2007 Institute of Medicine's *Disability in America* report recommended that the ICF model be used to define disability in disability research.[5] Second, the ICF model is more comprehensive than other approaches and reflects modern social conceptualizations of disability with its inclusion of participation restrictions and environmental interactions in its definition. Third, we had been charged by the agency funding the project, the National Institute on Disability and Rehabilitation Research (NIDRR), to examine the group of people with disabilities broadly—inclusive of physical, sensory, cognitive, and mental health impairments. Conducting a comprehensive review that encompassed these broad categories using diagnostic or condition-specific definitions and procedures would not be possible without choosing some disabling conditions over others. In summary, the ICF definition of disability suited this project because of its emphasis on functional limitations and participation restrictions, elements of the concept that were important to Expert Panel members and appropriate to the population scope suggested by NIDRR.

The ICF defines "disability" as an umbrella term for impairments and activity and participation limitations. The ICF is a useful explanatory tool for understanding the interrelationships among health conditions, environment, and personal factors and body functions, activities, and participation.[4] The ICF model stresses a definition of disability

that includes the interface between the individual and environment rather than concentrating solely on impairments within the individual. This approach reflects the multidimensional nature of barriers (social, physical, attitudinal) to good health experienced by people with disabilities.[6]

Operationalizing the conceptual definition

Under the leadership of a co-author (DZJ) who is a reference librarian, we implemented a multi-step process to translate the ICF conceptual definition into a comprehensive search strategy. Because our literature search topics were health-related, we first operationalized our search for Ovid MEDLINE. We expected to get the highest volume of results from that search engine, given its biomedical scope. The steps in our process were: 1) create a subject heading search for MEDLINE; 2) create a key word search for MEDLINE; 3) conduct quality control checks for the MEDLINE search; and 4) replicate subject heading and key word searches for additional databases.

MEDLINE subject heading search

In our first step generating the electronic search strategy we created a set of subject headings. For each electronic database, subject headings are assigned to articles according to key concepts or methodological elements of the article. In the case of MEDLINE, Medical Subject Headings (or MeSH terms) are assigned by trained indexers at the National Library of Medicine. Because of the biomedical focus of MEDLINE, many of the available MeSH headings rely on diagnostic and condition-specific language and definitions.

First, we attempted to select all existing MeSH headings consistent with the ICF definition of disability (including impairments, activity limitations, and participation restrictions). We carefully reviewed scope notes (definitions provided for subject heading terms in each database) and subject heading tree structures (hierarchical branches used for indexing related terms). This step provided available terms in each database from which to construct a list of terms that was as comprehensive as possible while maintaining consistency with the ICF definition. Due to the focus of MeSH terminology, the strategy became overwhelmed by condition-specific terms. The Expert Panel was concerned that relying on condition-specific terms was extremely unwieldy; this strategy would result in the use of hundreds of terms and require expert opinion around likelihood of functional impairment associated with each potentially disabling condition in the MeSH term database, and then still reviewing high numbers of irrelevant potential papers where conditions and diagnoses were not linked to, or described in terms of disability.

To create a more targeted strategy and maintain consistency with the ICF definition, the Expert Panel decided to locate subject headings related to ICF chapter headings