Consensus Statement of the International Summit on Intellectual Disability and Dementia
Related to Nomenclature


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1 The authors are the primary members of the Summit working group on nomenclature. This consensus statement was developed as an output from the 2016 International Summit on Intellectual Disability and Dementia, held in Glasgow, Scotland, 13-14 October 2016, and hosted by the University of Stirling and University of the West of Scotland, funded by the RS MacDonald Trust, the Scottish Government, and Alzheimer Scotland. Collaborating sponsors included the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in the United States and the University of Illinois at Chicago. The Summit was composed of individuals and representatives of many international and national organizations with a stake in issues related to adults with intellectual disability affected by dementia. The contents of this statement were partially developed under a grant from the United States Department of Health and Human Services, Administration for Community Living (ACL), National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Grant # 90RT5020-03-00. However, those contents do not necessarily represent the policy of the US Department of Health and Human Services, nor the endorsement by the US federal government. The opinions expressed represent those of the Summit participants and of the NTG.
Abstract

A working group of the 2016 International Summit on Intellectual Disability and Dementia was charged to examine the terminology used to define and report on dementia in publications related to intellectual disability (ID). A review of related publications showed mixed uses of terms associated with dementia or causative diseases. Like general applications, language related to dementia in ID field often lacked precision and could lead to a misunderstanding of the condition(s) under discussion. Most articles related to ID and dementia reporting clinical or medical research generally provided a definition of dementia or related terms; social care articles tended toward term use without definition. Toward terminology standardization within studies/reports on dementia and ID, the Summit recommended (a) gaining familiarity with dementia-related diagnostic, condition-specific, and social care terms (as identified in the working group's report), (b) creating a guidance document on accurately defining and presenting information about individuals or groups referenced, and (c) that in reports on neuropathologies or cognitive decline or impairment, definitions are used and data include subjects' ages, sex, level of ID, residential situation, basis for dementia diagnosis, presence of Down syndrome (or other risk conditions), years from diagnosis, and if available, scores on objective measures of changing function.
Introduction

Language can and does shape and form our perceptions of a condition or situation. As noted by Alzheimer’s Europe (2013, p. 11), “Some words and metaphors are used liberally and paint a very biased picture of dementia, whilst others are avoided and considered demeaning, depersonalizing, and insulting. Even standard medical terms are sometimes used with great caution due to an awareness of the possible impact on people’s lives and wellbeing. Words clearly matter. They describe, communicate and reinforce our current perceptions of dementia.”

Nomenclature (or terminology) is a system of names or terms, or the rules for forming these terms in a particular field of arts or sciences. Reviews of publications (i.e., journal articles, book chapters, reports, plans) involving intellectual disability show varied uses of terms associated with dementia or the diseases causing it (Janicki et al., 2016). Terms in use (including dementia, Alzheimer’s, and other similar descriptors) often lack precision or consistency when used loosely and applied inappropriately. This may be attributed to a lack of understanding of the distinction in the terms, the nuances involved with neuropathologies, or inconsistent use of language as well as absence of or inconsistency in an agreed upon core group of methods used in diagnosis. As in general applications, language related to dementia in the intellectual disability field also lacks precision and often leads to a misunderstanding of the condition(s) under discussion.

This lack of precision in general applications, as witnessed by recent efforts in the mainstream Alzheimer’s and dementia field to address the same issue, appears common. This concern over coherency regarding terminology was discussed by Taylor (2016) at the Alzheimer’s Disease-Related Dementias 2016 Summit, held under the auspice of the National Institutes of Health in the United States (Foundation for the National Institutes of Health, 2016). Taylor listed a range of terms that are in use in the field and stimulated a dialogue on dementia-related nomenclature regardless of the etiology, specific clinical syndromes, and underlying etiologies. She noted a number of problems stemming from inconsistency in terminology, such as Alzheimer’s disease being used synonymously with dementia, low public awareness of other forms of dementia, and a lack of recognition that ‘Alzheimer’s disease’ services are also applicable for those persons affected by non-Alzheimer’s based dementias.

The problems stemming from inconsistent terminology were also discussed at a meeting of the U.S. National Advisory Council on Alzheimer’s Research, Care, and Services, which under the National Alzheimer’s Project Act (NAPA) is responsible for the US National Plan to Address Alzheimer’s Disease
Among the issues raised was the recent adoption of updated clinical terminology within the DSM-V (APA, 2013), and the range of terms in use for various dementias (Petersen, 2016). As a result, the Council inserted a recommendation into the 2016 U.S. National Plan Update that stated that “Emphasis should be given to the standardization of terminology in dealing with cognitive and dementing disorders.” Further, the 2016 Update recommended that “an integrated conference should be convened to develop consistent language for cognitive disorders among scientists, care providers and the public... [and there is a need to] engage all of the stakeholders around these issues to reach a consensus for the benefit of persons with dementia, their family members and caregivers, and the scientific and service communities” (ASPE, 2016).

**Conveyance of the notion of dementia**

Language usage and terminology is germane to how people affected by dementia are viewed and to what extent the terms used minimize stigma (Garand, Lingler, Conner, & Dew, 2010). Clearly, ‘people-first’ language [i.e., adults with dementia] creates positive imagery and can go far to minimize negative perceptions. Language uses such as ‘adults with dementia’ are preferable to terms, such as ‘demented, victim, and sufferer’, which tend to be pejorative and maximize stigmatization (DEEP, 2015). Such positive terms also focus on the individuals rather than the condition.

Communicating the definition and process of dementia to people with intellectual disability creates a further conundrum. To enable understanding, language and phrasing needs to be at a word-level that organizations communicating with the general public, caregivers, advocates, or adults affected by dementia can effectively convey the concepts associated with dementia. Further, the concepts need to be communicated in a manner so as to explain the essence and implications, and convey the seriousness of the condition while not creating confusion or undue anxiety.

To examine the degree of concept conveyance to the general public through the level of language used, the Summit working group analyzed both the reading ease and grade level of definitions conveyed by different dementia, health, and disability organizations when defining dementia (see Janicki et al., 2016 for the full report). Of the 16 definitions extracted from major organization websites and documents, the reading ease level ranged from 60.70 to 0.0 (\(\bar{X} = 26.68\)) and the grade level ranged from 7.8 to 18.6 (\(\bar{X} = 13.84\)).

2 It appears that most of the definitions were expressed using complex

\[^2\text{In general, the higher the reading ease score, the more generally understandable wording is; with respect to the grade level, lower scores correspond with low grade level reading abilities.}\]
concepts, even when directed at the general public. For those directed toward professionals, clearly they were in the realm of technical language. An aspect of communicating is the ease with which the general population grasps the concept behind the disease or neuropathology – so avoiding ‘high science language’ in documents directed toward general readership audiences can facilitate understanding. Using terms and definitions that are in common usage can help to ensure the communication of messages. Conversely, creating definitions that minimize the course and eventuality of brain changes leading to dementia can leave conditions untreated.

Language and terms are often a challenge for intellectual disability organizations, as they have to convey both information about an insidious co-incident condition and forewarn caregivers of the condition’s severity and eventual impact. How wording is constructed depends on the audience and message to be conveyed, and often the explanations lean toward complexity. This is true even among Down syndrome advocacy organizations, where the definitions and explanations of dementia (and Alzheimer’s disease) used to inform their constituents tend toward complexity (Janicki et al., 2016). However, when materials are developed specifically for people with intellectual disability, concepts can be explained in a simpler manner. As an example of a plain language definition of dementia, the Down’s Syndrome Scotland’s (n.d.) publication for adults with intellectual disability, states “Dementia is an illness in the brain. It affects many things, but mostly the way people remember and do things.”

While it was not the function of this Summit statement to offer a standardized definition of ‘dementia’, it is recognized that the condition’s primary features are characterized by the progressive loss of brain function that occurs with certain neuropathological diseases or trauma, often associated, but not necessarily related, to aging (others have addressed this issue in depth – see Chertkow et al., 2013; Small et al., 1997). Such neuropathologies include, among others, Alzheimer’s disease, Parkinson’s disease, Pick’s disease, and cerebrovascular accidents. The neuropathologies will vary and have differing effects – but all have in common the eventual expression of progressive behavioral and cognitive changes defined as dementia. This expression includes marked memory disorders and impaired reasoning, and personality and behavioral changes. However, it is recognized that features that may initially be taken for dementia-like behavioral dysfunctions may be the result of adverse drug reactions, depression, psychological trauma, or a range of other causes – with their defining feature a clearing or reduction of symptoms upon treatment (Desai & Grossberg, 2001).

Further, it was not the intent of this Summit statement to rectify inconsistencies in dementia-association language usage across the general field of dementia (see Table 1), but to promote the
understanding of the distinctions among the terms in prevalent usage, and advance the application of precise usage and agreement on dementia related terms that are commonly used in association with intellectual disability. Such a result would advance clearer differentiation and appropriate usage among clinical terms such as: dementia, Alzheimer’s disease, cognitive impairment, Alzheimer’s disease spectrum, pre-clinical Alzheimer’s disease, dementia due to Alzheimer’s disease, mild cognitive impairment due to Alzheimer’s disease, early versus late onset disease, and mild, moderate and advanced dementia (Alzheimer’s disease), and others. While we are not proposing a standard definition of dementia or the acceptance of range of associated terms that would apply to work in intellectual disability – as no such consensus on terms exists in the general dementia literature or documents (save for those that appear in the DSM-5 (APA, 2013) or ICD-10 (WHO, 1992) for diagnostic purposes) – but are suggesting that workers do provide an operational definition of dementia of their choosing so as to offer readers a clear understanding of the variables and notions related to the population being described.

Insert Table 1 about here

Applications of terms

How terms are used can affect clarity in understanding which subject population is being referenced and what conditions are being discussed. In a sampling of articles and reports related to intellectual disability and dementia found in the literature undertaken by the Summit’s working group, term-usage was found to be variable and at times less than clear (see Janicki et al., 2016). Authors in general used ‘dementia’ as a common term defining the nature of the condition being discussed in their article or report. However, there was often mixed reference to Alzheimer’s disease, dementia of the Alzheimer’s type, and generic ‘dementia’ without linkage to standard definitions (such as those in the DSM-5 and ICD-10). While the usage served the intended purpose – of defining the general concern of the article – it left open interpretations of how the condition was identified in the subjects, to what degree it was progressing, and what may have been the underlying neuropathology. While in general most of these data may not always be readily available in social care research, it should be available in medical research and in articles advancing or relying upon standardized assessments.

Defining the subject population also has import and implications for research related to dementia in the intellectual disability field. The Summit working group’s study (Janicki et al., 2016) also noted the high preponderance of articles in the intellectual disability and dementia literature that
focused predominantly on Down syndrome. Given the high risk for Alzheimer’s disease among adults with Down syndrome this is not unexpected. However, it is important that authors are clear when reporting results and generalizing effects that the information provided relates to dementia in adults with Down syndrome, as there may be differential patterns of onset, effect, and mortality in the greater population of adults with intellectual disability. As often in articles and reports the number or percentage of subjects with Down syndrome is not identified within the study populations of adults with intellectual disability, this may confound generalizability unto the greater population of adults with intellectual disability. Also, as most studies involving adults with Down syndrome relate to dementia of the Alzheimer’s type, this also should be noted in the subject descriptions, and/or any variations in forms of dementia should be noted. Lastly, subject recruitment sections in reports should contain concise definitions of dementia and at what stage such recruitment occurred.  

The Summit working group observed that most articles related to intellectual disability and dementia reporting clinical or medical research were more apt to provide a definition of dementia or related terms, while social care articles tended to only use the term itself and not define it or provide substantiation of study subject diagnoses. It would be helpful if social care articles also provided definitions and the basis for ascribing dementia to the persons in the studies, thus offering more precision and permitting cross-article comparisons and contrasts. Further, often many of the articles examined failed to define the subject population with respect to age, sex, level of intellectual disability, etiology, and other demographic variables. When definition of subject populations in articles on dementia and intellectual disability is loose or absent, this impedes credence and generalizability. Also, judicious use of common terms among key words in manuscript submissions will aid in locating relevant articles following publication (e.g., Alzheimer’s disease, cognitive impairment, dementia, Down syndrome, neurocognitive disorders, neuropathology, intellectual disability, etc.)

Commentary

The intent of this Summit statement is to promote the understanding of the distinctions among terms in prevalent use with respect to intellectual disability and dementia, and to advance usage that

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3 Identifying staging in dementia in persons with intellectual disability can be more difficult than in the general population as in the general population staging is based on changes in activities of daily living (ADLs). With dementia of the Alzheimer’s type, the assumption is that every individual starts the disease process without impairment and goes though different stages more or less homogeneously. However, with other dementias (i.e., FTD), this staging system may not be as consistently homogeneous. In adults with intellectual disability, although the staging is affected by the degree and nature of the intellectual disability, efforts should still be made to define it as accurately as possible.
more accurately reflects the concepts cited and agreement on commonly used dementia and intellectual disability-related terms. Terminology needs precision and to accurately convey the conditions and services being discussed. The Summit proposes that authors provide operational definitions of conditions being considered, ancillary demographic and clinical data, and study population parameters, particularly the numbers (and percentages) of subjects with Down syndrome, and information about how diagnoses were obtained, as well as the protocols and instruments employed. This would help offer readers a clearer understanding of the population being described and facilitate replication in future studies and comparisons across existing studies.

Recommendations

The Summit saw as its goal to address issues associated with nomenclature (or terminology), specifically seeking agreement on a common terminology related to cognitive impairment and dementia among persons with intellectual disability and recommending a move toward standardization of terminology within studies and reports on dementia and intellectual disability. With this in mind, the Summit recommends:

- To promote positive imagery, organizations and workers should adopt and use image enhancing language when describing persons with intellectual disability affected by dementia and avoid language that stigmatizes or dehumanizes;

- To promote standardized understanding of the meaning of terms used to describe services and conditions related to dementia and intellectual disability, that a taxonomy be created and adopted for general use. A taxonomy of unvetted terms prevalent in dementia and intellectual disability publications is found in Appendix B of the full Summit report (see Janicki et al., 2016) and can offer user guidance on the most prevalent concepts;

- To help with reporting and describing events or conditions related to intellectual disability and dementia, that a guidance document be created on how to accurately define and present information about individuals or the group being referenced and include both formal diagnostic criteria and general definitions of the various dementias. We recommend that the guidance document be supported by a consortium of associated intellectual disability, gerontology, and dementia groups, and appear in a relevant publication (for archival purposes); and

- To standardize reporting of subjects and outcomes from studies, researchers and workers follow recommendations for standardizing data in reports addressing neuropathologies or
cognitive decline or impairment. Such reports should use recommended definitions and at a minimum include the subjects’ ages, sex, level of intellectual disability, residential situation, basis for dementia diagnosis, presence of Down syndrome (or other risk condition), years from diagnosis, and if available, scores on an objective measure of changing function from a recognized and validated dementia scale.

References


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Adapted from Janicki et al., 2016. *See Janicki et al., 2016 for full text of definitions. INT: International