



RESEARCH ARTICLE

How Individuals with ME/CFS Are Referred to in Medical Research: A Content Analysis of Identity-First and Person-First Language

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Abstract

This study examined the use of person-first and identity-first language in published Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) medical research articles. Person-first language emphasizes the individual before their condition (e.g., “person with diabetes”), whereas identity-first language foregrounds the condition (e.g., “diabetic”). Because language has been discussed as a potential contributor to stigma in some chronic illness and disability contexts, documenting language patterns in the scientific literature may provide insight into how individuals are represented. The current study analyzed how individuals with ME/CFS were described in a sample of 85 medical research articles. Across these articles, references to individuals with ME/CFS appeared 3,211 times. Identity-first language was the most frequently used form of terminology (61.9%), followed by person-first language (22.9%) and other descriptors (15.2%). Most articles (72.9%) used both identity-first and person-first language. These findings highlight prevailing linguistic patterns in the ME/CFS research literature and underscore the importance of continued examination of language use in scientific communication.

Keywords: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; person-first language; identity-first language; language patterns; stigma

INTRODUCTION

Person-first language places emphasis on the individual before their condition, such as referring to a “person with diabetes,” whereas identity-first language foregrounds the condition, as in describing someone as “diabetic.” Person-first language prioritizes the individual’s identity as multifaceted, with illness representing only one aspect of a broader and more complex self (Botha et al., 2023; Dunn & Andrews, 2015). In contrast, identity-first language emphasizes the condition as a defining feature of the person. The American Psychological Association (2020) recommends that researchers and practitioners use language that reflects the preferences of the communities being described, recognizing that linguistic choices can shape perceptions and experiences.

This study is guided by an integrative framework that situates language use within broader processes of stigma and social representation. Specifically, we examine how person-first and identity-first language function not only as

linguistic choices but also as indicators of how individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) are positioned within medical discourse. Drawing on perspectives from critical disability studies, which emphasize the role of language in shaping legitimacy, identity, and power relations, the current study treats naming practices in scientific literature as socially meaningful rather than purely descriptive. Within this framework, stigma is not directly measured but serves as an important contextual lens for understanding why patterns of language use warrant empirical attention.

Debates about person-first and identity-first language have emerged across a range of health and disability contexts. For example, in HIV research, advocacy efforts have emphasized the use of person-centered terminology such as “people living with HIV,” in response to historically stigmatizing phrases that framed individuals primarily through their diagnosis (McPherson et al., 2023; The Lancet HIV, 2023). Similarly, guidelines promoting inclusive language in scholarly communication have sought to standardize terminology that reflects respect and cultural sensitivity (Coalition for Diversity and Inclusion in Scholarly Communications, 2022). At the same time, some disability communities, including autistic individuals and members of the Deaf community, have expressed a preference for identity-first language as a way of affirming shared identity and community belonging (Dunn & Andrews, 2015; Kenny et al., 2016; Taboas et al., 2023).

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These differing preferences highlight that language choices are not neutral but are shaped by social, cultural, and historical contexts.

Although these debates span multiple conditions, issues of language may be particularly salient in illnesses where legitimacy has historically been contested.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a complex, multi-system condition characterized by symptoms such as post-exertional malaise, cognitive impairment, and sleep disturbance (Carruthers et al., 2003, 2011; Lorusso et al., 2009). Despite growing biomedical recognition, individuals with ME/CFS have frequently encountered skepticism and delegitimization within both medical and social contexts (Pheby et al., 2021; Geraghty & Blease, 2019). Earlier work has documented how individuals with ME/CFS have had their symptoms attributed to psychological causes and have reported experiences of misunderstanding and marginalization (Green et al., 1999; Dickson et al., 2007). More recent analyses have further highlighted how contested illness status can shape patient-provider interactions and influence perceptions of credibility within healthcare systems (Geraghty & Blease, 2019).

Within this context, language used in scientific and clinical discourse may play a role in how individuals with ME/CFS are represented and understood. Historically stigmatizing terms such as “yuppie flu” trivialized the illness and contributed to its delegitimization (Richman et al., 1994). In addition, the earlier use of the term “chronic fatigue syndrome” has been criticized for minimizing the complexity and severity of the condition by emphasizing a common and nonspecific symptom (Bhatia & Jason, 2023). These examples illustrate how naming practices can shape broader interpretations of illness, particularly in conditions marked by contested legitimacy.

A critical disability studies perspective provides a useful framework for understanding why linguistic choices in ME/CFS research matter beyond issues of accuracy or politeness. Scholars have argued that language functions as a central mechanism through which disability is socially constructed, represented, and granted—or denied—legitimacy (Davis, 2013; Garland-Thomson, 2005; Linton, 1998; Shakespeare, 2013; Titchkosky, 2011). Institutional naming practices, including the routine use of terms such as “ME/CFS patients,” are not neutral descriptors but can reflect and reproduce broader structures of authority within medical discourse. The grammatical structure of identity-first medical labels may position the disease category as a primary defining feature of the individual, potentially reinforcing processes of medicalization and marginalization.

Importantly, identity-first language in disability activism often emerges from within communities as a form of identity affirmation and resistance to externally imposed definitions. In contrast, medical terminology such as “ME/CFS patient” is typically generated within clinical and research contexts rather than by individuals with lived experience. This distinction underscores the importance of examining how language is used in scientific literature, particularly in fields where patients have historically had limited influence over how their experiences are represented.

Despite growing attention to inclusive language in other health contexts, relatively little research has systematically examined how individuals with ME/CFS are described in the medical literature. The current study addresses this gap by analyzing the use of person-first and identity-first language in a sample of ME/CFS medical

research articles. By documenting patterns of language use, this study aims to contribute to ongoing discussions about representation, inclusivity, and the role of scientific communication in shaping understandings of contested illnesses.

MATERIALS AND METHODS

Study Design

This study employed a content analysis of published medical and scientific articles to examine the use of person-first and identity-first language in the ME/CFS research literature. Content analysis is a systematic method for identifying and quantifying patterns in textual data, allowing for the examination of how individuals are described within scientific discourse.

Article Selection and Search Strategy

Articles were identified between June 4 and August 2, 2024, using structured searches of multiple academic databases, including Google Scholar, PubMed, ScienceDirect, and JSTOR. Search terms included combinations of “ME/CFS,” “ME,” “CFS,” and “myalgic encephalomyelitis/chronic fatigue syndrome.”

To supplement database searches, additional articles were identified from an existing curated set of publications used in prior reviews of ME/CFS case definitions. Reference lists of retrieved articles were also examined to identify additional relevant publications.

Inclusion and Exclusion Criteria

Articles were included if they: Were published in peer-reviewed journals. Were written in English. Focused on ME/CFS or related diagnostic constructs. Included narrative text in which individuals with ME/CFS were described. Articles were excluded if they: did not include references to individuals with ME/CFS (e.g., laboratory-only or methodological papers without patient descriptors), were not available in full-text form, or were duplicate records identified across databases

Screening Procedure

Search results were screened for relevance based on titles and abstracts, followed by full-text review to confirm eligibility. Duplicate records were removed prior to final selection. Because the aim of the study was to characterize patterns of language use across a range of publications rather than to estimate population parameters, a purposive sampling approach was used. A total of 85 articles were selected to provide representation across publication years, journal types, and ME/CFS case definitions. Accordingly, the sample reflects a diverse cross-section of the literature rather than a statistically representative random sample.

Coding Procedures

Articles were imported into the reference management software Mendeley and reviewed by the primary author and trained raters. Using a structured coding approach, raters identified and annotated each instance of identity-first language (e.g., “ME/CFS patient”) and person-first language (e.g., “patients with ME/CFS”).

The unit of analysis was each instance in which individuals with ME/CFS were explicitly described in the text. Frequency counts of identity-first and person-first terminology were recorded for each article.

Article Classification

For each article, the following characteristics were recorded: journal name, year of publication, country of authorship, ME/CFS case definition used, and article type (e.g., empirical study, literature review, informational article).

For articles with multiple authors from different countries, the country of the corresponding author was used for classification. When multiple case definitions were referenced, the primary case definition described in the methods section was recorded. Article type was determined based on the primary purpose of the publication.

Interrater Reliability

The first author and two independent raters evaluated the articles. Interrater agreement was calculated as the percentage of agreement across coded instances, defined as the number of agreements divided by the total number of coding decisions (agreements plus disagreements), multiplied by 100. Agreement ranged from 84% to 92%. Discrepancies were resolved through discussion, with a third rater consulted when consensus could not be reached.

RESULTS OF STUDY

A total of 85 articles were included in the content analysis. Across these articles, references to individuals with ME/CFS appeared 3,211 times. Identity-first language was the most frequently used form of terminology. Terms such as “ME/CFS patient(s)” occurred 1,988 times, representing 61.9% of all coded instances. Person-first language, including phrases such as “patients with ME/CFS,” “people with ME/CFS,” and “individuals with ME/CFS,” appeared 736 times (22.9%). Additional descriptors, such as “ME/CFS population” or other non-standard phrasing, accounted for 487 instances (15.2%).

These findings indicate that identity-first terminology predominates in the ME/CFS research literature, although person-first and alternative descriptors are also used with notable frequency.

Article-Level Language Patterns

Of the 85 articles, 62 (72.9%) used both identity-first and person-first language. A smaller subset of articles relied exclusively on a single form of terminology: 13 articles (15.3%) used only identity-first language, whereas 10 articles (11.8%) used only person-first language. No articles were found that entirely avoided referring to individuals with ME/CFS.

DISCUSSION

The present study examined patterns of person-first and identity-first language in a sample of ME/CFS medical research articles. The findings indicate that identity-first

terminology, particularly phrases such as “ME/CFS patient(s),” was the most frequently used form of reference, accounting for the majority of coded instances. Person-first language appeared less frequently but was nonetheless present across many articles. At the article level, most publications used a mixture of both forms of terminology, suggesting that language practices in this field are not standardized.

These findings are descriptive and reflect patterns of language use within published research articles. The study did not directly assess stigma, patient experiences, or the effects of language on clinical interactions. However, the observed patterns may be relevant to ongoing discussions about how individuals with ME/CFS are represented within medical discourse. Prior scholarship has suggested that language can function as one mechanism through which illness legitimacy, credibility, and social meaning are negotiated (Davis, 2013; Garland-Thomson, 2005; Titchkosky, 2011). Within this broader context, the predominance of identity-first terminology in ME/CFS research may warrant further consideration.

Importantly, the issue is not simply whether identity-first or person-first language is inherently preferable. As demonstrated in other disability and health contexts, language preferences vary across communities and are shaped by historical, cultural, and political factors (Dunn & Andrews, 2015; Kenny et al., 2016; Taboas et al., 2023). Identity-first language may be embraced in some communities as a form of identity affirmation, while in other contexts, person-first language is preferred as a way of emphasizing the individual beyond their diagnosis. The present findings therefore highlight the importance of considering not only the form of language used, but also who determines that language, the context in which it is applied, and whether it aligns with the preferences of those being described.

In the case of ME/CFS, a condition with a history of contested legitimacy, naming practices may carry particular significance. Historically stigmatizing labels and dismissive framings have contributed to misunderstanding and marginalization of individuals with this illness (Geraghty & Blease, 2019). While the current study does not demonstrate causal effects of language on stigma, it identifies patterns of terminology that may intersect with these broader dynamics. As such, language use in scientific publications can be understood as one component of a larger system of representation, rather than as an isolated factor.

Practical Implications

The findings have several practical implications for researchers, journal editors, and reviewers. First, authors may benefit from increased awareness of how language choices shape the representation of individuals with ME/CFS. This includes considering whether terminology reflects current best practices in inclusive language and whether it aligns with emerging perspectives from affected communities.

Second, journal editors and reviewers may consider encouraging greater consistency and transparency in language use. This could involve the development of editorial guidelines or recommendations that prompt authors to reflect on their terminology and, where appropriate, justify their choices.

At the same time, any recommendations regarding preferred language should be made cautiously. The present study does not assess the preferences of individuals with ME/CFS, clinicians, or other stakeholders. As a result, it cannot determine which forms of language are most appropriate or acceptable. Establishing such

recommendations requires direct empirical research that centers the perspectives of those with lived experience.

CONCLUSION

This study provides a systematic analysis of language used to describe individuals with ME/CFS in medical research articles. The findings indicate that identity-first terminology predominates, although person-first and other forms of language are also used across the literature. By documenting these patterns, the study contributes to broader discussions about representation, inclusivity, and the role of language in scientific communication.

LIMITATIONS

Several limitations should be considered when interpreting these findings. First, the analysis was limited to articles published in English, which may not reflect language practices in other linguistic or cultural contexts. Second, the sample size of 85 articles, while sufficient for identifying general patterns, does not capture the full scope of the ME/CFS literature. Third, although efforts were made to systematically identify and code articles, the article selection process was not designed to produce a fully representative or exhaustive sample. Finally, the study did not assess the language preferences of individuals with ME/CFS, clinicians, or other stakeholders. As a result, conclusions about the appropriateness or impact of specific terminology remain speculative.

Future research should directly examine language preferences among individuals with ME/CFS and explore how terminology influences perceptions, clinical interactions, and experiences of care. Such work would provide a critical empirical foundation for developing evidence-based recommendations regarding language use in this field.

DECLARATION

Ethics approval and consent to participate

No human subjects so not needed

Consent for publication

Not applicable.

Availability of data and materials

Will be made available to anyone that wants to see our data

Conflicts of interest Statement

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Artificial Intelligence-Assisted Technology

Used to help with some phrasing and grammar and spelling checks.

Authors' contributions

First Author (R Yousif): A. Yousif designed the research, collected the data, analyzed the data, and wrote the manuscript.

Second Author (LAJ): L Jason contributed to performing statistical analysis, and assisting in the interpretation of results. In addition, L Jason participated in revising the manuscript and providing relevant suggestions for article improvement.

ABOUT THE AUTHORS

RY is finishing her BA at the University of Alaska and she completed this research while interning at the Center for Community Research, DePaul University, during the summer.

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