Schizophrenia

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How researchers refer to individuals with schizophrenia: person-first and identity-first language in academic papers

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Stigma associated with schizophrenia has been well-documented in both society and healthcare settings. However, the use of stigmatizing language in research papers remains largely unexplored. This study examined how researchers refer to schizophrenia in peer-reviewed articles, aiming to characterize the descriptive terms used to refer to individuals with schizophrenia and assess the adoption of person-first language. We conducted an electronic search on PubMed using the MeSH term "schizophrenia" and randomly selected 500 articles. Descriptive terminology was categorized as neutral (e.g., "schizophrenia patients"), person-first (e.g., "person with schizophrenia"), or identity-first (e.g., "schizophrenic patient"). Reference terms were assessed based on their alignment with a person-first perspective. Of the 500 studies, 475 (95%) included at least one term referring to people affected by schizophrenia. Among them, 238 (50.1%) used identity-first terms, 228 (48%) used person-first terms, and 91 (18.2%) employed both. Over time, the use of identity-first terms decreased. The decline in identity-first terms over time suggests a positive impact of the person-first movement. Despite these encouraging findings, our data also indicate that there is still room for improvement in reducing the use of identity-first terms. We propose recommendations for researchers to promote less stigmatizing language.

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INTRODUCTION

Stigma encompasses negative beliefs and attitudes that result in behaviors characterized by avoidance, rejection, or fear of people perceived as different[1]. Among mental conditions, schizophrenia stands out as one of the most stigmatized[2,3]. Even today, people often associate schizophrenia with predetermined negative outcomes, such as dangerousness or inevitable functional decline[3–6].

In a survey by the Global Mental Health Peer Network, 80% of respondents in 45 countries agreed that "stigma and discrimination can be worse than the impact of the mental health condition itself"[2]. Stigma can lead to severe consequences: it exacerbates marginalization and social exclusion, reduces access to healthcare, and limits educational and employment opportunities.

Considering the role of language, a central question emerges: can words truly convey or perpetuate stigma? Linguistically, one effective approach to reducing stigma is the use of person-first language instead of identity-first language. Studies have shown that person-first language (e.g., "people with schizophrenia") elicits more empathy and less social distancing than identity-first language (e.g., "schizophrenic person")[7–11]. Person-first language emphasizes the person rather than the condition and is aligned with anti-stigma principles that uphold individual dignity[11,12]. Its adoption has increased in recent years, and empirical evidence supports its effectiveness in reducing stigmatizing attitudes among those who use it[13–18]. Conversely, some studies have not found a correlation between the use of person-first language and a reduction in stigma[16,19], suggesting that previous experiences may play a larger role in perpetuating stigma than language alone. In the case of schizophrenia, individuals with lived experience frequently report that being defined by their diagnosis is offensive and dehumanizing, aligning with the person-first perspective[20,21]. Despite recent efforts, stigma against individuals with mental health conditions persists at various levels, ranging from self-stigma (also known as internalized stigma) to public and structural (or institutional) stigma[22–25]. These forms of stigma are interconnected and mutually reinforcing, and each can be shaped, at least in part, by the dominant language in medical and academic discourse.

An important, yet often overlooked, contributor to stigma is the language used in scientific research. Healthcare professionals play a crucial role in shaping perceptions of schizophrenia. Some studies have found that mental health professionals, compared to the general population, may hold more negative expectations and fewer positive beliefs regarding people with schizophrenia[3,12,26]. In this context, researchers and scientific publications become key influencers. Though academic literature is primarily read by other scholars, it serves as a foundation for educational materials, clinical guidelines, and public health communication, thereby indirectly influencing the public.

Previous content analyses have shown a predominance of identity-first language in literature on various conditions such psoriasis[27], HIV[28], hearing loss[29], amputation[30], and obesity[14,31,32].

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This applies even to psychiatric conditions, such as substance use disorders[13,15–18] and autism[33], highlighting the need for change. However, the field still lacks studies that specifically examine how schizophrenia is referenced in academic writing. Moreover, little is known about whether language use has changed over time or whether specialized journals are more aligned with anti-stigma guidelines.

Therefore, the objective of this study was to investigate how researchers refer to people with schizophrenia in a random sample of published articles. Specifically, we analyzed the terminology used to describe individuals with schizophrenia, aiming to provide a broader understanding of how stigma may be conveyed in academic discourse[2,7–9]. To our knowledge, this is the first paper to explore this issue specifically in schizophrenia research.

Our initial hypotheses were as follows:

1. The use of person-first language has increased over time in academic publications.

2. Journals specialized in schizophrenia research are more likely to use person-first language compared to non-specialized journals.

MATERIALS AND METHODS

Search strategy

An electronic search on PubMed was conducted on May 21, 2023, using the following terms: (schizophrenia [MeSH Terms] AND (Schizophrenia [Title])). We included articles solely in the English language, with no temporal or geographic restrictions. Along with the content validation attributed to the MESH classification, manual checks of articles ensured the relevance to schizophrenia research. No exclusion criteria were used other than the English language.

The database search yielded 55,525 records. After removing duplicates through the Rayyan platform, we randomized the articles into a list and randomly selected 1000 of them. We then selected the first 500 available for full reading. Fifty-five articles were not available online and, in these cases, we selected the next ones on the list.

Software development

We developed a keyword-finding software with the assistance of ChatGPT to extract data, using Python programming language and the PyCharm platform. The code was designed to read PDF files and conduct a scan to recognize specified keywords along with their contextual information. These keywords were variations of terms used to refer to individuals with schizophrenia (e.g., *schizophrenic, person with schizophrenia*). The software identified the three words preceding and the three words following each keyword, as well as all content from the chosen word up to the first full stop. The occurrences were documented in a Microsoft Excel spreadsheet.

To assess the accuracy of the code in identifying reference terms, we compared its results with manual data extraction. The manual extraction was made by two authors (M.D. and G.K.) independently, who conducted two rounds of review each assessing the same 20 articles. The software accurately identified all instances of the specified terms in scientific texts when compared to manual extraction.

Data extraction and statistical analysis

For each article, the following was extracted: title, year of publication, corresponding author's country, journal (specialized in schizophrenia research or not), and the terminology used to refer to individuals with schizophrenia.

We identified all reference terms used and then classified each one according to adherence to person-first language, guided by established guidelines (such as those from the American Psychological Association — APA)[2,7–9]. Each term was categorized as:

- Person-first (e.g., *individuals with schizophrenia*),
- Neutral (e.g., *schizophrenia patient*),
- Identity-first (e.g., *schizophrenic patients*).

(See Table 1 for examples).

We classified as person-first those expressions that emphasize the person rather than on the condition. Terms like "person with schizophrenia" were classified as person-first, while phrases such as "patient with schizophrenia" or "subject with schizophrenia" were considered neutral, as they emphasize the clinical or research role over the individual. Terms found exclusively in the references section were excluded from the count, as they do not reflect the authors' own language choices.

Each article was ultimately categorized according to its overall language use, based on the most frequently used term type. The classification was determined using the mode of occurrences within each article.

Finally, to examine temporal trends, articles were divided into tertiles by publication year (1951–2005, 2006–2013, and 2014–2023) and the journals were classified as either specialized in schizophrenia research or non-specialized, according to their editorial scope.

The decision to stratify the data into tertiles aimed to create three equally sized groups, ensuring enough articles in each for robust analysis. Also, the 1951 baseline was not predefined but rather reflects the earliest record retrieved in our search, as no time restriction was applied to the database query.

We analyzed the data using SPSS software (version 21), explored the distribution of all study variables, and checked the normality of the distribution of the sample size using the Shapiro–Wilk test. None of the variables presented a normal distribution, therefore we performed non-parametric tests. The Mann–Whitney U test and the Kruskal–Wallis H test were employed to evaluate differences across groups based on continuous or ordinal variables. Specifically, the Mann–Whitney U test was applied for comparing two independent groups (journal type), while the Kruskal–Wallis H test was applied to assess differences among three or more independent groups (publication periods). Chi-square tests were conducted to examine the association between categorical variables. P values < 0.05 (two-tailed) were considered statistically significant.

Table 1. Classification of terms used to refer to individuals with schizophrenia.

Classification	Reference terms examples
Person-first	Individuals with schizophrenia; People with schizophrenia; Person with schizophrenia; People living with schizophrenia
Neutral	Schizophrenia patients; SCZ patients; Patients with schizophrenia; Subjects with schizophrenia; Participants with schizophrenia; Schizophrenia group
Identity-first	Schizophrenics; Schizophrenic patients; Schizophrenic subject; Schizophrenic group

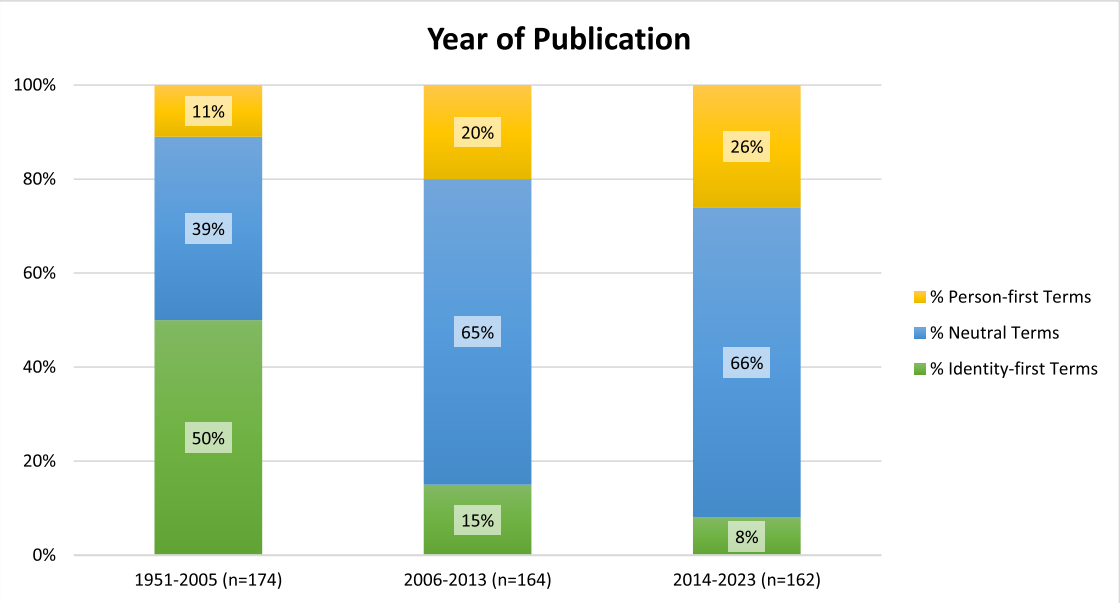

Fig. 1 The distribution of reference terms used to describe individuals with schizophrenia, categorized into three publication periods. The terms are grouped into three categories: Identity-first terms; Neutral terms, and Person-first terms.

RESULTS

Sample characteristics and classification of reference terms

We included 500 articles published from 1951 to 2023, categorizing the periods of publication into three tertiles: 1951–2005 ($n = 174$; 34.8%), 2006–2013 ($n = 164$; 32.8%), and 2014–2023 ($n = 162$; 32.4%). A total of 86 articles (17.2%) were published in journals specialized in research on schizophrenia.

Among the 500 studies analyzed, the vast majority (475 articles, 95%) employed some form of reference term when describing individuals with schizophrenia, while the remaining 25 articles (5%) did not use any specific addressing term. Of the 475 studies that included reference terms, nearly half adopted identity-first language (238 articles, 50.1%), while a slightly smaller proportion adopted person-first language (228 articles, 48%). A smaller subset of articles adhered strictly to one terminology: 23 articles (4.8%) used person-first terms exclusively, and 46 articles (9.7%) relied solely on identity-first language. We used the most frequently used term type (e.g., the mode) as representative for the analysis.

Temporal and journal-based trends in language use

Regarding the year of publication (Fig. 1), the period 1951–2005 accounted for the highest percentage of use of identity-first terms (50.1%), followed by the period 2006–2013 (15.2%) and 2014–2023 (7.8%) ($H(3) = 124.70$, $p < 0.001$). The highest percentage of use of person-first terms occurred in the period 2014–2023 (26%), followed by 2006–2013 (19.6%), and finally 1951–2005 (11.1%) ($H(3) = 34.71$, $p < 0.001$). Supplementary material also provides information about changes in reference terms over the years.

Regarding the type of journal, non-specialized journals employed a higher percentage of identity-first terms (26.4%), compared to specialized journals (18.6%) ($U = 13.28$, $p = 0.016$). As for person-first terms, non-specialized journals showed a lower percentage (18.0%) compared to specialized journals (21.7%), but this difference was not statistically significant ($U = 16.32$, $p = 0.618$).

Over time, we found a predominance of identity-first terms in both types of journals until 2005 (49.0% in specialized journals and 52.2% in non-specialized ones) (Figs. 2 and 3, and Supplementary Material 1). From 2006 to 2013, there was a significant increase in the use of neutral terms replacing identity-first ones compared to the previous period, especially in journals specialized in schizophrenia research (4.86% identity-first versus 74% neutral). Finally, from 2014 to 2023, specialized journals increased their use of identity-first terms to 12.0%, while non-specialized ones reduced their usage to 6.25%. In this period, the usage of person-first was similar in both groups.

DISCUSSION

Identity-first language was used in half of the papers and showed a declining trend over time, while person-first language became increasingly prevalent. Indeed, the first period (1951–2005) contrasts markedly with the most recent one (2014–2023), underscoring substantial progress achieved in the field. This finding supports our first hypothesis, which posited that the use of person-first language would increase over time in academic publications. Journals focused on schizophrenia did not significantly differ in terminology use compared to general psychiatry journals, contrary to our second hypothesis that journals focused on schizophrenia would be more likely to use person-first language. A noteworthy caveat is the increase to 12% in the use of identity-first language in the most recent period among journals focused on schizophrenia. Consequently, our second hypothesis was not supported, even though the observed trend was aligned with the predicted direction.

Some guidelines, such as those from the APA[34,35], have already adopted the person-first perspective, and our results may reflect the positive impact of this discussion and the role of formal recommendations. The APA formally endorsed person-first language in its Publication Manual starting in the 6th edition (2009) and reaffirmed this stance in the 7th edition (2019), which influenced broader academic standards in psychology and health sciences. Similarly, the World Health Organization and the U.S. National Institute on Drug Abuse have published recommendations encouraging non-stigmatizing and person-centered terminology in the last decade. These milestones provide context for interpreting the observed trends in literature.

Our study categorized publication years into three distinct periods. The first period (1951–2005) encompasses both the years preceding and the initial emergence of person-first language

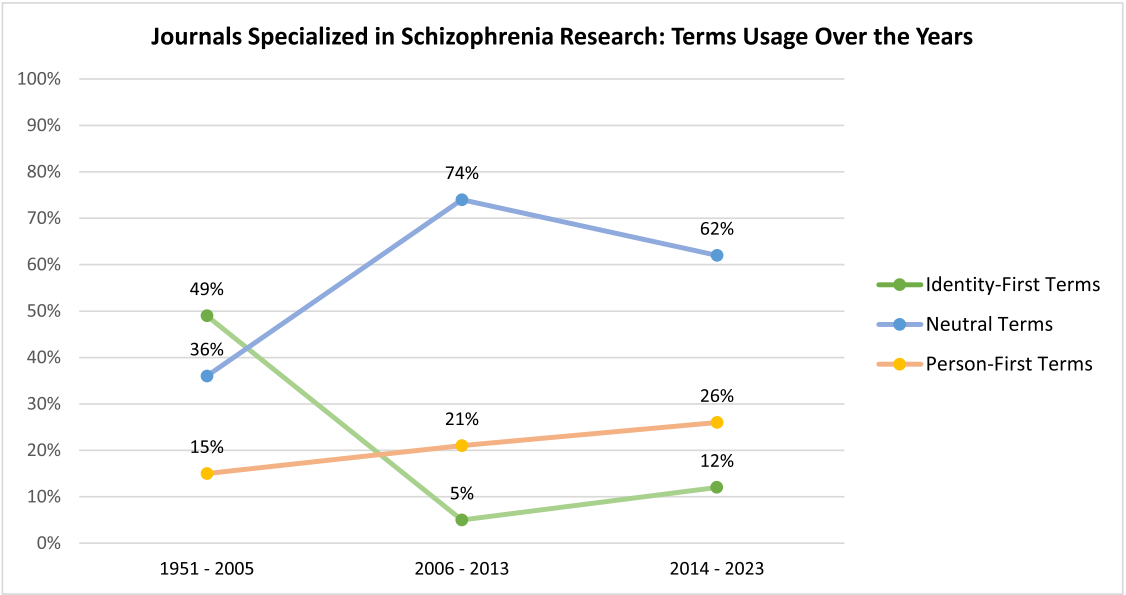

Fig. 2 Distribution of reference terms used by journals specialized in schizophrenia research across three publication periods. Identity-first terms declined sharply after 2005, while person-first and neutral terms showed a gradual increase.

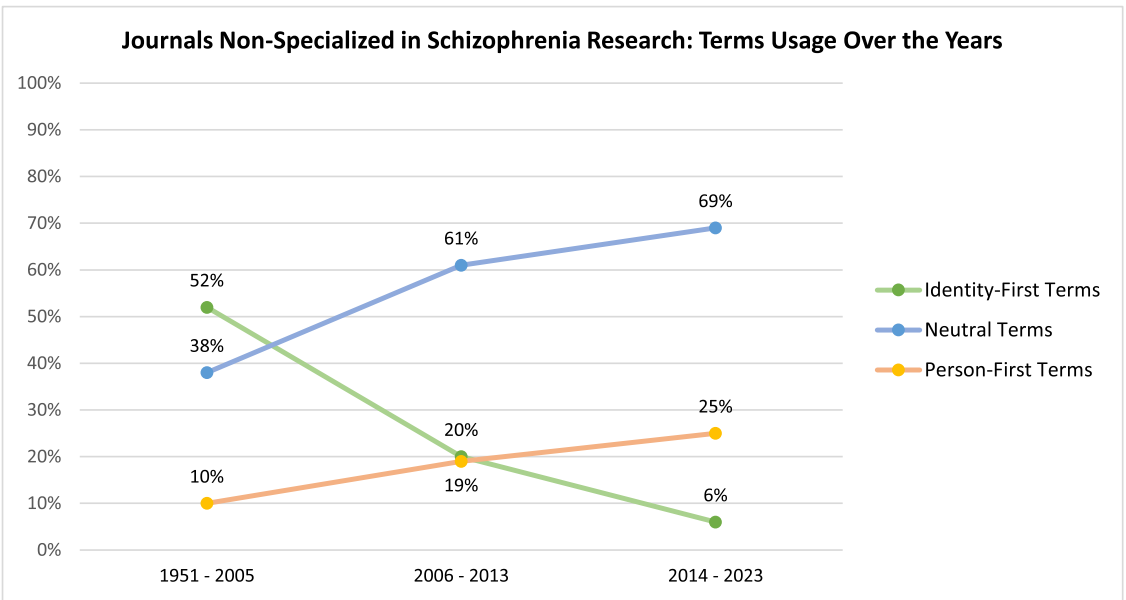

Fig. 3 Distribution of reference terms used by journals non-specialized in schizophrenia research across three publication periods. Identity-first terms show a steady decline, while neutral and person-first terms gradually increase over time.

advocacy. While the person-first approach began to take shape in the late 20th century (particularly throughout the 1970s and 1980s) it was not formally codified in major institutional guidelines until the early 21st century. The second period (2006–2013) corresponds to a phase of expanding institutional support, marked by endorsements from disability rights organizations and academic publishers. This shift is evident in the evolution of language guidelines, most notably in those issued by the APA, which explicitly advocated for person-first language. Importantly, we observed a notable decrease in the use of identity-first language from the first to the second period, suggesting that growing awareness and institutional support may have begun to influence academic terminology.

The third period (2014–2023) is characterized by a continued, although less pronounced, increase in the use of person-first terminology, reflecting the broader institutionalization of inclusive language practices. For example, in 2021, the U.S. Preventive Services Task Force (USPSTF) committed to using person-first and non-stigmatizing language in all recommendation statements, research plans, and public communications[36]. This broader cultural and institutional shift likely contributed to the sustained integration of inclusive language in academic publishing. An important caveat is the observed increase in identity-first language in the most recent period within journals focused on schizophrenia. We attribute this, in part, to the growing influence of a biologically oriented perspective, which may prompt authors to adopt identity-first terms aligned with diagnostic categories (e.g., "schizophrenic patient"). Nonetheless, continued examination of the linguistic practices employed by these journals is warranted.

One issue that warrants further discussion is the category we proposed as neutral reference terms. Would it be more appropriate to emphasize the importance of avoiding any identification of individuals by their diagnosis[37], or would that be excessive? Should this neutral category instead be reclassified under person-first language? We chose to maintain a separate category to allow for a more nuanced discussion. We included expressions such as "patients with schizophrenia" in this category, as the term "patient" can, within the healthcare system, be used to refer to a person's identity, even though it denotes a social role that an individual may occupy only during a specific period of their life. Moreover, we believe that answering this question requires a specific investigation to understand how people with lived experience perceive these terms, and whether such distinctions influence stigmatizing practices.

We also recognize several limitations in our study. Although we attempted to examine geographical differences in the origins of the articles, our analysis was limited by data constraints, resulting in a predominance of European and North American studies and fewer from Africa, Central and South America, and Asia. Additionally, as this is the first study to address stigma on schizophrenia in the language used in scientific journals, specific consensus definitions do not exist, which may benefit from further discussion. We followed the consensus and best evidence of stigma recommendations developed for society in previous studies, adapting to the context of researchers[2,3,7–9]. We selected 500 random studies for analysis to generate a feasible and unbiased sample. While this may limit the number of studies included, it allows for more manageable and accurate manual evaluation. While we have emphasized the shift in language as a positive step in anti-stigma campaigns, we acknowledge that linguistic change is only one component of a broader framework required to effectively reduce stigma.

Based on our findings and on person-first movement principles, we suggest the following recommendations for future studies on schizophrenia:

1. To adopt the person-first approach. In this sense, we suggest that the term "schizophrenic" should be discouraged by editors of scientific journals, by incorporating this criterion into author guidelines.
2. Whenever possible, research should seek to include representatives of people with lived experience, giving them a voice in the conception, conduct, and dissemination of studies. A feasible way to achieve this is through the implementation of focus group discussions with individuals with schizophrenia, allowing their perspectives to be directly incorporated — for instance, in the ongoing debate on terminology and the role of language in either reinforcing or reducing stigma in research writing. A second approach is in the emerging discipline of citizen science for mental health[38], which involves public engagement in scientific research activities, and has transformative potential for mental health research[39].

In conclusion, while the stigma reduction movement has contributed to positive shifts in language use over time, the persistence of negative labels in research on schizophrenia underscores the need for continued efforts to address not only terminology but also underlying biases in scientific discourse. Future studies should expand sample sizes and incorporate nuanced analyses to capture subtler aspects of this phenomenon, such as how authors' professional backgrounds may influence terminology used. As researchers, we must critically examine the impact of language in shaping perceptions and outcomes. Given that academic publications serve as a vital reference for opinion leaders, the absence of discussion on this topic highlights the urgency of fostering a broader debate on how language influences both scientific narratives and real-world experiences in schizophrenia.

DATA AVAILABILITY

All data are available for scientific purposes by request.

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AUTHOR CONTRIBUTIONS

M.D. and G.K. share first authorship. M.D., G.K., A.Y., B.H., and A.G. contributed to the conceptualization of the study. M.D., G.K., A.Y., and I.P. conducted the literature search and screening. M.D. developed the keyword-finding software and data processing tools. C.Z., M.D., G.K., B.H., and A.G. performed the statistical analysis and interpretation of results. M.D. and G.K. carried out the manual data extraction. M.D., G.K., A.Y., B.H., and A.G. participated in the writing of the manuscript. R.B., N.C., J.O., G.T., M.S., J.J.M., S.E.L., and M.C.R.A. provided critical review and revisions. A.G. gave final approval of the manuscript. All authors have read and approved the final version of the manuscript.

COMPETING INTERESTS

The authors declare no competing interests.

ADDITIONAL INFORMATION

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