

What's in a Name? A Scoping Review of Preferences for Person-First, Identity-First, and Other Models for Naming Serious Mental Illness and Disability

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Background

Context:

- Various language models, including Personal First Language (PFL), Identity First Language (IFL), mad studies, and the Consumer/Survivor/Ex-patient (CSX), voice hearing and neurodiversity movements are used by professional organizations to describe people diagnosed with serious mental illness (SMI).
- However, the preferences of those with lived experiences are unclear.

Study Objectives:

- This study aims to conduct a scoping review on language models, focused on identifying literature about the preferences of those with SMI to prevent stigma and discrimination.

Methods

Setting and Subjects:

- Literature included peer-reviewed research, Master's/undergraduate honors theses, dissertations, published reports, and opinion articles
- Related to mental illness or disabilities
- Literature reviewed were published between 1980-2021

Three searches were conducted using four databases

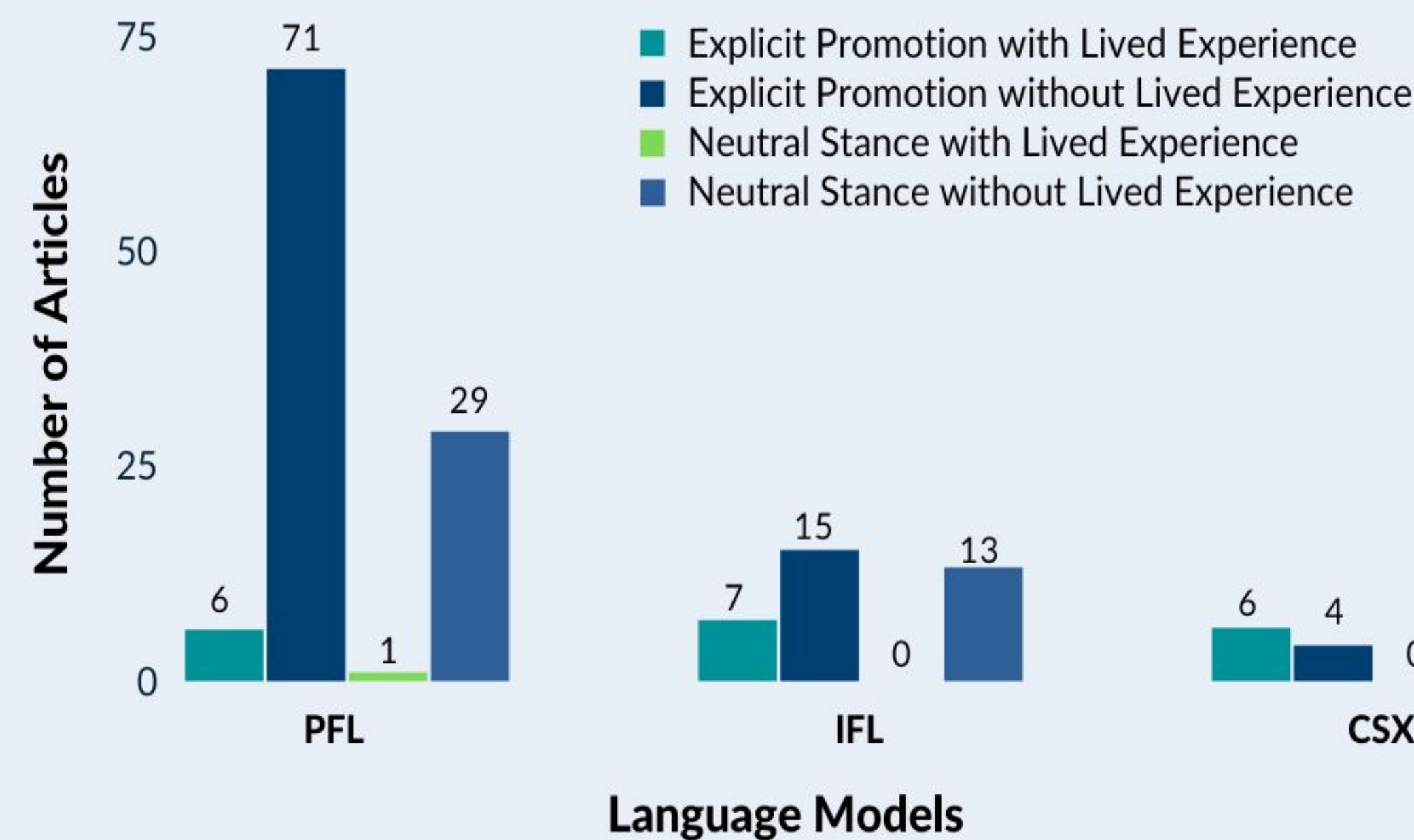
Search 1 identified articles using PFL and IFL to describe SMI or disabilities

Search 2 identified language models besides PFL and IFL

Search 3 targeted non-peer-reviewed blogs aiming to increase representation of people with lived experience

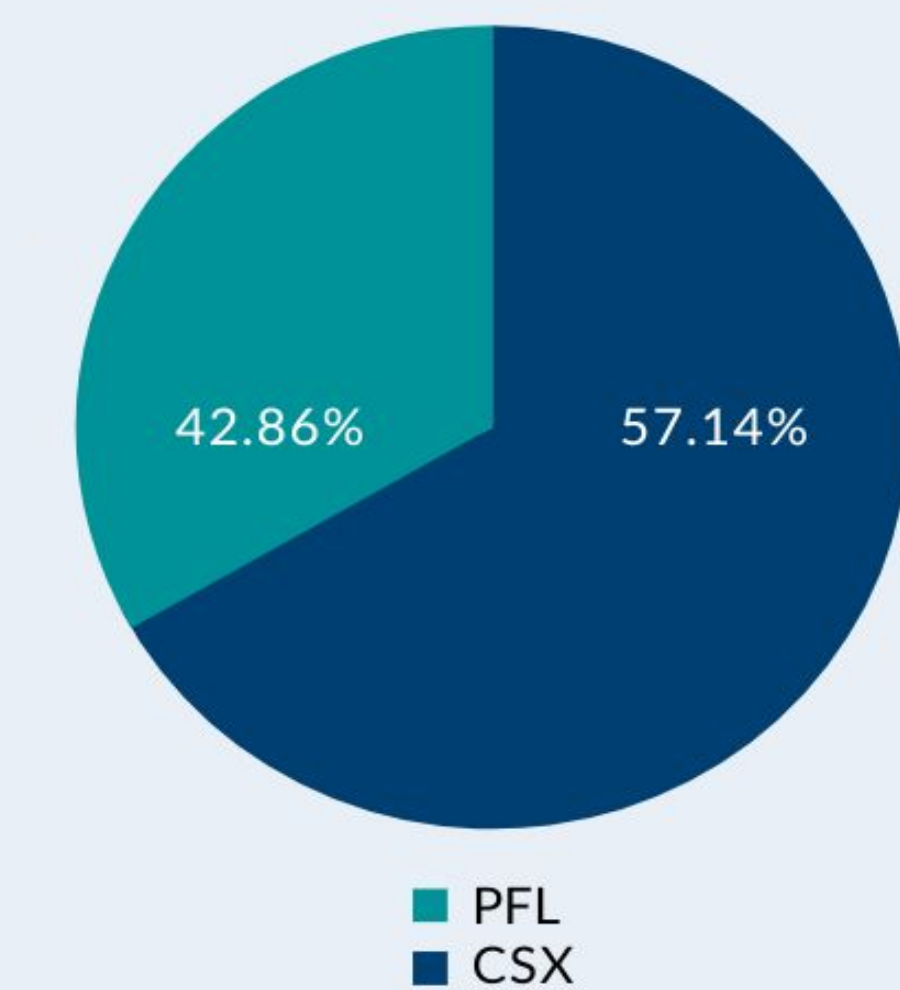
Results

Endorsement of Language Models By Authors With and Without Reported Lived Experience



- 136 articles were reviewed
- The predominant language model was PFL (107), followed by IFL (35), and CSX (11)

Explicit Promotion of Language Model In Articles About SMI



- 7 articles were found about SMI
 - Inclusion criteria: articles specifically identify the population as those with SMI, schizophrenia, psychiatric disabilities, or psychiatric survivors

Examples of Language Models

PFL

“person with schizophrenia”
“person living with a disability”

IFL

“schizophrenic”
“deaf”
“disabled person”

CSX

“psychiatric survivors”
“survivor(s)”
“customer”

Conclusion

- Language preferences of people with SMI and of lived experience perspectives are understudied in peer-reviewed literature.
- Lots of authors who call for PFL are authors without lived experience.
- However, in literature, PFL doesn't seem like what the majority of those with SMI want.
 - The majority of those with SMI prefers CSX (4 out of 7 articles).
- Future research should consider why people with lived experience prefer models besides PFL and IFL.