

«I'M STILL HERE AND MY OPINION MATTERS»: A SCOPING REVIEW ON THE EXPERIENCE OF EPISTEMIC INJUSTICE AMONG PEOPLE LIVING WITH DEMENTIA

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INTRODUCTION

The concept of "epistemic injustice" (Fricker, 2007) refers to a partial or complete exclusion of certain categories of people from the construction of knowledge.

Two main forms have been identified:

- **Testimonial injustice** (a person's testimony is not given credibility because of the listener's biases);
- **Hermeneutic injustice** (a person or group of people struggle to communicate their experiences because society is unable to understand their perspective)

People living with dementia (PLWD) are particularly vulnerable to epistemic injustice because of the cognitive, emotional and social aspects related to their condition and this may negatively affect their quality of life.

OBJECTIVES

- Exploring how epistemic injustice (EI) affects the experience of people with dementia (PLWD);
- Understand its impact on the quality of life of people with dementia.



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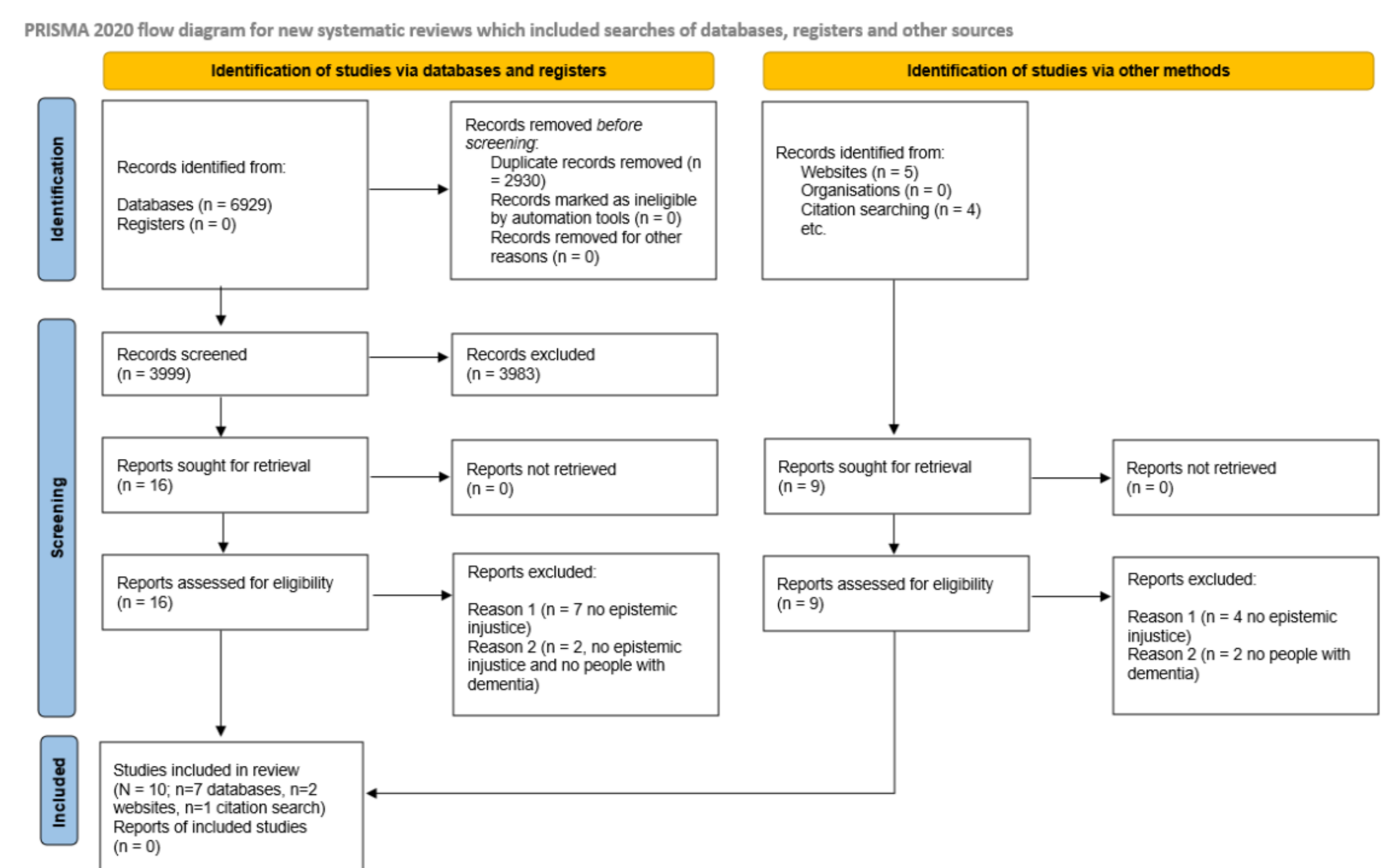
Take home message

**Too often studies talk ABOUT people with dementia,
but do not talk WITH people with dementia**

MATERIALS AND METHODS

Peer-reviewed studies and studies from the grey literature analysing the relationship between EI and the experience of PLWD in different contexts were included.

Searches were conducted on major databases (Web of Science, Proquest, PubMed, Scopus, EbscoHost) and in grey literature (Open Alex, AlmaStart Discovery Tool) in November 2024. Two independent reviewers selected abstracts and full-texts. Subsequently, a thematic analysis was conducted.



RESULTS

Ten studies were included (7 peer-reviewed articles, 2 from the grey literature and 1 from the bibliographies of the included studies).

Methodological heterogeneity was high, with most of the studies (n = 7) characterised by theoretical reflections.

Epistemic injustice emerged in various contexts (theoretical and methodological perspectives, participation in research, inclusion at the institutional level, Anticipated Treatment Provisions - DAT)

DISCUSSION

The review highlighted the variety of contexts in which the presence of IE can be observed.

Most of the studies are theoretical and do not directly interview PLWD. To date, no specific indicators have been identified to describe this phenomenon and studies have mainly been conducted in Europe over the last ten years.