

Strengths, Gaps, and Future Directions on the Landscape of Ethics-Related Research for Spinal Cord Injury

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Objectives

- To characterize the landscape of academic publications pertaining to ethics-related variables in SCI.
- To identify gaps in ethics-related research to support better person-centred design and reporting.

Background

- The medical aspects of SCI have received considerable attention in the academic literature, but discourse pertaining to the ethical implications of SCI is limited.
- An intersectional approach to ethics research in SCI is essential as experiences of affected individuals are shaped by factors such as race and gender.

Methods

Search strategy: Key terms pertaining to SCI and ethics in academic literature (2012-2021) in PubMed and Google Scholar databases.

Data extraction: Year and country of publication, article foci, research and recruitment methods, participant demographics, and key findings.

Content analysis of ethics-related discourse: Content analysis methods (Saldana, 2012) were used to code for *a priori* and emergent ethics discourse.

Results

70 papers met inclusion criteria.

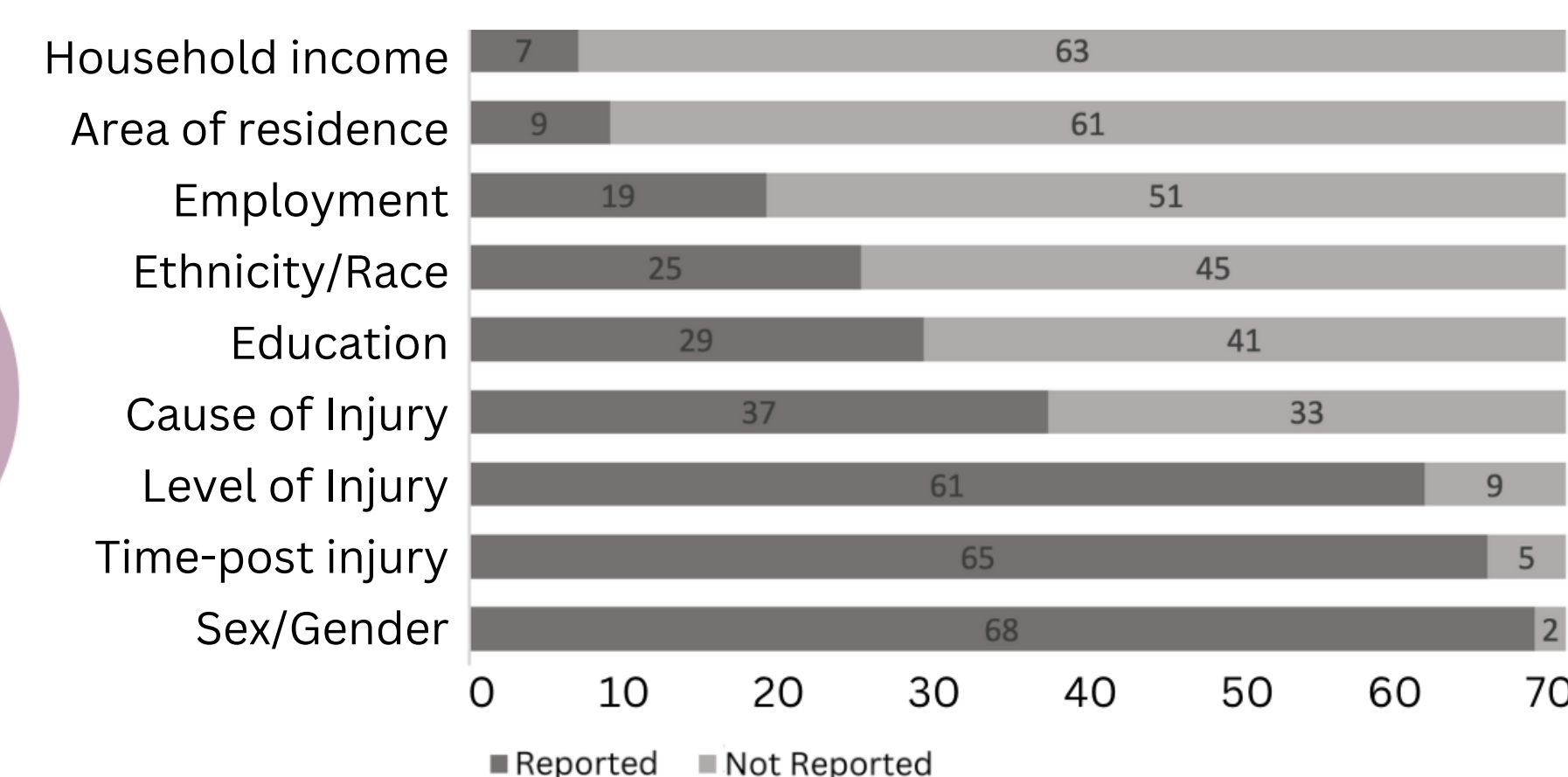
Majority **qualitative studies**
Qualitative (N=47), quantitative (N=19), mixed methods (N=4)

Publications from **21 countries**
Majority from US (N=17), Canada (N=11), Australia (N=7)

MAJOR FOCI



DEMOGRAPHIC VARIABLES



ETHICS DISCOURSE

Key themes:

Relationships (62%)	Knowledge (44%)
Access (53%)	Divergent values (43%)
Intersectionality (46%)	Independence (43%)
Identity (45%)	Justice (39%)

*Percent of total publications (x/70)

- Role of **relationships** in the lives of individuals with SCI was the most reported ethics-related theme.
- Intersectionality** mainly focused on differences in experiences based on sex and gender.
- Divergent values** related to conflicting views between patients and healthcare providers.
- Independence** was more frequently discussed than autonomy. These terms were often conflated.

Discussion

- Increased reporting of all participant demographic variables** related to health outcomes and experiences would enrich this body of literature.
- Range of ethics-related discourse identified reflects the **breadth of ethical implications in SCI**, with relationality as a key ethics-related theme.
- Future neuroethics inquiry may explore the theoretical and practical **distinctions between autonomy and independence** in the SCI context.