Using the COM-B Model and Theoretical Domains Framework to understand disclosure experiences, influencers, and needs among autistic youth and young adults

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Background

- Deciding whether to disclose being autistic or one’s autism-related needs at work is mentally taxing and involves calculated considerations.1
- Canadian autistic youth and young adults are understudied regarding how they navigate disclosure and what they need to support disclosure decisions, as well, the potential role of gender on disclosure.

Objectives

To explore and understand the workplace disclosure experiences, influencers, and needs among Canadian autistic youth and young adults and compare across genders.

Methods

Data Collection

- Generic qualitative design with six online focus groups (two-to-five participants per group), using Zoom web-conferencing software.
- Used the COM-B (Capability, Opportunity, Motivation, Behaviour) Model1 to guide focus group questions.

Participants

- Eligibility Criteria: Aged 15-29, had autism diagnosis, paid employment experience, no comorbid visible disabilities, lived in Canada, and spoke English fluently.
- Sample (n = 23):
  - Mean age = 22.8 years
  - 13 men, 8 women, 1 transman, 1 transwoman
  - 10 employed part-time, 2 full-time, 11 unemployed

Analysis

- Deductive thematic analysis, on NVivo 12, using the Theoretical Domains Framework.3

Results

- Participants discussed the role of, and disclosure needs around concepts from 13 of 14 TDF domains, organized into five themes.
- The TDF domain of environmental context and resources was discussed the most and optimism was discussed the least.

Disclosures influencers, needs, and experiences related to the theoretical domains framework

Workplace Environment

- TDF domains/subthemes
  - Environmental context and resources
  - Social influences
  - Workplace needs
- Examples: Workplace culture, job roles, needing workplace accommodations

Perceptions of Disclosure Outcomes

- TDF domains/subthemes
  - Beliefs about consequences
  - Optimism
  - Emotion
- Examples: Discrimination, fear, increased acceptance and understanding

Personal Factors & Identity

- TDF domains/subthemes
  - Social & professional role and identity
  - Beliefs about capabilities
- Examples: Autism identity, intersectional identities, disclosure confidence

Disclosure-Related Ambitions and Determination

- TDF domains/subthemes
  - Goals
  - Intentions
- Examples: To educate others about autism, to receive accommodations, intentions of when to disclose

Know-Hows of Disclosure

- TDF domains/subthemes
  - Knowledge
  - Skills
  - Behavioural regulation
  - Decision-making processes
- Examples: Disclosure logistics & experiences

Discussion

- Results provide newfound understandings into the vast, highly individualized disclosure needs of autistic youth and young adult.
- This work can inform future research, practice, and development of tools, supports, and interventions to support autistic youth and young adult clients.

Limitations

- Participants self-disclosed their autism.
- Excluded those who did not have access to technological devices and/or internet and did not speak English.
- Only 23 participants and in Canada – broader applicability should be approached with care.

Future Directions

- Explore, in greater depth, the role of gender and other intersectional identities on disclosure decisions.
- Develop tools/supports (e.g., decision-aid) for autistic youth and young adults with components informed by behaviour-change strategy categories, which link to the TDF domains.
- Targeting employer level factors via industry-specific training to increase autism knowledge and create inclusive environments that foster disclosure conversations.
- Disseminate findings across professionals who support autistic youth and young adult clients.

References


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