Critical analysis of distress management in individuals with IDD and impacts for suicide prevention

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Introduction

Generally speaking, distress is described as an emotion, a thought, or a behavior that appears in connection with a stressful life event and that interferes with the person's ability to cope with it.
Distress is a complex emotional state, often poorly described and understood, especially in people with IDD.

Studies of distress in people with ID or ASD provide very few explicit definitions of distress, rarely considering it outside of a diagnosis of a mood disorder. Several studies indicate that people with ID or ASD have characteristics that make understanding distress more complex than with the general population, such as:

- emotional regulation issues
- non-verbal signs of distress that can be varied and difficult to interpret
- specificities of comorbid mental disorders
- and association with externalized symptoms (disruptive behaviors).

While awareness has increased of the fact that people with IDD exhibit suicidal behaviors (SB) at an equa or greater prevalence than the general population has increased, the emotional, social, physical distress that usually accompany these SB is still poorly understood, and its assessment is often mainly based on observable behavior.

Objective

This critical review aims to explore the ways **distress is defined, measured and acted upon** in individuals with IDD and to analyze the impact this has on our understanding of suicide risk and its prevention in these populations.

Methods

This critical review followed the Guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) : identification, screening, eligibility and inclusion.

databases queried: Pubmed and Psychinfo

The authors selected four principal key concepts:

- **Individuals with IDD**
- **Distress**
- **Quality of life**
- **Emotion management**

Grey literature and papers that were not reviews were not considered.

Inclusion criteria:

- The included papers had to be reviews;
- The main studied population had to present ID and/or ASD;
- The study had to directly or indirectly address distress
- Literature published until December 2021

A total of 4207 articles were identified, and 2021 were screened for relevance by title and abstract after exclusion of duplicates.

Seventy-three articles were read (full text) and 31 more were excluded according to the inclusion criteria.

41 reviews were included in the critical review.

Conclusion

istress as a construct in people with IDD is rarely defined and seems implicitly suggested when a mental health iagnosis is provided by a psychiatrist. This association may lead to a misunderstanding of various expressions of motional pain that are not validated by such diagnoses. Distress is also often observed through disruptive behavior hat is then targeted by behavioral interventions. These interventions, by concentrating on behaviors instead of the nderlying emotional distress, may reinforce said distress.

his partial and largely behavioral conception of distress has significant impacts on the understanding of suicidal risk individuals with IDD. When assessment is centered on observable behavior, and interventions on the isappearance of disruptive behavior, we may miss the emotional burden of distress and subsequently increase uicidal risk.

ecommendations:

- Properly define distress as a construct in people with IDD that includes emotional, cognitive and social dimensions, irrespective of psychiatric diagnosis.
- Assess the validity of existing distress assessment measures for people with IDD
- Design distress assessment measures specifically for people with IDD
- Develop effective intervention strategies for distress in people with IDD that do not only target behavioral symptoms.
- Offer better training for clinicians in order to recognize specific signs of distress in people with IDD as well as underlying causes.

Results

The 41 reviews in this analysis were categorized into **three complementary domains** of research on distress in individuals with IDD:

Description of distress (N=19)

In general, the studies included defined distress as the presence of a mental health diagnosis. This was in fact often an inclusion criterion. It is therefore interesting to note that in most cases, manifestations of distress were only considered if they presented as clinically significant.

Other ways that distress was identified:

- **Standardized questionnaires**
- **Participant interviews**
- **informant interviews**
- **Participant medical history consultation.**

There was often more than one method of identifying distress included in each review. Methods used to define or understand distress were varied but all lacked in precision. Definition of distress was often associated with the way to measure it.

Included dimensions of distress:

- **Mental health diagnosis: Depression, Anxiety, Psychosis, etc.**
- **Quality of Life**
- **Behavioral problems**
- **Physical health**

Distress as a construct in research with individuals with IDD was rarely defined.

Evaluation of distress (N=11)

Most included studies aimed to identify standardized instruments that evaluate mental health conditions in people with IDD, or explored adapting existing instruments to an IDD population. **No study identified specific tools or processes designed to assess distress as a construct independent from diagnosis in people with IDD.**

In many cases, distress was included as a dimension opposite satisfaction in overall quality of life questionnaires:

- **Lifestyle Satisfaction Scale (Heal & Chadsey, 1985)**
- **Quality of Life Questionnaire (Brown & Bayer, 1992)**

Recommended instruments were often over 20 years old, and the reviews proposed no newer, more validated alternatives. For example, the following instruments were designed for a typical population and adapted or simply used with IDD participants:

- **Reiss Screen for Maladaptive Behaviour (Reiss, 1988)**
- **Anxiety, Depression and Mood Scale (ADAMS; Esbensen et al., 2003)**

In most cases, the identified instruments relied on third-party observation or informant reports. The participant with IDD was rarely interviewed directly.

Distress in individuals with IDD rarely seems to be evaluated as an independent construct.

Interventions for distress (N=11)

In the included reviews, the following were investigated as an intervention for distress in people with IDD:

- **meaningful occupation**
- **dance and exercise programs**
- **anger management treatments**
- **treatment for anxiety with a CBT protocol**
- **third-wave therapies**
- **antidepressant and antipsychotic medication**
- **Staff training**

These interventions usually targeted observable behaviors or diagnosed symptoms via behavioral o pharmaceutical methods.

They also often measured the effectiveness of the interventions through the reduction of these observable behaviors or diagnosed symptoms, and did not include measurements of psychological wel being. Distress was therefore often equated to, and addressed as a behavioral problem.

Notably, the review examining a CBT protocol for anxiety was the only study that did not include a measure of problem behaviors as a marker for effectiveness.

Distress as a construct in individuals with IDD is rarely targeted through intervention without the presence of diagnoses or problem behaviors.

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