

- **Name of the study:** Professionals' Perceptions of the Needs of Individuals with Intellectual Disabilities Coping with the Loss of a Close Person
- **Year:** 2024
- **Type of research:** thesis
- **Catalog Number:** 890-660-2021
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### Abstract

#### **This work was supported by a grant from Shalem Fund**

The life expectancy of people with developmental intellectual disabilities (ID) has increased in recent years, and as a result, many more of them live to experience death and the loss of their relatives. Faced with the concept of death, people with ID experience distress and show signs of mourning, as do people with typical development. Despite the recognition of the importance of grief processing procedures to reduce distress, and the broad agreement regarding the need for equal participation of people with disabilities in all areas of life, studies indicate a lack of emotional support for people with disabilities who experience the loss of a loved one, and their exclusion from mourning rituals.

The purpose of the study is to examine the personal and professional factors that contribute to professionals' perception of the emotional and practical needs of people with ID and their intention to integrate them into grief processing procedures.

In the study, 154 staff participated, including medical, treatment and nursing professionals who care for people with ID. The participants were asked to answer questionnaires concerning knowledge about the perception of death among people with ID, attitudes towards people with ID, fear of death, and professional ambiguity, and a questionnaire examining the professionals' perception of the emotional needs of people with ID and their intention to include them in grief processing procedures.

The research findings indicate that knowledge about the understanding of death among people with ID, and attitudes towards disability, are associated with a clear positive relationship with the professionals' intentions to provide emotional support to people with ID who have experienced loss and to integrate them into mourning ceremonies. As for the feeling of professional ambiguity experienced by professionals, it was found to hold a distinctly positive relationship with their intention to include people with ID in mourning ceremonies.

The first and second research hypotheses said that the way in which professionals perceive how people with ID understand the concept of death will be positively associated with (1) the perception of their emotional needs after the loss of loved ones, and (2) providing a mental and practical

response to deal with it. These hypotheses were confirmed: A positive relationship was found between professionals' knowledge about how people with ID understand death, and perception of their emotional needs and intention to provide a mental and practical response. The third and fourth research hypotheses assumed that participants' general attitudes towards people with ID will correlate with their perception of patients' emotional need and their willingness to provide mental and practical care to patients facing loss. These hypotheses were also confirmed. A positive relationship was found between the attitudes of professionals and the perception of their emotional needs and their intention to provide a mental and practical response. The fifth and sixth research hypotheses said that a negative relationship would be found between a professional's personal fear of death and his perception of ID peoples' emotional needs in the loss of their loved ones, and providing a mental and practical response to deal with it. These hypotheses were not confirmed: no connection was found between fear of death and perception of needs and provision of mental and practical response. The seventh and eighth research hypotheses, which said that there would be a positive relationship between the role ambiguity of professionals and the perception of ID peoples' emotional needs in the loss of their loved ones and the provision of mental and practical response to deal with it, were partially confirmed. A positive relationship was found between the feeling of role ambiguity and the provision of a practical response, but no relationship was found between role ambiguity and the perception of ID peoples' emotional needs and the provision of an emotional response. The ninth research hypothesis assumed that the way in which professionals will perceive the emotional needs of people with ID will mediate the relationship between the personal and occupational variables (knowledge about understanding death, attitudes, fear of death and a sense of role ambiguity) and their intentions to provide them with a mental and practical response to deal with the loss. The hypothesis was confirmed, because the perception of emotional needs mediated between the factors: understanding of death, attitudes and the feeling of ambiguity and the professionals' intentions to provide a mental and emotional response.

This study is one of the first to examine variables that positively contribute to the inclusion of people with ID who have experienced loss in grief processing procedures. The research findings point to the importance of personal and occupational factors that contribute to professionals' perception of the emotional needs of people with ID, with an understanding of the importance of their participation of people with disabilities in loss processing procedures, as people without ID. At the theoretical level, the research adds a layer to the understanding of the promoting factors and barriers to integration of people with disabilities in the public sphere. At the applied level, insights that emerged from the research findings may be helpful in promoting training practices, teaching and implementing organizational policies for people with ID, enriching the profession of caring for people with mental disabilities throughout the life cycle in general, and in situations of loss in particular.

## **Keywords**

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death of a close person, professionals, knowledge of the concept of death, attitudes, role ambiguity, fear of death.

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