

☼ **Name of the study:** Life stories Narratives of Adults with Dual Diagnosis of Intellectual Disability and Mental Disorders: Personal Identity, Quality of Life and Future Orientation

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Abstract

The main purpose of the current study was to examine the narratives of life stories told by adults with dual diagnosis of intellectual disability and mental disorders, through the aspects of: personal identity, quality of life and future orientation. There were 12 participants with dual diagnosis of intellectual disability and mental disorders of schizophrenia and personal disorders, who reside in assisted living.

The research model is based on the "Three Function Model of Autobiographical Memory" (Pillemer, 2003; Bluck, Alea, Habermas, & Rubin, 2005; Harris, Rasmussen, & Berntsen, 2014) which is taken from the domain of cognitive psychology. The model presents three functions which are used in autobiographical memory, upon which the life stories are formed: the first function is identity-the memory of events from the past, assisting the person to understand himself as a consistent individual. The second function is communication and society-remembering events from the past and expressing them in a narrative way in front of significant others, all of which assist in developing significant social ties, which contribute to the improvement of the quality of life. The third function is learning and planning the future-in which autobiographical memory constitutes a basis for the building of a life story (Banks & Salmon, 2018) and it is used as a way to draw some conclusions for solving contemporaneous problems as well as to plan the future on the basis of the lessons of the past.

The method of the research was Narrative qualitative by applying a semi built-in interviews, aiming at drawing out of them the life stories of the participants, in affinity to three focuses: personal identity, their life quality in the present and their future orientation. In the research we used the "Peabody Test" (Dunn & Dunn, 1997) and the Raven Test (Raven, Court, & Raven, 1977) for testing basic cognitive abilities. The analysis of the findings was conducted in three stages (Shkedi, 2003; Tracy, 2019): the first analysis stage, the mapping stage and the theoretical analysis-the stage of the themes. The first stage of the analysis raised a chronological division of the stories according to three central periods of life (childhood, adolescence and

adulthood). In the mapping stage there was a process of focusing and organizing the general categories that were found in the first stage, with the goal of finding some connections between them and understanding their relationship. In order to validate the findings that were derived in the mapping stage, and as a preliminary process for the third stage of the analysis, the sayings of the tested in each and every category were counted, and statistical testings were done to the sayings in the different categories. The results of the two first stages of the analysis and the results of the statistical testing produced theoretical conceptualization which constituted the third stage of the analysis (the theoretical stage.) This led to the three central themes of the research: personal identity and disability awareness, contemporary quality of life and future orientation.

The questions of the research were framed on the basis of the research model and they were:

1. How the personal identity of adults with dual diagnosis has been reflected in their life stories?
2. What does the life stories of adults with dual diagnosis teach us about their contemporary quality of life?
3. What is the future orientation of adults with dual diagnosis?

The findings of the study revealed three main themes based on the research model: personal identity and disability awareness, contemporary quality of life and future orientation. From the perspective of personal identity -the mental disability is dominant in the personal identity of the participants and it was significantly higher than their awareness to the intellectual disability, which constitute a secondary component in their sense of identity. It is possible to explain this central finding by using the stigma model (Corrigan, 2004) which is composed of cognitive aspects (stereotypes), emotional aspects (prejudices) and behavioral aspects (discrimination) (Kenny, Bizumic, & Griffiths, 2018). This central finding is congruent with the research of viewpoints, that found that the intellectual disability is found at the bottom of the ladder of a social acceptance and encompasses a difficult social stigma which constitute a source of shame concealment and denial (Rasdale, Warman & Phalen, 2018; Gordon, Tantillo, Feldman, & Perrone, 2004). In the present research the participants preferred to assume upon themselves an identity of a person with a mental disorder and to deny the intellectual disability. The main reason for it is that the mental disability is considered by the public as a disability that can be treated, and sometimes it is considered less severe than an intellectual disability (Ditchman, Werner, Kosyluk, Jones, Elg & Corrigan, 2013).

From the perspective of contemporary quality of life, it has been found that an average of the sayings, indicating the positive attitude of the family and the friends in the present toward the participants, was higher in a significant way, from the average of the sayings indicating positive

attitude in the past. Also the attitude of the team of the caregivers was better in the present in comparison to the one in the past. Hence, we concluded that the life quality of the participants of the research is much better in the present in comparison to the past. The central explanation for this is based on the disability paradox theory (Fellinghauer, Reinhardt, Stucki, & Bickenbach, 2012: Honeybul, Gillett, Ho, Janzen, & Kruger, 2016), which attributes importance for a supportive environmental factor like participating in leisure activity and in an employment, a significant cognitive activity and in a quality of social ties. All of which constitute a mitigating factor on the negative influences of disability as well as assisting in the process of adjustment and in structuring positive meaning to the general experience of life.

From the perspective of future orientation the findings indicate that there are aspirations in regard to employment, relations, family and health. But the main aspiration, in a significant way, is the aspiration for independence and for having control over their lives, considering the fact that the participants live in a supportive living. This finding is consistent with studies that found out that people with disability, that live in a supportive living, are unsatisfied with the component of independence and control over their lives (Rot & Hozmi, 2014). The future orientation that was reflected in the life stories of our research, portrayed a passive character, focusing on the existential domain or on satisfying immediate needs. Missing from it were wishes of being active in planning and in abstract thinking about the future, as well as an intrinsic motivation for the fulfillment of goals. The central explanation for it is based on the future time perspective theory (Simons, Vansteenkiste, Lens, & Lacante, 2004: Liu & Feng, 2019), which differentiate between three main components of characterization of future thinking: a motivational –emotional component, a cognitive component and a behavioral component.

The main conclusions of the research are: from the perspective of personal identity - most of the participants were not aware of the dual diagnosis of intellectual disability and mental disorder at the same time and feel confused. Therefore, it is important to assist them in developing their self-acceptance and a better realistic perception of the characteristics of their disability, side by side mediating of sense of capability as well as trust in their own ability.

From the **perspective of quality of life** - providing life supporting environment, participating in sufficient leisure's activity as well as instilling social skills and improving cognitive skill, can assist people with mental and intellectual disabilities to better adjust to their disability as well as to improve the quality of their lives.

From the **perspective of future orientation** - it was concluded that it is important to build for people with mental and intellectual disability, a supportive and secured environment, however enabling them at the same time, to have spaces of supervised independence which

are based on skills of choice and self-advocacy. It is also important to help them develop effective thinking-skills for future planning.

In the context of the phenomenon of the stigma which had followed their life stories all along, we concluded that it is important to recognize the damaging influence of the stigma, as well as to implement an effective strategies of reducing it through, for example, the intergroup contact theory (Pettigrew & Tropp, 2006 ; Corrigan, Roe,& Tsang, 2011) which enables a balanced, direct and interpersonal interaction between people with disabilities and others around them, the purpose of which is to lead to a deeper understanding of the characteristics of people with disabilities, and to reduce the prejudices against them.



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