

The Effect of a Pilot Group Psycho-education Program on the Death Attitude and Life Perception in the Case of an Adult with Intellectual Disabilities

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Abstract

Often people with intellectual disabilities are protected from exposure to death, dying and end-of-life issues, but this protection leaves the person unprepared for the grieving of unavoidable losses, and unaware of the changes implied by the old age of their caregivers. Considering the person with an intellectual disability as an immature being, lacking the ability to feel complex emotions, contributes to the tendency that both professionals and families have to avoid speaking with them about the difficult topic of death. Our goal is to design and implement a psychoeducational program that approaches the topic of death as a natural stage in life, for adults with intellectual disabilities. The effects that psychoeducation about death had on both death attitude and the perception of life are discussed based on a case presentation of one of the group members.

Keywords:

intellectual disability; death attitude; end-of-life issues; psycho-education

Zusammenfassung

Oft werden Menschen mit geistiger Behinderung vor Todes-, Sterbe- und Lebensendprobleme geschützt. Jedoch sind diese Personen dadurch nicht vorbereitet, um mit der Trauer um unvermeidbare Verluste umzugehen und sind sich der Veränderungen nicht bewusst, die das Alter ihrer Pflegekräfte mit sich bringt. Weil Personen mit einer geistigen Behinderung oft als unreife Wesen betrachtet werden, denen die Fähigkeit fehlt, komplexe Emotionen zu fühlen, trägt dazu bei, dass sowohl Fachkräfte als auch Familien es vermeiden, mit ihnen über das schwierige Thema Tod zu sprechen. Unser Ziel ist es, ein psychoedukatives Programm zu entwerfen und umzusetzen, das sich mit dem Thema Tod als natürliche Lebensphase für Erwachsene mit geistiger Behinderung beschäftigt. Die Auswirkungen der Psychoedukation über den Tod sowohl auf die Einstellung zum Tod als auch auf die Wahrnehmung des Lebens werden anhand einer Falldarstellung eines der Gruppenmitglieder diskutiert.

Schlüsselworte:

intellektuelle Behinderung;
Todeseinstellung;
Lebensendprobleme;
Psychoerziehung

1. Introduction

The loss of a loved person is a universal experience that most people lived or will live throughout their lives and can sometimes be dramatic for a number of people. Some can overcome the grief experience, while others need professional help in order to deal with the psychological consequences of grief, a complex and unique process for each individual (Humphrey & Zimpfer, 2008). Experiencing loss is universal and ubiquitous, but the manner each person goes through the process is very personal.

Various steps in the grief process have been identified and described as overlapping in the case of typically developed individuals: shock, disbelief and denial; intermediary acute mourning and social withdrawal; and restoration (Shuchter & Zisook, 1994, in Summers & Witts, 2003). The intensity and length of loss-related pain differs from one person to the other and each person experiences it

differently, depending on a number of personal, relational, contextual factors.

2. Grief and mourning in people with intellectual disabilities

The experience of grief and mourning has been considered legitimate in the case of persons with intellectual disabilities. Beginning with the '80s, Oswin (1991) approached the normality of pain and sadness in persons with intellectual disabilities and acknowledged the implications of loss-related grief in this population.

Two major factors have been identified to explain the lack of awareness of the grief experience: (1) the use of euphemisms for the taboo subject of death (such as, death as somebody's going to heaven, or going to sleep), in an attempt to avoid the difficult emotional significance, and (2) the attitude toward people with intellectual disabilities as unable to function emotionally in a way that would help them feel complex emotions. Thus, people with intellectual

disabilities are confronted with a “double taboo” when it comes to loss and suffering, resulting in their mislabelling as behaviourally challenging (Oswin, 1991) and their mistreatment with solely behavioural interventions or medication following the loss of a dear one. Also, they can be excluded from burials or other mourning rituals of the family, as well as from discussions about their own mortality and life-threatening physical illnesses (Lord, Field, & Smith, 2017). The misunderstood sadness can be associated with several consequences, from self-harming behaviour to the loss of bowel control (Summers & Witts, 2003), as well as the higher risk for complicated grief (Irwin, O’Malley, Neelofur, & Guerin, 2017).

Generally, the caregivers tend to avoid speaking about the loss of a family member or friend in front of a member with intellectual disability, due to the hypothesized lack of ability to understand the meaning of loss, as well as the family need to protect the person from suffering. Protecting persons with intellectual disabilities from finding out about death is a common phenomenon, even though they are surrounded by events related to death and loss. People with intellectual disabilities experience the same profound emotions and suffer from the loss of loved ones as any other person (Grey, 2010), although the “eternal children” attitude still persists among professionals (Lord, Field, & Smith, 2017).

Although internationally people with intellectual disability have a lower life expectancy (Lord, Field, & Smith, 2017), the need to prepare them for the death of family members is an important issue. Having an intellectual disability does not have to mean dying at a young age and people with disabilities are exposed to the loss of dear ones and the bereavement that follows.

For a number of reasons, the mourning process differs from person to person and sadness for the death of a significant one is a normal emotional response. Although the intellectual disability does not necessarily imply a different experience of loss, the chances are higher for a person to need special care in such moments (Grey, 2010).

The amount of support varies from individual to individual, often being restricted to the need for practical life changes (Grey, 2010), but there are situations in which people with intellectual disabilities need support from professionals in overcoming the bereavement process (Lord, Field, & Smith, 2017).

Depending on the severity of the intellectual disability, a person might be dependent on others for assistance with day to day tasks. This dependency can increase the complexity of the grieving process and the healing process after the loss can be longer. Several factors can impact this process and the understanding of the messages about death, dying and the rituals around the grieving process are one of these important factors (Grey, 2010, Hodges, 2002).

3. Assessment and intervention on death and life significance in intellectually disabled populations

Some authors suggest that the experience of grief is not totally related to the comprehension of the concept of death and that people with intellectual disabilities have only partial understanding of the causality, finality, cessation, universality, and inevitability of death (Lord, Field, & Smith, 2017). Depending on the level of intellectual functioning, the ability to understand the death concept varies greatly.

Only recently the topics of death, dying, end of life have raised the interest of researchers, due to the fact that they are sensitive, taboo topics, avoided by caregivers and considered too distressing for people with intellectual disabilities (Stancliffe, Wiese, Read, Jeltis, & Clayton, 2017). Consequently, the paucity of assessment instruments developed or adapted for this category was noted and the need to use adapted instruments was emphasized.

Also, support and intervention programs for bereavement related issues in persons with intellectual disabilities are quite scarce. Irwin et al. (2017) identified various interventions according to Read’s model of support and noted that the first level refers to the need of education, information delivery and sharing experiences in groups. Most people with intellectual disabilities live and/ or work within specialized services, where support for bereavement, end of life and loss-related topics is most likely to be offered (Tuffrey-Wijne & Rose, 2017), although protection of beneficiaries from death-related topics is often encountered in such settings.

The topic of death and especially the attitude toward death have been related to the concept of meaning of life (Kang, Lee, Park, Kim, Jang, & Lee, 2010, Jung, 2013), a significant factor in the field of mental health, related to the wellbeing and lifestyle that people experience. Thus, a positive correlation was reported between the attitude toward death and the meaning of life in various populations and the authors recommend the inclusion of the meaning of life concept in educational programs that approach attitudes toward death.

4. Method

The current study aims to investigate the effectiveness of a psychoeducational group program targeting the development of the awareness of death as a natural stage of life in adults with intellectual disability. Targeting the concepts of life and death, the program aims at changing the attitude toward death and the increase of the significance of life within a group setting.

4.1. Participants

A convenience sample of 6 adults (4 women and 2 men) with intellectual disabilities, all beneficiaries of a day-care centre for adults with disabilities situated in a small Romanian town was selected. All the participants were middle aged adults with ages between 32 and 48 years, from

urban areas, all living with their families. Regarding the severity of the disability, two of the participants presented mild intellectual disability, one moderate disability and three severe disability. The participants' diagnostics were homogenous: epilepsy and spastic cerebral palsy, associated with a mild vulnerability toward depression, but the severity of the neurological symptoms varied. All the participants graduated from inclusive education institutions, with at least 8 years of studies.

The group participants were members of the same day centre for people with disabilities, so they were familiar with each other and all were motivated to participate due to the fact that the group theme met their specific need to find out more about the concept of death, a sensitive theme that they did not approach very easily with their family members. Participants who had a tendency to become group deviants were excluded, as suggested by Yalom & Leszcz (2015). Motivation, satisfaction of needs and satisfaction from relationships with other members were three important inclusion criteria identified by Yalom & Leszcz (2015) for a successful group therapy. Although our group was mainly psychoeducational, inclusion and exclusion criteria were considered important in order to insure the effectiveness of the activities.

4.2. Instruments

The topic of death has been rarely approached by research in the field of intellectual disability, and therefore instruments assessing death attitude, awareness and other end of life issues are usually adapted from those used for the general population. Some cautions regarding the linguistic accessibility need to be taken in order to decide that an instrument is appropriate to use for intellectually disabled people: avoiding negative wording, past tense, using simple words, short sentences, clear vocabulary, avoiding complex terms, using concrete examples and images to explain abstract terms. Also, the response scale needs to be simple, in order to ensure that the items are understood (Stancliffe et al., 2017).

The Death Attitude Profile – Revised (DAP-R, Wong, Reker, & Gesser, 1994) was used in the current study to measure the attitude toward death in adults. The scale is composed of 32 items and for each item the agreement or disagreement is rated on a Likert-type scale. Five dimensions of death attitude are being measured: (1) Fear of Death (7 items), (2) Death Avoidance (5 items), (3) Neutral Acceptance (5 items), (4) Approach Acceptance (10 items), and (5) Escape Acceptance (5 items).

The Perceived Life Significance Scale (PLSS, Hibberd, 2013) was used to assess the extent to which participants acknowledged the value associated with goals, relationships or various aspects of present and future experiences. The scale assesses the intrinsic value of one's activities, as well as various activities in the lives of adults. The scale consists of 19 items, with answers reflecting the agreement or disagreement rated on a Likert-type scale.

The scale consists of three subscales: (1) Active significance (8 items), (2) Receptive significance (5 items), and (3) Negative significance (6 items). The scale is useful in the assessment of the effectiveness of psychotherapeutic interventions on the perception of life.

The wording of the items was an aspect that was carefully considered during the linguistic adaptation of the instruments and was considered accessible for intellectually disabled people.

4.3. Procedure

The participants volunteered to be included in a therapeutic group and the informed consent was obtained from all of them. Also, families and caregivers were informed about the goals of the psychoeducational program.

Both scales were given to the participants in written format for completion and the first author assisted each participant in reading the items and rating them on the Likert scale. Each time a participant tended to respond desirably, a verbal signal was sent to ask for a reconsideration of the answer. The cautions cited by Stancliffe et al. (2017) were considered and both the instruments were evaluated as appropriate for the participants, in both the manner of item wording and the nature of the Likert scale. The assessment was performed in two stages, before and after the group psychoeducation program, in order to determine the changes in death attitudes and perception of life following the participation to the group activities.

The research activities lasted 8 weeks and were structured in three main stages: (1) pre-intervention (baseline) assessment, (2) group sessions of psychoeducation, 2 sessions/ week for 5 weeks, (3) post-intervention assessment with the same measures as in stage 1.

Meaningful benefit for the group members was targeted, so the methods, strategies and activities designed for the purpose of the psychoeducational group were carefully selected and adapted for the specific of the members' disabilities and personal resources.

The activities within the ten sessions of the psychoeducation program were inspired from Neimeyer (2017) and Rogers (2007). Abstract concepts were exemplified, visual material was used, and various analogies were made with real life situations. Each experiential exercise was processed within the group discussions and each participant had the chance to develop hope, to share information with others, to strengthen empathy, altruism, socializing, and to have a cathartic experience during the session, considering part of the primary factors identified by Yalom & Leszcz (2015) for the change that participants make in their lives after group therapy.

Table 1. Brief presentation of the theme and content of the psychoeducational group sessions

Session No.	Content	Materials
1	Group opening: information on the sessions, establishment of a set of rules, creation of a calendar, planting of seeds to follow their development	Wheat seeds Coloured pencils to create a calendar
2	Presentation of “Life cycles in humans”, death as a natural life stage, identification of own life stage	Power Point presentation Card with life stages
3	Presentation of the story “Grandma’s dead” (Pașca, 2008) and discussion of questions referring to death	Power Point presentation of the story
4	Role play, grandmother’s death funeral	Puppets for adults
5	Identification of grief-related emotions, own and other group members emotions, group discussion about emotions	Pictures with emotional expressions
6	Emotional regulation basics, expression and emotional control of powerful emotions	Breathing buddies Various objects for grounding exercises
7	Group collage on the topic of “Life after death”	Glue, materials for collage
8	Group interactive activity: means to remember deceased significant persons	Hand puppets for adults
9	Assessment and closure: answering questions about death, dying, after life	
10	Assessment and closure: discussion about the wheat seeds, comparison with human life and development	Wheat planted in session 1

Group cohesiveness was qualitatively monitored during the ten group sessions and acceptance, support, deepening of relationships (Yalom & Leszcz, 2015) were reinforced during each session while participants shared their reactions and feelings.

5. Results. Case presentation

All the participants in the group participated in the psychoeducation program with interest and were actively involved in the group activities. Their interest was high due to the specific life stage, as all of them were adults who were confronted with the loss of family members or relatives.

Some of the participants responded desirably to the measures and we hypothesize the presence of the acquiescence in participants’ reports. We will detail the results and experience of one of the group members, as well as the context of her life that modelled her response to group psychoeducation.

Group participant AG is a 32-year old woman, living in the town in which the day centre is situated. She graduated four grades in a mainstream school and has an equivalent of eight years of educational background. She is a beneficiary of the centre for twenty years.

She lives with her parents, both retired in the same year that the group took place and has one sister living in a big city with her family and the participant describes their relationship as good.

Regarding the level of independence in daily living activities, the participant is encouraged by her family to take responsibilities, needs some amount of help in accomplishing her routines, but sometimes rejects the help from her mother with verbal and physical aggressions. There is a high degree of latency in her daily routines and a low capacity to adapt to changes.

Nine years before the group, both AG’s maternal grandparents, who lived in the same house with her, died only a few months apart. The parents chose not to tell AG about their death and in order to protect her they sent her away to an aunt until each of the funerals was over. The participant realized what happened, but never asked questions and several changes in her behaviour were immediately noticed by the parents: she refused to go to the church, she protested when she encountered persons wearing black, she refused to listen to religious music, and she never since then entered in the room in which her grandparents died.

During the baseline assessment, the participant stated her belief that after death people go to angels, but other spontaneous ideas about death, dying of after death experiences did not emerge during the pre-test phase.

We noticed, that apart from her tendency for desirable responding to the questions of the two questionnaires, an increased level of fear and avoidance of death can be observed and a low acceptance of the death as part of life. Regarding the perception on life, the scored showed a moderately positive perception, with a low tendency toward negative perception.

Table 2. Participants' raw scores at baseline and post-intervention

Participant	Assessment ¹	DAP-R ²					PLSS ³		
		1	2	3	4	5	1	2	3
AG	1	46	35	28	40	25	38	28	14
	2	32	35	21	45	29	46	25	9

¹stage of assessment: (1) baseline, (2) post-intervention

²DAPR-R subscales: (1) Fear of Death, (2) Death Avoidance, (3) Neutral Acceptance, (4) Approach Acceptance, (5) Escape Acceptance

³PLSS subscales: (1) Active significance, (2) Receptive significance, (3) Negative significance

The figures below present the changes in scores that were obtained following the participation in the group sessions for the participant's attitude toward death (DAP-R) and perception of life (PLSS). Although not very spectacular, the slight changes in the participant's scores show the relevance and usefulness of such programs. The participant included in the group was a person with intellectual disability that lost some close family members

and was still living with her family, both her parents were still alive. Therefore, her personal confrontation with death was related to the loss of her grandparents many years ago, a loss that was never worked through. Her reported level of fear of death was high, as well as her tendency to avoid death. At the same time, she also reported a high level of acceptance of death. The participant's need to understand the concept of death is obvious.

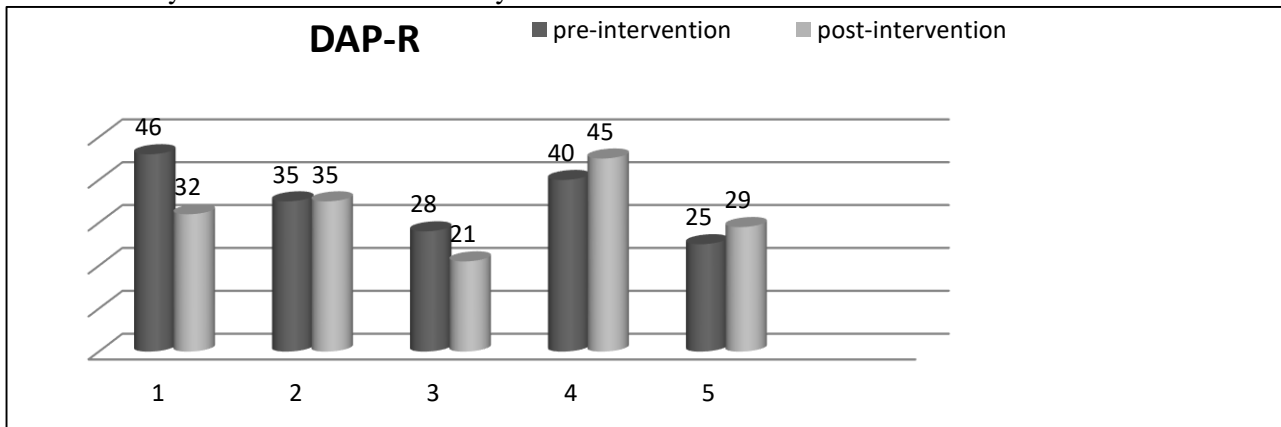


Figure 1. Participant's scores for DAP-R at baseline and post-intervention

DAPR-R subscales: (1) Fear of Death, (2) Death Avoidance, (3) Neutral Acceptance, (4) Approach Acceptance, (5) Escape Acceptance

AG has a concrete level of understanding things and the concept of death is hard to understand, especially in a context in which she was protected from suffering by avoidance of exposure to end-of-life rituals in the family.

After the psychoeducational group, a slight increase in death acceptance and a decrease in the fear of death, as measured with the DAP-R, were noticed, following the exposure to grief and death-related group discussions and activities. For our participant, who reported a very high

level of fear, it is obvious that psychoeducation cannot be the only intervention.

Although not very consistent for the participant, the changes in scores prove that an intellectually disabled person could benefit from psychoeducation regarding death and end of life issues. Her acceptance of death as a normal part of life can have a decreasing effect on her fear of death and can be a buffer against problematic grieving.

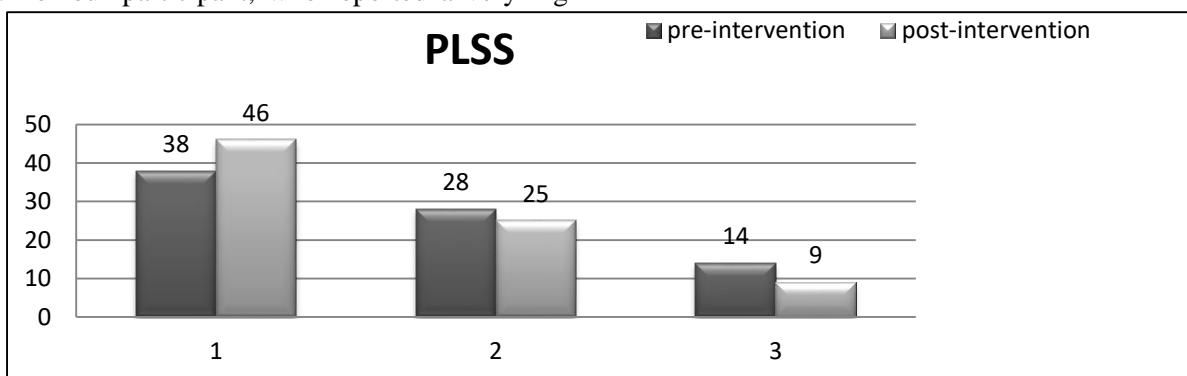


Figure 3. Participants' scores for PLSS (Active Significance) at baseline and post-intervention

PLSS subscales: (1) Active significance, (2) Receptive significance, (3) Negative significance

With respect to the perception of life, the participant's scores slightly increased for active significance of life, and slightly decreased for receptive and negative significance, showing some positive effect of the exposure to death-related topics on the value that the participant attributed to her life.

A relation between death acceptance, low fear of death, and life significance can be acknowledged in the case of AG. Although not generalizable based on a case presentation, an association can be noticed between the decrease of fear of death, the increase of acceptance, and the increase of significance of life.

Following the group psychoeducation, there were some changes in the participant's behaviour around the issue of death, the mother noticed a more natural way of asking and discussing about death from AG, a more direct and less avoidant approach of the topic. Also, some new behaviours emerged with respect to the grandparents' room, as the participant started to walk into the room, look through the personal stuff, she started to process their death, affirming that they were old, ill and their time had come for them to die.

6. Discussion

Some changes were noticed in the scores of the case we presented, following the 5-week psychoeducation program, showing slight changes in both death attitude and perception of life of the participant. Although the changes in scores were not spectacular, which was not expected after a short psychoeducation program, such intervention could significantly impact the members of a group that go through life events related to loss, grief, death and end of life (such as the death of a family member), or those who have personal reason to be more receptive, or are in a stage of their life that makes them interested in such topics.

The report of the results shows that there is a relation between death attitude and perception of life, the participant showed increase in the acceptance of death and also showed the increase of active significance of life.

The concrete level of understanding, specific to persons with intellectual disabilities, determines several difficulties in the understanding of the death concept. There is a tendency to avoid the discussion of this topic with intellectually disabled people, due to the desire to protect them from strong negative emotions that family members, as well as the staff from the day-care centres. The scores show that persons with intellectual disabilities do have a certain degree of awareness of death, as well as a certain degree of fear related to death. Avoidance of topics concerning death may lead to a risk of misinterpreting death as a unnatural phenomenon.

A certain degree of valuing of one's own life was added to the participant's perception of her life by the fact that she directly approached the topic of death.

The group sessions positively impacted all the members, the open discussions about a sensitive topic had

a positive effect on their exposure to a taboo subject that is sometimes avoided by caregivers, in a life stage in which loss is inherent for each of them.

7. Conclusions

Our study shows that implementing a psychoeducational program for the development of death acceptance has an effect on the perception of death as a natural stage of life. Adults with intellectual disabilities are confronted with the ubiquitous experience of loss and death, as they are at the life stage when their parents are getting old, their grandparents are death or close to dying, so the need to openly discuss the taboo topic of death is stringent.

Although significant changes can be obtained in a longer time period, some people with intellectual disabilities can have benefits even from such a small number of group sessions, depending on their life circumstances and events, as well as disability-related factors, such as the severity of their disability. Family factors, such as the amount of discussions that caregivers are open to have, can furthermore impact the persons' attitude about life and death.

One important limitation of the current study is the use of assessment scales developed for the population with typical development. Although the phrasing was accessible for the participants' level of understanding, some of them might have had difficulties interpreting some of the items that they did not signal to the first author who helped them fill in the assessments. Also, a tendency toward desirable responding and acquiescence were noted. Therefore, the results should be considered with caution.

Another important limitation is the small group number of participants, meaning that our results cannot be generalized. Our goal to pilot a psychoeducation program was mainly to show a manner of approaching the sensitive topic and to present some possible activities, but there is a need to expand the research to a much larger population in order to be able to draw more general and consistent conclusions.

Authors note:

Alexandra Fodor (psychologist, MA graduate) works in a centre for children, young adults with disabilities and their families that supports the inclusion of this vulnerable population in society, as well as their quality of life and well-being. She is a professional interested in the implementation of science-informed programs in the field of disability and in the development of knowledge and skills that practitioners have in the field of psycho-pedagogical assistance of people with disabilities. Her research interests are: intellectual disability in adulthood, death and end-of-life issues, grieving in people with intellectual disabilities, well-being and disability.

Carmen Costea-Bărluțiu (special educator and psychotherapist) is currently a Lecturer in the Department of Special Education, School of Psychology and Educational Sciences, Babeș-Bolyai University, Cluj-Napoca, Romania and a systemic couple and family psychotherapist in private practice. Her interests and training in psychotherapy include: Ericksonian Hypnotherapy, Schema-focused therapy, Mentalization-based treatment, Attachment-based interventions. She has professional and research interests in: attachment theory in human development and psychotherapy, parenting and disability, mental health and disability, systemic psychotherapy and family well-being.

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