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Analysis of the preparation of individuals with intellectual disabilities for the death of loved ones and experiencing grief after loss. A contribution to research[1]

Analiza sytuacji przygotowania osób z niepełnosprawnością intelektualną do śmierci bliskich i przeżywania żałoby po stracie. Przyczynek do badań.

Abstract. This article attempts to answer the question of how the preparation of individuals with intellectual disabilities for the death of loved ones and the experience of grief after loss is handled. Based on an analysis of existing sources[2] the author argues that in the 21st century, not all individuals with intellectual disabilities still receive adequate assistance when faced with the death of a loved one and support during the grieving process. The reasons for this situation are: (1) stigmatizing and stereotypical thinking rooted in the previous century, which leads to the underestimation of the cognitive and emotional abilities of individuals with intellectual disabilities; (2) the desire to excessively protect individuals with intellectual disabilities from difficult experiences; (3) a lack of appropriate knowledge and skills in the area of thanatology among caregivers of individuals with intellectual disabilities. The author of the text notes that the exclusion of this group from discussions about death has negative consequences for their psychophysical health. At the same time, she emphasizes the importance of including individuals with intellectual disabilities in topics related to death, appropriate preparation for the loss of loved ones, and adequate support after the loss. The general conclusion from the literature analysis is that there is a need for

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[1] Niniejszy tekst powstał pod opieką naukową dr hab. Małgorzaty Michel, prof. UJ.

[2] K. Rubacha, *Metodologia badań nad edukacją*, Wydawnictwa Akademickie i Profesjonalne. Grupa Kapitałowa WSiP, Warszawa 2008.

education in the area of thanatopedagogy and topics related to proper preparation for the death of loved ones and experiencing grief after loss for individuals with intellectual disabilities. This education should target those who interact daily with this social group, such as their caregivers, educators, assistants, social workers, and healthcare professionals. Their knowledge and appropriate thanatopedagogical competencies will lead to proper preparation and support for individuals with intellectual disabilities facing the loss of loved ones and grief after loss.

Keywords: death, grief, intellectual disability, exclusion from the topic of death, tabooization of death, thanatopedagogy

Abstrakt: Niniejszy artykuł jest próbą odpowiedzi na pytanie o to, jak wygląda sytuacja przygotowania osób z niepełnosprawnością intelektualną do śmierci bliskich i przeżywania żałoby po stracie. W oparciu o analizę źródeł zastanych[3] autorka tekstu stawia tezę, że w XXI wieku wciąż nie wszystkie osoby z niepełnosprawnością intelektualną otrzymują adekwatną pomoc w sytuacji śmierci bliskich i wsparcia w czasie żałoby po stracie. Przyczyną tego stanu rzeczy są: (1) stygmatyzujące i stereotypizujące myślenie zakorzenione w poprzednim stuleciu, które prowadzi do niedoceniania zdolności poznawczych i emocjonalnych osób z niepełnosprawnością intelektualną; (2) chęć nadmiernej ochrony osób z niepełnosprawnością intelektualną przed trudnymi doświadczeniami; (3) brak odpowiedniej wiedzy i umiejętności w obszarze tanatycznym wśród opiekunów osób z niepełnosprawnością intelektualną. Autorka tekstu zauważa, że wykluczenie tej grupy z tematów śmierci, niesie ze sobą negatywne skutki dla ich zdrowia psychofizycznego. Jednocześnie ukazuje ważność inkluzji osób z niepełnosprawnością intelektualną w tematy związane ze śmiercią, odpowiedniego przygotowania na odejście bliskich oraz adekwatnego wsparcia po stracie. Wnioskiem generalnym z przeprowadzonego procesu analizy literatury jest to, że istnieje potrzeba edukacji w obszarze tanatopedagogiki i tematów związanych z odpowiednim przygotowaniem do śmierci bliskich i przeżywania żałoby po stracie dla osób z niepełnosprawnością intelektualną. Edukacja ta powinna objąć osoby na co dzień przebywające z tą grupą społeczną, tj. ich opiekunów, edukatorów, asystentów, pracowników socjalnych oraz pracowników służby zdrowia. Ich wiedza oraz odpowiednie kompetencje tanatopedagogiczne przełożą się na adekwatne przygotowanie i wsparcie dla osób z niepełnosprawnością intelektualną, mierzących się z utratą bliskich i żałobą po stracie.

Słowa kluczowe: śmierć, żałoba, niepełnosprawność intelektualna, wykluczenie z tematu śmierci, tabuizacja śmierci, tanatopedagogika

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[3] K. Rubacha, *Metodologia badań nad edukacją*, Wydawnictwa Akademickie i Profesjonalne. Grupa Kapitałowa WSiP, Warszawa 2008.

Introduction

Death is an inseparable stage of life, the arrival of which everyone can be certain of, as "everyone must die eventually: whether animal or plant – in fact, everything that lives."[4] Despite this, death is a difficult topic, one that is rarely discussed. Its significance is diminished through trivializing depictions in the media, films, and books. The issue related to death and the symbols associated with it is often repressed.[5] Frequently, people are not prepared for its arrival, nor are they given adequate support at the time of losing someone close. This leads to a process of tabooing the topic of death, repressing it, and ignoring it. However, this phenomenon is relatively new. It was first described by Geoffrey Gorer in his article titled *The Pornography of Death*, in which the author argued that it is only in contemporary society that death has become something scandalous, disgusting, and repulsive. As a result, it has been placed on the list of unspeakable topics, while in the past it was considered an important stage in the entire human life.[6] It should be emphasized, however, that for a certain social group, the death taboo existed much earlier than in a whole society. This concerns individuals with intellectual disabilities, who were and still are excluded from discussions about death and the associated rituals. In the past, this was due to the belief that this group, because of their cognitive deficits, could not understand the phenomenon of death. Furthermore, it was believed that they could not form interpersonal relationships and, as a result, did not grieve the death of loved ones or experience mourning after a loss.[7] Although this view has been challenged by scientific

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[4] A. Grąbecki*, O życiu i śmierci w przyrodzie*, Ludowa Spółdzielnia Wydawnicza, Warszawa 1963, s. 123.

[5] Zob. M. Zawiła, *Religia i śmierć. Trajektoria umierania i jej religijne elementy na przykładzie środowisk hospicyjnych w Polsce*, Wyd. Uniwersytet Jagielloński, Kraków 2007,

[6] Zob. A. Van Gennep, *Obrzędy przejścia*, Państwowy Instytut Wydawniczy, Warszawa 2006.

[7] Zob. E. Zasępa, *Psychologiczne aspekty doświadczania żałoby u osób niepełnosprawnych intelektualnie*. w: „Porozmawiajmy o śmierci", red. B. Antoszewska, J. Binnebesel, Wydawnictwo Uniwersytetu Warmińsko-Mazurskiego, Olsztyn, 2014, s. 212–224.

research (Hollins, S. & Esterhuyzen A. 1997, MacHale R. & Carey S. 2002)[8], in reality, individuals with intellectual disabilities are still excluded from discussions about the death of loved ones, not receiving adequate preparation or support in the face of loss, and therefore they are unable to process and cope with it. This has its basis in mistaken beliefs about their cognitive and intellectual functioning, sometimes in excessive care and the desire to protect these individuals, as well as in the lack of appropriate competencies in thanatopedagogy among those who care for individuals with intellectual disabilities.

The death of loved ones and grief after loss in the lives of individuals with intellectual disabilities

Currently, we are witnessing a paradigm shift in the perception of individuals with intellectual disabilities in the context of their functioning. Despite the existence of an official classification of levels of intellectual disability based on medical and psychological parameters[9]—mild, moderate, severe, and profound—individuals diagnosed in this manner are treated individually, with an emphasis on their traits and potentials that go beyond official classifications. Additionally, research findings and educational experiences indicate that multifaceted support and appropriate stimulation improve the quality of their lives and enable them to function psychosocially in a satisfactory manner. This is particularly evident in the group of individuals diagnosed with mild and moderate intellectual disabilities.

An important aspect of working with individuals with intellectual disabilities should also be preparation for the death of loved ones,

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[8] Zob. S. Hollins, Esterhuyzen A., *Bereavement and Grief in Adults with Learning Disabilities*, „British Journal of Psychiatry” 170, nr 6, 1997, s. 497–501.

[R]. MacHale, S. Carey, *An Investigation of the Effects of Bereavement on Mental Health and Challenging Behaviour in adults with a Learning Disability*, „British Journal of Learning Disabilities” tom 30, nr 3, 2002.

[9] Zob*. American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders DSM-5*, przeł. Piotr Sebastian Krawczyk, wyd. 5, Edra Urban & Partner, Washington 2013, s. 15-19.

the emotions, feelings, fears, and reactions that arise at that time, as they experience the death of loved ones and grief after the loss. The way they react depends on many factors, including the degree of disability[10]. Individuals with mild intellectual disabilities have the ability to reflect on death, its causes, consequences, inevitability, and irreversibility. However, they perceive it in a very concrete way – as a transition to another, often better world, where eternal happiness prevails. Individuals with moderate intellectual disabilities are also aware of the irreversibility and universality of death, which causes them significant fear. On the other hand, individuals with severe and profound intellectual disabilities do not understand this phenomenon and perceive it intuitively, often in a very selfish manner. They frequently display anger and resistance to daily activities, as there is no longer anyone taking care of them. It happens that they express sadness and burst into tears, but this reaction is often a result of imitating people in their close environment[11].

It is also important to note the universal reactions of individuals with intellectual disabilities, which are manifestations of grief. This often manifests in crying, falling into a stupor, inappropriateness, irritability, or hyperactivity.[12] Sometimes, aggression directed at people from the close surroundings who try to take the place of an important person occurs. Additionally, serious manifestations of self-harm can be observed. Unable to cope with the lack of skills to express their own feelings and the overall loneliness, an individual with intellectual disabilities harms themselves to regain balance, attract others' attention, or communicate their pain. At the same time, during the mourning period, they may constantly search for the deceased person and exhibit stereotypical behaviors such as pacing back and forth, rocking, and other stereotypes. Regression can also occur, manifesting

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[10] Zob. M. Parchomiuk, *Starzenie się, starość i umieranie osób z niepełnosprawnością intelektualną*, Oficyna Wydawnicza Impuls, Kraków 2019, s.199–200.

[11] Ibidem..

[12] Zob. P. Dodd, S. Downling, S. Hollins, *A review of emotional, psychiatric and behavioral responses to bereavement in people with intellectual disabilities,* „Journal of Intellectual Disability Research" nr 7, 2005.

as a deterioration in communication or the appearance of physiological disorders, such as involuntary urination. A common feeling is also the sense of responsibility for the tragedy that has occurred. Especially since in the past, an individual with intellectual disabilities might have heard words like “You will finish me,” “I will die because of you,” etc., from the lost loved one. These memories, along with the inability to understand metaphors, lead to the belief that they contributed to the disappearance of the loved one, which creates an additional difficulty in going through the mourning process.

Reasons for excluding people with intellectual disabilities from the subject of death

The above analysis shows that individuals with intellectual disabilities are capable of experiencing the death of loved ones. It is therefore worth considering, what are the reasons for excluding this group from the topic of passing? Based on the analysis of the existing sources, three main groups of reasons for this situation can be identified:

1. Underestimation of the intellectual and emotional capacities of people with intellectual disabilities

It turns out that sometimes the lack of adequate support for individuals with intellectual disabilities in the face of the death of loved ones and experiencing grief is caused by mistaken beliefs about the limitations resulting from the disability and the associated deficits. Stereotypical thinking, rooted in the previous century, leads to the belief that individuals with intellectual disabilities, due to their reduced cognitive competencies and difficulties in the social domain (including forming bonds and maintaining relationships), are unable to experience loss. Their difficulties in understanding such an abstract phenomenon as death, with its finality, universality, and inevitability, often lead to the exclusion of these individuals from discussions about passing. Despite the development of science, changes in classification, and the general perception of this social group[13], as well as research on them, including aspects of experiencing death and grief (Kloeppel D.A. & Hollins S. 1989; Dodd P., Dowling S. & Hollins S. 2005)[14], have outdated these mistaken beliefs, in the 21st century, one can still encounter thinking rooted in this stereotype. A part of society does not recognize that individuals with intellectual disabilities are capable of forming relationships. They build bonds with other people and, as a result, notice their departure. The death of loved ones—especially parents or caregivers, with whom they have built symbiotic bonds throughout their lives—is particularly significant for them.It is they who provide support, understanding, and serve as a pillar on which individuals build their own world. At the moment of the final loss of this point of reference, an individual with intellectual disabilities becomes aware of the absence, feels a sense of threat, and experiences immense disorientation. The loved one, who always cared for them, met their needs, took care of them, and spent time with them, has suddenly disappeared. Sometimes, especially in the first days after the death of a loved one, an individual with intellectual disabilities may function as they did before, and it may seem that they haven't noticed what has happened at all. However, this is just a temporary reaction—initially, the person with intellectual disabilities may not be aware of what is happening. This is related both to cognitive and adaptive deficits, as well as to the lack of an explanation for the situation or the concealment of the event. However, intellectual disability is not the same as a dysfunction of sight or hearing. Therefore, despite their cognitive difficulties, the individual, after some time, begins to notice various signs and symbols, hears conversations about what really happened, and then makes efforts to understand the entire situation. The uncertainty they feel begins to be associated with fear and anxiety, which lead to the emergence of chaos. Then, grief is ad-

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[13] Zob. K. Ćwirynkało, *Społeczne funkcjonowanie osób z lekką niepełnosprawnością intelektualną*, Wydawnictwo Edukacyjne „Akapit", Toruń 2010.

[14] D. A. Kloeppel, S. Holllns, *Double Handicap: Mental Retardation and Death in the Family*, "Death Studies" tom 13, nr 1, 1989, s. 31–38. P. Dodd, S. Dowling, S. Hollins, *A review of the emotional, psychiatric and behavioural responses to bereavement in people with intellectual disabilities*, „Journal of Intellectual Disability Research" tom 49, nr 7, 2005.

ded to these difficult and incomprehensible feelings. It is the result of understanding the irreversibility of the changes that have occurred or noticing the absence of a loved one combined with the inability to find them. The way grief is experienced is an individual matter, dependent on the life experiences of the person and the closeness with the deceased. An important element of grief are also secondary losses[15], as the death of a loved one often involves the necessity of changing the place of residence, moving to other family members, or to a care home. This new situation disrupts the natural rhythm of the day for an individual with intellectual disabilities. An unfamiliar place deprives them of a sense of security, stability, and their own identity. They also face the need to adapt to new rules, accept the demands of living in a group, and adjust to the limitation of their autonomy, which can further intensify the manifestations of grief. However, society often interprets them as emotional and behavioral difficulties which are symptoms of disability and regression in functioning. This is due to ignorance and stereotypical thinking.

2. Attempt to protect them from difficult experiences

It should be emphasized that the exclusion of individuals with intellectual disabilities from the topic of death is not only the result of a lack of knowledge or stereotypes, but very often constitutes an attempt to protect these people from negative feelings, sadness, and pain[16]. As Monika Parchomiuk notices: "The attitude of the surroundings towards the issue of death in the life of an individual with intellectual disabilities often resembles the approach to a child, who is protected at all costs from a topic that is difficult to accept and understand."[17] Caregivers do not explain the situation, they lie, remain silent, and take

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[15] Zob. M. I. Fernández-Ávalos i in., *Actions Taken and Barriers Encountered by Professionals Working with Adults with Intellectual Disabilities Who Experience Grief: A Qualitative Approach,* "Death Studies" tom 48, nr 4, 2024.

[16] Zob. D. Wolska, *Osoba z niepełnosprawnością intelektualną w obliczu śmierci i umierania*, „Niepełnosprawność – Zagadnienia, Problemy, Rozwiązania", nr 4, 2019, s. 61–76

[17] M. Parchomiuk, *Starzenie się, starość...* op. cit. s. 202.

away the opportunity for the final farewell and participation in the funeral. They want to reduce unnecessary stress, avoid the need to face a phenomenon that is not fully understood by the individual, and the rituals associated with it. Trying to protect the person with intellectual disabilities from reality, they take away their "ability to experience the cycles in nature […] birth – aging – death."[18]As research shows, such actions do not reduce stress; on the contrary, they increase it. Moreover, they can provoke frustration and anger, which may surface even after it. Individuals with intellectual disabilities, who notice the actions of their loved ones, feel that this leads to the denial of their needs, taking away their opportunities and space to talk about their feelings or thoughts,[19] and not providing the support they need.

3. Lack of appropriate theoretical knowledge and practical skills in the context of conversations about death among caregivers of individuals with intellectual disabilities

The third reason for the exclusion of individuals with intellectual disabilities from the issues surrounding the experience of death is the lack of appropriate thanatopedagogical competencies among their caregivers, including social workers and healthcare professionals. Research shows that employees of various centers where individuals with intellectual disabilities reside are aware of the needs of their charges arising from the loss of loved ones,(Tuffrey-Wijne I, Finlayson J. i in., 2020; Wiese M., Dew A. i in. 2013)[20], the necessity of preparing them

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[18] I. Fornalik, *O tym co nieuniknione… Osoba z zespołem Downa a doświadczenie śmierci*, w: Kaczmarek B. B., *Trudna dorosłość osób z zespołem Downa. Jak możemy pomóc?"*, Oficyna Wydawnicza „Impuls", Kraków 2011, s. 156.

[19] I. Tuffrey-Wijne i in., *People with intellectual disabilities who are affected by a relative or friend with cancer: A qualitative study exploring experiences and support need*, "European Journal of Oncology Nursing" 16, 2012, 512–519.

[20] Zob. I. Tuffrey-Wijne i in., *Communicating about death and dying with adults with intellectual disabilities who are terminally ill or bereaved: A UK-wide survey of intellectual disability support staff*, "Journal of Applied Research in Intellecrual Disabilities", tom 33, nr 5, 2020. M. Wiese i in., '*If and When?': The Beliefs and Experiences of Community Living Staff in Supporting Older*

for experiencing grief, and providing adequate support during its duration. However, they do not always know what to do or how to apply all the theoretical knowledge in practice. The lack of specific guidelines to assist them with this task further increases their anxiety and uncertainty. Although they understand the behavioral and emotional manifestations of grief in individuals with intellectual disabilities and are aware of the negative consequences that arise when the loss is not processed, they do not have access to reliable tools that would allow them to identify the situations of their charges, assess the level of risk, and plan appropriate support.

How to convey information to an individual who does not communicate verbally? How to talk about something as abstract as death? How to react? How to provide support? How to adapt actions to the level of disability of the recipient? These are just a few of the many questions asked by caregivers.[21] However, despite the uncertainties, some of them want to help their charges. They begin to take actions that are not always based on a concrete support plan. They try to involve individuals with intellectual disabilities in various activities, games, and tasks in order to divert their attention from the loss and focus it on rebuilding,[22] helping to create a new routine, and developing their identity in light of the situation. On the other hand, they try to nurture the memory of the deceased as far as possible, focusing on the orientation towards the loss.[23] As a result, they focus the attention of their charges on painful experiences, engage in conversations with them, reminisce, and accompany them in their grief. At the same time, they create space for the individual with intellectual disabilities to decide what they want to do immediately after the death of a loved one – whether they want to say goodbye, participate in the funeral and related rituals, or if they feel no need or willingness to engage in such activities. However, this element

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People with Intellectual Disability to Know about Dying,"Journal of Intellectual Disability Research" tom 57, nr 10, 2013.

[21] M. I. Fernández-Ávalos i in. *Actions Taken and Barriers* op.cit.

[22] Zob. M. Stroebe, H. Schut, *The Dual Process Model of Coping with Bereavement: A Decade on**, "OMEGA - Journal of Death and Dying" tom 61, nr 4, 2010.

[23] Ibidem.

is not always possible, as some families of individuals with intellectual disabilities effectively involve caregivers/employees into a conspiracy of silence.[24] They do not inform specialists about the terminal illness or death of the loved one, or they forbid disclosing this information to the individual with intellectual disabilities, thus taking away their ability to decide about the final farewell. In this situation, open communication between professionals and support during grief become even more difficult. Caregivers see that the charge is aware of what is happening, is suffering, but they cannot help in any way, which in turn causes anger, a sense of helplessness, and injustice.[25] It should be also noted that the professionals themselves experience discomfort related to the loss in the lives of their charges, sadness, but also uncertainty about the future of the individual with intellectual disabilities, as they know that the lack of proper communication, preparation, and support may lead to negative consequences.

Recommendations for practice

There is no doubt that an individual with intellectual disabilities perceives the death of loved ones and experiences it in their own, unique way. Understanding, patience, empathy, support, and proper preparation are all that they need, yet often simply do not receive. Isolated from the facts, excluded from farewell ceremonies, and unaware of what has happened, the individual is deprived of the right to grieve.[26]The lack of support at various stages of grief, increasing loneliness, and the accumulation of negative emotions eventually resurface as a delayed grief response,[27] affecting the individual with

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[24] M. I. Fernández-Ávalos i in., *Actions Taken…*, op. cit.

[25] Ibidem.

[26] Zob. K. J. Doka, *Individuals with intellectual disabilities: Struggling with loss and grief*, “End-of-life care for children and adults with intellectual and developmental disabilities”, 2010. online: Individuals with intellectual disabilities Struggling with loss and grief.pdf, dostęp z dn. 1.04.2024.

[27] Zob. B. Stecler, *Doświadczenie żałoby*, w: „Porozmawiajmy o śmierci”, red. B. Antoszewska, J. Binnebesel. Wydawnictwo Uniwersytetu Warmińsko-Mazurskiego, Olsztyn 2014, s. 212–224.

double intensity and carrying more serious consequences. As a result, the barriers set by society, the lack of inclusion, and an accepting space lead to a life of separation[28] – resignation from any cognitive and physical activities, immersion into one's own unspoken despair, isolation from others, and depression.

Therefore, the topic of death and grief in the lives of individuals with intellectual disabilities cannot be ignored, avoided, or assumed to be non-existent for them. On the contrary – it is crucial not only to support but also to properly prepare this social group for the concept of passing, as it is an important aspect of caring for their mental health and well-being. Therefore, in the process of upbringing and lifelong education, emphasis should be placed on addressing the topic of passing. This is a difficult task, yet the difficulty arises not only from the limitations of the individual with a disability but also from the attitudes of those on the other side. It is the caregivers who must overcome the taboo imposed by culture, treat death as a companion that opens eyes to the value of life and the price of time, even for individuals with intellectual disabilities.

Work on this aspect of life with an individual with intellectual disabilities can begin with an honest conversation, without hiding the facts, trivializing problems, or silence. It is necessary to abandon an overly protective attitude aimed at eliminating suffering and to answer all questions, regardless of whether they concern fear, pain (both physical and emotional), or whether an answer is known. Honesty and giving hope are key in this process,[29] as well as speaking directly and avoiding metaphors. This helps protect the individual from their concreteness and tendencies to escape into a world of fantasy, while also allowing them to express their own feelings and thoughts. In conducting such a conversation, literary forms or methods from the realm of art, such as fiction, can be helpful. Examples of books worth using in the process of consciously experiencing grief, which also serve as tools for bibliotherapy, include: *"Oscar and the Lady in Pink"*, *"Duck, death, and the Tulip"*, and *"Goodbye, Mr. Muffin"*. Screened fairy tales, such as *"Coco"* and *"The Lion King"*, may also prove useful. These are just examples from many works that address the issue of death, grief, or a will. Therefore,

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[28] Zob. M. Parchomiuk, *Starzenie się, starość…* op. cit. s. 213.

[29] Zob. D. Wolska, *Osoba z niepełnosprawnością*, op. cit. s. 61–76.

fairy tale therapy and bibliotherapy serve as tools that allow the topic of the passing of human life to be introduced in activities conducted with an individual with intellectual disabilities. At the same time, they help in building acceptance and understanding of the surrounding reality in the individual. Based on these, one can develop appropriate attitudes in individuals with intellectual disabilities towards the passing of life and help them come to terms with this fact, while also combating the fear of the unknown. However, it is important to remember that not every individual with this type of disability has the ability to communicate verbally. Due to limited verbal communication, the environment should remain sensitive to all non-verbal messages and, using the same channels, try to reach the individuals.

It is important to emphasize that preparation for death, which will come "someday," is not enough. It is crucial to provide appropriate support to the individual with intellectual disabilities at the time of losing a loved one. They should be engaged in the events happening around them, considering their level of intellectual development, while avoiding infantilising them. This is important because, despite their disability, the range of experiences of an individual with intellectual disabilities is much richer than that of a cognitively able young child.[30] The awareness of the negative consequences resulting from concealing the fact of the death of an important person should lead to providing the individual with intellectual disabilities, as much as their abilities and willingness allow, the opportunity for a real farewell to the deceased. They should be given the opportunity to have contact with the body of the deceased during the rituals and farewell ceremonies, as this serves as a tangible proof of death. Participating in the funeral and collectively experiencing the loss allows the individual to be included in the community, offering closeness and support in return for rejection and isolation. It provides an opportunity for the expression of emotions and helps combat confusion. At the same time, it allows them to confirm the reality of death. However, even in this situation, we must not forget to provide guidance on how to behave, what is acceptable, and what should not be done, as often the bereaved simply do not know. In the longer term, it is necessary to create

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[30] I. Fornalik, *O tym co nieuniknione…* op. cit. s. 155.

circumstances for the individual to nurture the memory of their loved one, both verbally and non-verbally. One can engage them in memory therapy and create an atmosphere of remembrance[31] by looking at mementos left by the deceased, photographs, exposing them to scents, music, or films. In religious families, it is important to include the individual with intellectual disabilities in various religious ceremonies held in honor of the deceased after the burial, such as prayers, services, singing hymns, visiting graves, and lighting candles. Although the individual may not fully understand what is happening, the overall atmosphere of the situation and the closeness of others gives them a sense of belonging and shared emotion. Moreover, psychological support from a psychologist, psychiatrist, or a group within the framework of group therapy can be provided, which will help reduce the level of loneliness and build a sense of belonging to the community.

In the long term, it is important to work on creating appropriate tools that help diagnose the situation of an individual with intellectual disabilities, the stage of grief they are in, the risk of delayed grief, and a range of negative consequences for the individual's psychophysical health. It is also essential to develop appropriate work plans and actions that will help those supporting individuals with intellectual disabilities navigate the area of proper preparation for death. Despite the existence of specific examples of good practices developed in the field of thanatopedagogy for individuals with this disability (Sołowska A. 2019; Tuffrey-Wijne I. 2013; Tuffrey-Wijne I., Rose T., et al. 2017),[32] this area requires further development.

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[31] Zob. A. Drzazga, *Temat starości i śmierci w życiu osób z niepełnosprawnością intelektualną,* [w]: Cytkowska B., „Dorośli z niepełnosprawnością intelektualną w labiryntach codzienności", Wydawnictwo Adam Marszałek, Toruń 2011, s. 450–272.

[32] Zob. A. Sokołowska, *Korzyści i straty z asystentury osobom z niepełnosprawnością intelektualną w L'Arche w oczach asystentów poznańskiej wspólnoty*, „Niepełnosprawność-zagadnienia, problemy, rozwiązania", tom 31, nr 2, 2019, s. 122–163. I. Tuffrey-Wijne i in., *Communicating about death and dying: Developing training for staff working in services for people with intellectual disabilities,"Journal of Applied Research in Intellectual Disabilities",* tom 30, nr 6 2017. I. Tuffrey-Wijne, *A New Model for Breaking Bad News to People with Intellectual Disabilities*, "Palliative Medicine" tom 27, nr 1, 2013, s. 5–12.

Summary

In the 21st century, individuals with intellectual disabilities sometimes do not receive adequate support or preparation for the death of loved ones, resulting in negative consequences for their psychophysical health. This presents a challenge for modern society, as advancements in medical care have improved not only the quality but also the average lifespan of such individuals. In 2010, the population of individuals with intellectual disabilities aged over 65 accounted for 10% of the entire population with this disability, and according to prognosis, this figure will rise to 30% by 2030.[33] Therefore, it is crucial for specialists to recognize that thanatopedagogical education is an important component of mental health education. Neglecting it leads to numerous psychophysical difficulties, including individuals with intellectual disabilities. Key elements here are understanding, support, and proactive efforts – death prevention. Thus, the topic of death, its causes, and consequences should be incorporated into the flow of daily activities and conversations. Moreover, all questions should be answered honestly, while remembering that the answers must be specific and free from abstract expressions. When death enters the life of an individual with intellectual disabilities in a tangible way, through the loss of a loved one, it is essential to provide them with the space to experience grief without overinterpreting various behaviours or attributing them to "troublesome" symptoms of the disability. On the contrary, efforts should be made to understand these behaviours, as "much depends on the specific situation, the individual person, their level of intellectual functioning, ability to understand conveyed information, family circumstances, and overall life situation"[34].

The general conclusion from the literature analysis highlights the need for education in the field of thanatopedagogy and topics related

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[33] E. Domagała-Zyśk, *Starsze osoby z niepełnosprawnością intelektualną – specyficzne potrzeby i współczesne rozwiązania,* [w]: M. Czechowska-Bieluga, A. Kanios, *Współczesne oblicza pomocy społecznej*, Wydawnictwo UMCS. Lublin 2014.

[34] I. Fornalik, op. cit. s. 173.

to proper preparation for the death of loved ones and experiencing grief after a loss for individuals with intellectual disabilities. Key to this is the appropriate training of those who interact daily with this social group, such as their caregivers, educators, assistants, social workers, and healthcare professionals. Their knowledge and adequate thanatopedagogical competencies will translate into proper preparation and support for individuals with intellectual disabilities facing the loss of loved ones and the grief that follows.

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