

END-OF-LIFE AND DYING IN PERSONS WITH INTELLECTUAL DISABILITIES: IMPLICATIONS FOR COUNSELLING, EDUCATION AND SUPPORT

Assist. Prof. Dr. Jan Chrastina

Institute of Special Education Studies, Palacký University Olomouc, Czech Republic

ABSTRACT

People with intellectual disabilities (ID) generally have a shorter lifespan, but the duration of quality life is becoming more and more extended. That is why supportive, holistically oriented palliative care is also gaining in importance in the period when a client with ID is dying or is in the end-of-life stage of life. Although recent years have seen a steady increase in published surveillance and theoretical studies, empirical data about the needs of palliative care for people with ID are still rather rare. Most of the staff working in the health, social, and other service sectors are confronted with the difficulty of caring for, the approach to be taken to, and communication with people with ID. These people need adequate support in the topics of death, dying, accompanying, and mourning. People engaged in the helping professions should not deliberately avoid these topics, but, on the contrary, become initiators of open, clear, and objective communication heading towards the greatest possible extent of help and support to people with ID. At the same time, it is a huge demand for education and a great challenge for the pre-graduate and professional training of helping professions.

***Keywords:** end-of-life, dying, intellectual disability, counselling, support*

INTRODUCTION

The end of human life and the period of dying are demanding life stages. The way in which these situations are handled influences many aspects of everyday life, as well as the life satisfaction, quality of life, and functioning of the parties involved (i.e. the dying person, people close to them and their family, lay and professional carers, and others). In the case of people with intellectual disability/disabilities (hereinafter referred to as “ID”), this topic is emphasized, especially in the phase of the deterioration of a serious medical condition and/or progressive disease, comorbidities, or a concurrent impairment within another category of disability. Important decisions (indication of palliative care, awareness, planning interventions, etc.) often depend on the estimated life expectancy, or the expected end of life. Although the quality of care provided, including palliative, psychosocial, and spiritual, is increasing and the indicators and preferences are getting higher year by year, people with ID may not always

get the care that reflects the individual needs and wishes of these people at the end of their lives.

Defining the end-of-life is not a simple and unambiguous matter. An appropriate definition is offered by the Leadership Alliance for Care of Dying People, which indicates that the end of life concerns those dying clients/patients who die in the course of the following 12 months, or in whom death is assumed in the near future, or those with conditions leading to sudden deterioration, or if their life is threatened with sudden and unexpected events (complications). According to the general medical approach, these conditions include premature babies, whose prospects for survival are poor, or patients with a persisting vegetative condition [1]. Furthermore, we can conclude that the end-of-life period is considered to be a period of time that precedes the physical death of a person, and in some clinical fields it is characterized as the period of the last six months of the life of a dying person [2].

By the end-of-life, we understand the period – hours, days, weeks, months – in the life of a person in which it is, from the medical science perspective, obvious that death is immediate and cannot be prevented [3]. The non-uniformly defined terminology concerning the end of life represents a significant obstacle to research and grant activities, as mentioned by Hui et al. [3], who, in their systematic review, conceptualized and defined terms such as "actively dying", "end of life", "terminally ill", "terminal care", or "transitive care". The care for a person at the end of their life represents especially palliative (or directly hospice) care, which will make it possible to handle as best as possible the severe pain of patients and other problems accompanying the dying stage (including, most often, dyspnoea, congestion, nausea, vomiting, delirium, and others).

It includes comprehensive, interdisciplinary, and individualized medical, psychological, social, educational, and spiritual support not only to the dying person, but also to his/her family, friends, and both formal and informal caregivers, and also other professionals involved in providing holistically-oriented care. Palliative care may be received even during treatment; it begins when a person needs it. The palliative care and end-of-life concept confirm life and death as normal and entirely natural processes and are not intended to accelerate or delay death. Appropriate interventions can help to apply the knowledge, experience, attitudes, and advice of a multidisciplinary team, usually with a common aim: to remove dysthanasia (complicated, prolonged dying and/or an undignified, delayed death), pay attention to the dignity and autonomy of a dying person, and apply teamwork focused on satisfying the needs of patients and their families with the aim of maintaining the quality of life of all the relevant persons in the difficult situation that the end-of-life period undoubtedly is.

The aim of the paper is to describe selected aspects (needs, specifics, approach) of the end-of-life period in adults with ID in the form of possible themes

for discussion and starting points for the preparation of possible recommendations for practice. Specific selected aspects are shown below **in bold**.

END-OF-LIFE PERIOD IN ADULTS WITH INTELLECTUAL DISABILITIES: POSSIBLE TOPICS FOR DISCUSSION AND RECOMMENDATED CONCEPTS FOR PRACTICE

At present, people with different categories of ID are living for longer than ever. Yet many of these people suffer from long-term and serious illnesses and therefore, most often because of the deterioration of their health condition or the occurrence of some complication (and/or the simultaneous occurrence of multiple disabilities), they may die earlier. This is one reason, though not the only one, why it is necessary to provide these persons with high-quality and tailor-made interventions that are individually designed and reflect the specific needs of dying persons with ID. These clients are not "strange" or "different" – **they want to hear the truth, but they require more support, help, and counselling**. Specific words, specific forms, specific images, specific examples – all these help people with ID understand a difficult situation in which they are usually **unable to orient themselves and make decisions**. It is always appropriate to involve a person with ID in the preparation of the process of parting, grieving, and performing rituals (funeral, memories, and mourning rituals).

People with ID (most often in the form of mental retardation or dementia) still represent "a kind of challenge" for many carers and professionals in helping professions. However, **clients with pervasive developmental disorders** (autism, autistic spectrum disorders, autistic symptomatology) **may represent an even bigger challenge**, but are not included in the topic covered by this paper because of their highly specific nature (although they may be included under the ID category, as these disorders do not constitute an autonomous category). The provision of personalized interventions is complicated **by the way and quality of speech and communication**, as well as the ability **to understand information, requirements, wishes**, etc. In the end-of-life period, very often there appear **abstract concepts** which these people can find hard to understand or to interpret the content of the communication independently, and make decisions that relate to their own discretion and desires (what care they would prefer, coping with the symptoms of their health condition, symptoms of dying, previously expressed wishes, etc.).

It is appropriate and desirable to **ascertain the views and wishes of the dying persons with ID** to be able to lay the basis for justified starting points for high-quality after-care, **counselling, and also education and research activities**. In this field, the number of empirical research studies is not as high as the number of theoretically conceived studies, which is caused by the difficulty of including **these persons in a research set and the demandingness/feasibility of the research** concerning the emphasis on ethical aspects and personal freedom to leave a study at any time. The data collection itself is also demanding as a result

of obstacles to communication and the ability to understand the questions in a questionnaire or an interview, or the requirements imposed on the skills and tactful behaviour of researchers. This may lead to a study possessing many limits and the distortion of the "factual reality experienced by people with ID". It is advisable to talk with family members, carers, and providers of health and/or social care about how and where the clients themselves can contribute to the development of care, improvement of interventions, compliance with specific needs and wishes, etc., e.g. also by engaging them in some studies. Naturally, this will be mainly possible with clients who have mild or at most moderate mental retardation (alphanumeric codes F70 and F71 according to ICD-10) or clients with non-advanced dementia without a significant cognitive deficit (alphanumeric codes F00 to F03).

To obtain information from clients, it is possible to **use the form of stories** (real and fictitious), **samples from books, or various worksheets** – these materials will make it possible to open the topic and bring the content closer to a more specific form with an emphasis on understanding the content and its significance for persons with ID. In this context we can find what are termed "**social narratives**", i.e. stories that confirm the reality of the situation and respond appropriately to the client's questions in the form of modified (simplified, key) text, photographs, or the use of (interactive) technologies supported by alternative and augmentative communication. Due to the fact that some clients with ID have insufficient verbal ability and may not understand non-verbal signals, "social narratives" facilitate the expression of clients' basic needs. Narratives can also be created by ID clients themselves. As they may have **problems with the verbal expression of sadness, grief, or mourning** stemming from the anticipated loss, these expressive techniques can help them in their self-expression.

For some clients, it may be **a problem to distinguish between "death" and "dying"**, which must be remembered, as well as the fact that it is not always appropriate and desirable that the interview is led by a person known to the client and close to them (it may result in influencing, the effect of social desirability, when the client tries to look better than he/she really is, etc.). It is advisable that as much information as possible is submitted and explained to clients with ID using an "**easy-to-read**" **approach**, and that a "**person-centred approach**" is also applied. In this way, it is possible to achieve respect for specific capabilities, abilities, and skills of clients, who can become activators of change and adopt a proactive approach in a wide range of interventions that are provided. The knowledge and data obtained in this way are also valuable sources of information for **education** (university, professional, counselling). It is not always necessary to implement face-to-face interviews; sometimes group work is appropriate so as to remove shame and engage the group's members continually in communication according to its dynamics. Naturally, **safe contact** (with clear rules) in a **safe environment** (in which orientation is easy) must be established.

Another problem can be seen in the fact that the **persons with ID do not always seek adequate and timely assistance, care, or counselling**. This may be a risk factor leading up to premature death. Many family members may perceive their adult relatives as "**big kids**", but death, dying, the afterlife, etc. are emotionally very demanding topics to talk about. Dying persons with ID should always know that there is always an **opportunity to share their requests, wishes, needs, and (in-) comprehension**, and that **the right person will always be there to listen to them**. This may be more difficult as a result of the communication disabilities of clients. Sometimes, even professionals providing care "only estimate" what a client actually knows about his/her health condition or life-limiting illness, how much he/she understands it, and how much the client is able to communicate about such demanding aspects of human life. Lots of clients with ID are dependent on (sometimes non-stop) care, which can lead to communication disputes related to the question "**and why should I die if you take good care of me?**" This issue is all the more challenging when care is provided in the client's natural home environment. In their study, Kirkendall et al. [4] describe the findings of research that persons with ID are often considered persons with insufficient capacity for being informed about the terminal stage of the illness (diagnosis).

The limited capacity of persons with ID for **independent, free decision making** about the appropriate way of care or the choice of palliative care (by his/her own decision) can cause the **undignified dying and death of persons with ID**. This situation can also **complicate the grief and mourning of those who survive them** [5]; we are talking about what has been termed **complicated grief and complicated mourning**. Following the above, it is always necessary **not to attribute various changes in behaviour, communication, needs etc., automatically to the occurrence of ID**. We can often meet the still prevalent view that the clients in this target group "**do not understand it anyway**" and therefore this target group becomes high-risk in the context of inadequately and poorly provided "wannabe holistic" care. In many published studies we can find statements that a lack of education and training, awareness, and understanding of the needs of people with ID on the part of the staff can lead to uniform or even **template-like provision of interventions, support, and care without understanding the specific nature of the situation of dying persons with ID**. In this regard, we find it highly desirable also to educate medical, social, and other staff **in special education interventions, basics of psychiatry, diagnostics, methods and counselling, facilitation, and supportive activities**.

Clients with ID often use residential (social) care services. In the Czech Republic, the homes for people with disabilities or special-regime homes often become the "natural home" of these clients. However, this may also be due to the **lack of effective cooperation and coordination between the different components of services and care**. Thus, a client with ID can become a "migrating patient" who is sent from one facility to another. Likewise, many people engaged in residential (social) services may have a **lack of experience, education, and**

resources to understand and meet the needs of people with ID across the age categories. This can represent a huge barrier to providing palliative care to these people in an adequate, holistic, and individualized environment.

Experts and carers have a range of educational materials, recommendations, and guidelines related to end-of-life care. However, it is a question of **how far the contents of these information sources can also be "applied and used" in persons with ID**. This can include, for example, spiritual needs, an explanation of the afterlife, the management of tumorous and non-tumorous pain, mental state and well-being, and other highly specific aspects associated with the end-of-life stage. The problems faced by dying clients with ID are truly fundamental; they may include physical pain, depression, various intense emotions, loss of dignity, hopelessness, and other symptoms/problems that should be "solved" appropriately at the end of their life. **Understanding the experience of dying persons with ID should help experts improve the care for these terminally ill clients.**

The quality and availability of care for the persons with ID who are dying deserves a holistic approach that includes the physical, personal, family, and spiritual sphere of a client and his/her immediate environment. The family of a dying person should always consider this concept as part of care. It is also important to **acknowledge that death is an integral part of the life story**. The main objective of the end-of-life concept is to establish a mutual understanding regarding the values, needs, and preferences of a person in care, which will shape his/her care plan on the basis of exactly these priorities. A person who is dying has a **lower decision-making** capacity [6]. Patients who participate in the planning of their own care are more likely to enforce their own interests. It means that the quality of life and satisfaction with the form of care will be on a higher level, which is related to a lower level of depression and anxiety in (bereaved) family members, as well as significantly lower costs of health care and other care provided [7]. The key question in the above concept is the perception of dignity mediated by the possibility of **being autonomous and controlling the state of affairs**. Previous research confirms that the perception of one's own dignity and autonomy contributes to understanding the needs and concerns of patients who are in the terminal stage of an incurable illness [8]. The loss of autonomy and control is interpreted as the loss of self and the loss of the feeling of dignity and its fulfilment. It seems that **staff members tend to avoid talking openly about death** and the communication after death (e.g. about funeral or farewell rituals) is actually easier for the staff than that before death [9]. The study identifies three factors that had a particularly strong impact on personal practice in communicating bad news related to death: (1) fear and anxiety about death; (2) life and work experience; (3) the organizational policy of the facility. Therefore, in practice we can encounter tendencies towards avoidance on the part of the staff. The strategies used by the staff to protect themselves and the people they support may be well meant, but they are not useful or desirable and should be addressed with a view to their cessation. It is essential to train **all employees in end-of-life issues, dying theory, and communication skills** [10], as well as actively to

identify and evaluate the views and opinions of people with ID when considering what is (and what is not) good care in the end-of-life period; this is an essential issue [11].

The problems of clients with ID in a difficult life situation can **manifest themselves in clients' symptoms** that should be monitored and evaluated correctly by the staff. These symptoms may include a change in usual activities being carried out, locking themselves away, fear of separation from others, anger, guilt, risky behaviour accompanied by anxiety, aggression, self-harming, etc. These symptoms can be associated with ID generally, not only in relation to loss, grief, or dying. In cooperation with a dying client with ID, it is appropriate to establish **"a grief support plan"**. A person with ID mostly experiences grief emotionally just like people from what are termed intact populations (however, the external manifestations may be different). Clients may experience **a lack of expressed interest and provision of support** or do not understand these activities properly and in a timely manner. In such cases, it seems appropriate to apply the principles of **supportive counselling**, as well as participation in various rituals, the use of visual material, etc. (any deficits in social interactions usually make the communication process more difficult). Persons with ID should be able to understand the differences between **"permanent loss"** and **"temporary/transitional loss"** – clients usually **fail to understand euphemistic phrases** (often very abstract) such as "he/she left", "is in a better place", "has become an angel", "afterlife", etc. Therefore it is appropriate **to use words with a perfective aspect** – died, is buried, death, etc. Sometimes, even the term "loss" is perceived as indeterminate and with unclear content and can be associated with specific issues ("has lost something", "someone stole something", "something was found", etc.). In such situations we can meet with reactions on the part of ID clients which may be perceived as inappropriate – for example, **unpredictable reactions** of the client in the form of laughter, smiling, disrespect for topics, insensitivity, and others.

CONCLUSION

The end-of-life stage in people with ID does not have a different form or specific features from that of people from what has been termed the intact population (without intellectual or other disabilities, or in a state of full health). The needs of dying persons with ID are the same as those of other dying people; they differ only in the ways in which they are fulfilled as a result of possible barriers, a lack of communication, the ability to express needs, and other specific features given by the ID itself. Understanding the needs of dying clients with ID and the possibilities of meeting them fully are the basic starting points for applying good practice in the end-of-life stage. Providing holistic palliative care should respect **"a person-centered approach"**. The problem is the availability of palliative care to people with ID, as well as a lack of experience and education and limits in the communication process on the part of carers and/or accompanying persons.

Palliative care for persons with ID in the end-of-life stage should be discussed in a natural environment and by natural communication through language, with reciprocal verification of the content of the information that is communicated. Clients should be encouraged to "talk about their wishes and needs at the time of dying" so that they can become active participants in providing professional care of a high standard, yet sensitively and humanely and with understanding for the experience and behaviour of persons with ID.

Persons with ID experience many obstacles in gaining access to quality health and social care and to counseling because of severe and terminal diseases, including late diagnosis, when the symptoms are misinterpreted because of the presence of ID and symptomatology [12]. With regard to the philosophy of social inclusion, it can be argued that understanding and fulfilling the needs for health and social care in older and terminally ill elderly people with ID require further professional assistance and study of this phenomenon [13].

Therefore anybody who is involved in the dying and death of persons with ID should always have the opportunity, time, and space to talk about death and dying without prejudice, shyness, or fear. Comprehensive care for this target group of dying clients must be available, accessible to all, fair, and focused on the quality of life (with maximum elimination of dysthanasia) to provide dying clients with ID with the same opportunities as those from what is termed the intact population.

The value of life during dying is as important as health itself. In addition, the awareness of the expected death of a loved one allows people to predict the time of death, thus allowing them to experience the anticipated period of grief and mourning. In the socio-cultural context of the Czech Republic, the topic of dying and death in persons with ID is discussed rather in the form of its theoretical bases – rigorous research activities are still lacking [14].

ETHICAL ASPECTS AND CONFLICT OF INTEREST

The author declares that the present study has no conflict of interest. The author also declares that the text includes appropriate citations of all bibliographical sources.

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