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CONCEPT OF DEATH IN YOUNG PEOPLE WITH INTELLECTUAL DISABILITY: A CONTRIBUTION TO THE PEDAGOGY ON DEATH

El concepto de muerte en jóvenes con discapacidad intelectual: una contribución a la pedagogía de la muerte

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ABSTRACT: Despite being an essential human condition, death is an under-researched area in the effort to improve people with intellectual disabilities' life quality. In this article we describe the concept of death among young people with intellectual disabilities. A mixed research methodology that includes quantitative and qualitative approaches was employed, including both a questionnaire and a semi-structured interview. Results indicate that participants have difficulty understanding of biological dimensions of death. Moreover, it has been found that participants present a wide range of opinions, attitudes and beliefs about death. Conclusions reflect on implications of these results

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for a possible pedagogy on death in young adults that would include accompaniment during bereavement.

KEY WORDS: concept of death; intellectual disability; pedagogy on death; bereavement.

RESUMEN: A pesar de ser una condición esencial del ser humano, la muerte es un ámbito poco investigado en el esfuerzo por mejorar la calidad de vida de personas con discapacidad intelectual. En este artículo se describe una investigación sobre el concepto de muerte en jóvenes con discapacidad intelectual. Se hace a través de una metodología mixta que incluye un enfoque cuantitativo y cualitativo, utilizando un cuestionario y una entrevista semiestructurada. Los resultados indican que los participantes tienen dificultades en la comprensión de las dimensiones biológicas de la muerte. Además, se ha encontrado una amplia variedad de opiniones, actitudes y creencias sobre la muerte. En las conclusiones se reflexiona sobre las implicaciones de estos resultados en una posible pedagogía de la muerte en personas adultas con discapacidad intelectual que incluya el acompañamiento en el duelo.

PALABRAS CLAVE: concepto de muerte; discapacidad intelectual; pedagogía de la muerte; duelo.

1. Background

THE SUBJECT OF DEATH IS USUALLY NEGLECTED OR MISPLACED in society and deprived of its natural educational relevance. The taboo of talking or even thinking about death is even greater in the case of people with intellectual disability, who in many cases, are deprived of this right in situations of close losses, and also in educational contexts in which pedagogical introduction of the death could play an important formative role (Rodríguez Herrero *et al.*, 2013). Intellectual disability is defined as a condition characterized by significant limitations in intellectual functioning and adaptive behaviour manifested in practical, social and conceptual skills (American Association on Intellectual and Developmental Disabilities, 2010).

This article presents a research that aims to help to normalize this situation through an approach towards introducing the concept of death to people with intellectual disability. The goal is to know whether the participants –75 young people with intellectual disability– understand biological dimensions of death, as well as their attitudes, ideas and beliefs about death. The ultimate purpose is to support people with intellectual disabilities who are grieving and to create programs that present death as a natural part of life (Dodd *et al.*, 2008). Understanding the concept of death may help to understand better the processes involved in the development of bereavement and to articulate an accompaniment to the bereavement process to prevent its ramifications.

We consider the concept of death from a complex perspective, focusing on the meanings that are given to the phenomenon of death. Thus, the concept of death would encompass two constructs (Rodríguez Herrero, 2012):

- Concept of biological death. This refers to death as a natural phenomenon, which is manifested in various ways: as total death (extinctions, disasters, etc.), in biological processes and cycles, as continuous death (cell replacement, etc.). It includes the understanding of biological characteristics of death (as shown below: non-functionality, permanence or irreversibility, inevitability and universality).
- Conceptions about death. The set of ideas, beliefs and attitudes presented in the discourse about death (Meeusen-van der Kerkhof *et al.*, 2006).

How the concept of biological death is acquired has been studied mostly in children; the scientific consensus is that the biological dimensions of death are usually acquired and understood between the ages of 7 and 11 years-old. This acquisition is linked to the stage of concrete operations in Piaget's theory (1969). In the formal operational stage, the child would understand the concept of biological death in a more abstract formulation (Cotton & Range, 1991).

There is also a consensus on the multidimensional nature of the concept of biological death (Viñas & Domenech, 1999), although some of the proposed sub-concepts differ among researchers. Within the concept of biological death, this research considers the sub-concepts non-functionality, permanence or irreversibility, inevitability and universality (Smilansky, 1987; Sigelman & Rider, 2005). These sub-concepts refer to (Corr & Corr, 1996):

- Non-functionality: Understanding that once a living thing dies all of the typical life-defining capabilities of the living physical body cease.
- Permanence or irreversibility: Understanding that once the physical body dies, it cannot be brought to life again.
- Inevitability: Understanding that death cannot be prevented nor eluded by strategy or dexterity.
- Universality: Understanding that all living things must eventually die.

This follows the model proposed by the Questionnaire of Death Concept (Ramos, 2010) used in the study.

There has been little research on the biological understanding of death in adults with intellectual disability. Research to date is based on the potential impact that the acquisition of the concept of biological death may have for the accompaniment in bereavement situations and for educational intervention within a Pedagogy of Death, understood as an emerging scientific field (Rodríguez Herrero *et al.*, 2012).

McEvoy (1989) studied the acquisition of a number of sub-concepts associated with biological death through an illustrated story told to people with intellectual disability. Gender, age and experience, in the case of having had a loss, do not appear to be variables that influence the acquisition of the concept of biological death. Global cognitive level and communication skills were more related to the understanding of death. Myredden and Narayan (1993) found similar results in a study in which the concept of biological death was assessed in people aged 16 to 20 years-old with mild

to moderate intellectual disability. The acquisition of the concept was correlative to the degree of intellectual disability of the participants. In a theoretical review, Dodd *et al.* (2005) found that many authors have concluded that there is a relationship between the acquisition of the concept of biological death and intellectual capacity. Unlike McEvoy (1989), Kennedy (2000) found that the fact of having had previous experiences of loss was much related to the acquisition of the concept of biological death in a study of 108 adults with intellectual disability.

Another variable that may be related to the understanding the concept of biological death is, according to McEvoy *et al.* (2002), emotional skills. In their study, it was found that 22% of participants had already acquired the concept of biological death. Emotional and verbal comprehension were good predictors of the acquisition of the concept.

Age, according to Seltzer (1989), is a significant variable in the acquisition of the concept of biological death of people with intellectual disability.

Conceptions about death, which can be understood as the set of ideas, beliefs and attitudes about death, have been investigated previously in people with intellectual disability (Meeusen-van de Kerkhof *et al.*, 2006). Authors found that there is a great diversity in how death is understood.

This past research provides the theoretical basis for the current study, which, when compared to previous studies, provides a holistic vision of the complexities of the concept of death, addressing not only biological understanding (Dodd *et al.*, 2005; Kennedy, 2000; McEvoy, 1989; Mc Evoy *et al.*, 2002; Seltzer, 1989) but also the ideas, beliefs and attitudes towards death (Meeusen-van de Kerkhof *et al.*, 2006).

2. Method

2.1. Participants

The sample consisted in 75 people with intellectual disability aged between 18 and 35, who, at the time of the study's field work, were attending either Madrid's Special education school *María Corredentora* (Spain) or belonged to the Promentor Program ("Training for the Labour Inclusion of Young People with Intellectual Disability"), which is developed by the *Prodis Foundation* in collaboration with the Universidad Autónoma de Madrid (Spain) (Izuzquiza, 2012). The questionnaires and interviews were conducted in 2012. Participants were selected through purposive sampling of people with intellectual disabilities associated with the Prodis Foundation, which supported the investigation, as well as other associated facilities.

Most of the participants were between 18 and 21 years-old, (amounting to) 65% of the sample studied, while 26% were between 22 and 25 years-old, and the remaining 9% were between 26 and 35 years-old. Among all the participants, 44% were male and 56% female.

With regards to the degree of intellectual disability, based on the criteria of the DSM-IV (2005), 52% of the sample had mild disability, 32% moderate and 9% severe.

The remaining 7% did not match in the criteria set by the DSM-IV, although all of them had an intellectual disability certificate.

The guarantee on the exercise of the subjects' rights as well as the ethics in the research procedure were certified by the Ethics Committee of the *Prodis Foundation*, an institution with a long history that has been repeatedly recognized for its best practices in the field of study. In addition, participants and their families gave their consent to participate in the research.

2.2. Design

The research is based on a mixed design which includes both a quantitative and a qualitative approach. The description of the concept of biological death was obtained through a questionnaire as part of the quantitative approach; while the understanding the conceptions of death was obtained by qualitative interviews.

2.2.1. Concept of Biological Death

On the concept of biological death, the different dimensions were assessed according to the scientific community criteria (Smilansky, 1987; Sigelman and Rider, 2005). This part of the research was conducted through a transactional, descriptive and correlational design (Hernández *et al.*, 2006).

To assess the acquisition of the concept of biological death among participants, the Death Concept Questionnaire by Ramos (2010) was used. The instrument presents 15 sentences, each of them accompanied by a picture. The participants had to answer if the statement was true, false, or unknown. Each sentence belonged to one of the following dimensions of the concept of biological death: 1) Non-functionality, 2) Permanence or irreversibility, 3) Inevitability and 4) Universality. The sentences included in the questionnaire are:

- 1) When someone dies, he cannot play (Non-functionality).
- 2) When someone dies in winter, he is cold (Non-functionality).
- 3) When someone dies, if he is hungry, he can eat (Non-functionality).
- 4) When someone dies, he is asleep (Non-functionality).
- 5) When someone dies, he comes back if he is called (Permanence).
- 6) When someone dies, he is dead forever (Permanence).
- 7) When someone dies, he can live again (Permanence).
- 8) When someone dies, we do not see him anymore (Permanence).
- 9) If you are on a trip when you are about to die, you can save yourself (Inevitability).
- 10) If you run a lot when death comes, you never die (Inevitability).
- 11) You can choose between dying or not (Inevitability).
- 12) Some people do not die (Universality).
- 13) All persons and all animals die someday (Universality).

- 14) My parents will live forever (Universality).
- 15) Pets never die (Universality).

The correction of the questionnaire was criterial and its use in adults with intellectual disability was previously validated by three experts and through a pilot test with four people with intellectual disability. In the questionnaire, it is assumed that the participant has 'fully acquired' the concept of biological death if all the sentences are responded to correctly. Each sub-concept has been 'acquired' if the answers to all the sentences addressing that sub-concept are correct. The respondent is 'in process', if one response is incorrect, and 'not acquired' if all are incorrect. The reliability of the instrument for the study sample was 0.825, according to Cronbach's alpha test, so the consistency and coherence of the results can be considered high.

2.2.2. Conceptions about Death

The methodological design that is used to understand the conceptions about death by the participants in this research is qualitative and is based on the characteristics of the phenomenological design. This methodology aims to understand the perceptions and meanings that the study population gives to a phenomenon (Bogdan & Biklen, 2003) or to a concept (Creswell, 1998). To access the meanings that participants gave to the object of study, a semi-structured interview guide was developed to include the following categories of analysis:

- 1) Attitudes towards Death: positive or negative dispositions related to different aspects of death (social standards, naturalness, rejections, phobias, indifference, etc.).
- 2) Ideas and beliefs about death: set of ideas underlying the meanings given to death, which surround death or post-mortem beliefs.
- 3) Formative potential of death: rating death as a resource for education and personal growth through reflection and social normalization.
- 4) Cultural rituals associated with death: functional concepts related to rituals and funeral rites.
- 5) Sensitivity and resilient resources: abilities linked to the appreciation of the feelings generated by the loss of a loved one in other people and generating personal resources to cope with significant losses.

The *Interview on the Conceptions about Death* was developed and validated, as was the questionnaire, through the assessment of three experts and of a pilot test with four people with intellectual disability. It included a brief story of easy reading with a picture and some questions. One-on-one interviews were conducted in quiet rooms by investigators in areas designated by the centers that participated in the research, with an approximate duration of 45 minutes. The interview began with a questionnaire which guided the subsequent development of the interview. The interview was

therefore made up of the story (with two different models for participants in the need of reading and reading comprehension support) as well as the questions included in the interview, as follows:

2.3. *Story*

- Model A: “Javier’s grandfather died two days ago at the age of 85. Javier feels sad because he loved him very much. Javier especially liked when his grandfather told him stories of his youth; Javier enjoyed listening to him very much. Javier has gone to the funeral of his grandfather. He feels supported because he has been surrounded by his family and because he was able to say goodbye to his grandfather with everyone else there. To remember him, Javier has decided to write a small book about the stories his grandfather told him with photographs of the two together”.
- Model B: “Javier’s grandfather has died. Javier feels sad. Javier has gone to the funeral and he felt loved by his family. Javier is going to write a book with photos of his grandfather to remember him”.

2.4. *Questions*

- What does this story tell?
- How does Javier feel? Why do you think he feels like that?
- Javier says that he has gone to the funeral of his grandfather. Do you know what a funeral is? Have you ever been to one? How was it? How did you feel?
- Javier feels supported by his family by being with them. Why?
- Where do you think Javier’s grandfather is after his death?
- Do you think it is important to remember loved ones? What can Javier do to remember his grandfather?
- What is death for you?
- Do you think it is ever normal to talk about death?
- Have you ever thought about your own death? What have you thought?
- Do you think it is important to live considering that one day we will die and that our loved ones will die? Why?
- Do you think that talking about death can help us deal better with the loss of a loved one? Why?
- What do you think about the subject of death in this interview?

Some questions were adapted to the comprehensive capacity of the participants.

3. **Results**

3.1. *Concept of Biological Death*

The complete acquisition of the concept of biological death occurred among 17.3% of the participants sampled (13), while 82.7% (62) have not fully acquired

the concept of biological death, according to the questionnaire presented previously (Ramos, 2010). A table with a summary of the acquisition of the different sub-concepts studied follows:

Table 1. Results of the acquisition of the sub-concepts of the concept of biological death			
Sub-concept	Acquired	In process	Not acquired
Not-functionality	30.7% (23)	4% (3)	65.3% (49)
Permanence or Irreversibility	54.7% (41)	8% (6)	37.3% (28)
Inevitability	50.7% (38)	5.3% (4)	44% (33)
Universality	36% (27)	5.3% (4)	58.7% (44)

In relation to questionnaire statements on death, the ones that most of the participants answered correctly were: “When someone dies, he can live again” and “When someone dies, we do not see him anymore”, representing 81.3% (61) of the sample. In contrast, the sentence that most of the participants answered incorrectly was: “My parents will live forever” with 54.7% (41) of the sample answering this item incorrectly.

Participants identified, on average, 1.73 sub-concepts. Table 2 shows the frequency of sub-concepts understood by the participants:

Table 2. Frequency of understood sub-concepts	
Sub-concept	Frequency
0 sub-concepts	21
1 sub-concept	15
2 sub-concepts	14
3 sub-concepts	13
4 sub-concepts	12

The statistical analysis suggests that the acquisition of the concept of biological death has a significant relation with IQ (measured by the WAIS IV tests), after the IQ data were reduced to categories. This was confirmed through the Spearman’s rho that resulted in a correlation coefficient of 0.608 between the two variables, with a significance of 0.00. This same test was used to check if there is any relationship

between a participant's age and their biological understanding of death, resulting in a low but significant correlation (Spearman correlation coefficient of 0.318, with a significance of 0.05).

However, it appears that there is not a significant relation either with the gender of the participant (a Mann-Whitney U test for nonparametric data resulted in a significance of 0.628, greater than 0.05) or with the fact of having had a loss of a significant person over the past 10 years (using the same statistical test, a significance of 0.773 is obtained).

3.2. *Conceptions about Death*

Below are the results of the qualitative and interpretative analysis of the interview conducted on conceptions about death.

In terms of the category of "Attitudes towards Death", a wide range of attitudinal measures with regard to the theme of death has been found. There are participants who believe that it is better to neither discuss this issue openly nor to think about it: "I do not think (it is better to talk about death); it is better not to think about it and live day to day. When you're older and through your 80s, then it will come" (participant 30); "Talking about death would be painful to our hearts, and it upsets me a little" (participant 34). Others believe that maybe it is good to treat it more naturally. Participant 41, for example, thinks that: "Not that I like death but I think we should talk more about it". Anyway, many participants agreed that nowadays death is a taboo subject: "A lot of people are affected by the issue and prefer to put it aside rather than having a conversation" (participant 3); "For many people death is a taboo subject" (participant 23).

In the category "Ideas and Beliefs about Death", different conceptions of death have been found. Death is conceived as something opposite to life: "Death is that you no longer live" (participant 18); it is also identified with the end of life: "The final stage, when the body stops functioning" (participant 29). Others, however, believe that death is a transition to another way of being: "Death is when your whole body shuts down, and you cannot do anything, and you go to the other world" (participant 5); as part of the life cycle: "It is important to know that the human being consists of this: to be born, reproduce and die. This is its motto. Death is inseparable" (participant 74). Sometimes death can deny one's individuality, as illustrated by participant 38: "Well, if I die, where will my future be?". And for others it is an unknown: "I do not know what death is" (participant 21). There are different ideas about death which express a diversity of conceptions, prejudices, fears, rejections or acceptances.

Regarding "the Formative Potential of Death" significant differences between participants are also perceived. Some participants reject the idea that death may have no guiding sense for life: "I think it is better not to think about death" (participant 42), while others argue that to think about and make death more natural in society and education can help prepare for life and help a person become a more mature:

“It would be good to talk more about death, because we will all die sooner or later” (participant 5); “I found it very interesting to talk about death, because in this way we know what it is to be human” (participant 74).

The knowledge of “Cultural Rituals associated with Death” appears unevenly among the study participants. Some of them identify the emotions they may have during these rituals: “My grandmother died, and then I went to the morgue and saw her there, it was very painful. I felt very sad, because I was with my family and you say goodbye to a person that you are not going to see again” (participant 1). While some participants seem to be familiar with these kinds of rituals, others indicate not knowing them. Among the former, participant 5 states, for example, that “a funeral is a place where you meet many people in mourning and where you really experience how a loved one or a family member is buried”.

The last category of analysis is “Sensitivity and Resilient Resources”. Many participants stress the importance of family and friends in the process of grieving the loss of a significant person: “I felt sad when I lost my grandfather but as I was with the whole family; I felt more supported” (participant 16). These supports require some confidence, considering the fact that death or loss is such an intimate subject, as expressed by participant 3: “I would talk about this topic with people I trust, not just with anyone”. Some participants, on the other hand, are made aware of their own mortality, leading them to worry, for example, if their disability can be associated with a reduced life expectancy: “I have sometimes thought that, being handicapped, maybe I may die before the average person. My parents say no, that it has nothing to do with that. I often think about it because it scares me” (participant 26). At the same time, other participants can see the potential guiding value of death with respect to life: “Before I die, I want people who have been around me to have enjoyed being with me” (participant 27).

4. Conclusions

Death is a perennial topic, as others subjects can be, such as love (Morentin *et al.*, 2006) or sexuality. It is not indifferent to people with intellectual disability. It worries them. They require a vital and pedagogic accompaniment that can help them to accept death in a natural and formative atmosphere, and a comprehension of death from the possibilities that can be given to think about death, to reflect about it and treat it naturally in order to live a better quality life (Rodríguez Herrero *et al.*, 2013). This article gives voice to those who historically have been denied these possibilities in a topic as human as death.

The results indicate that, as in the rest of the population, people with intellectual disability may have varying knowledge, attitudes, ideas and beliefs about death. With respect to the acquisition of the concept of biological death, cognitive difficulties may have to be overcome in understanding an abstract concept such as death. These results coincide with previous research (McEvoy *et al.*, 2002). A strong influence of the degree of intellectual disability has been shown to influence the understanding

of biological death, as found in other studies (McEvoy, 1989; Myreddi & Narayan, 1993; Dodd *et al.*, 2005). The fact that all the components that define biological death are not completely understood does not mean that those who experience the loss of a significant person in their lives, does not suffer or feel the natural pain that may come with the death of a loved one. This may suggest a need for additional support to work through their grief.

Similar to the evaluation of the results obtained in the Concept of Death Questionnaire (Ramos, 2010), the sentence which most participants responded to incorrectly in the current study is “My parents will live forever”. This indicates the difficulty of some to accept a range of emotions and feelings related to the possibility that people die who have greater emotional ties and dependence.

In relation to the conceptions of death analysed through an interview, there is a remarkable heterogeneity among participants in attitudes, ideas and beliefs about death. These results may not be distinctive in people with intellectual disability, but respond to the evolution of each participant in terms of emotional maturity or their own experiences with loss or death. Future research could verify whether this diversity also occurs in people without intellectual disability and on what that may depend. However, participants generally spoke naturally and fluently about death in the interviews, indicating that in a climate of trust, closeness and normality; death is not strange to them and can be addressed openly with young people with intellectual disability.

The results of this study invite us to wonder about the different routes of intervention on death in people with intellectual disability who live experiences of loss, or simply require an answer to their concerns. Education, through practices that treat death from a formative aspect, is the most valuable tool to build a society in which death is not a taboo subject but a part of the human condition from which to consider and guide the personal and collective life.

Pedagogy on Death includes both educational support in the mourning process (Rodríguez Herrero, Herrán & Izuzquiza, 2013a) as well as intervention prior to the occurrence of a loss, which aims to educate students on the educational opportunities of introducing the concept of death through values education (Rodríguez Herrero, Herrán & Cortina, 2012) and for the development of resilience (De Dios Uriarte, 2006). The results of this study provide new insights into how people with intellectual disabilities can be educated on death. As for the accompaniment during bereavement, aspects such as the support for the biological understanding of death and respect for one’s own development of ideas, beliefs or attitudes before the loss become important.

Among these supports, the following should be considered (based on the dimensions of support described by the American Association on Intellectual and Developmental Disabilities in 2011):

I. Intellectual Skills: to promote the understanding the concept of death; clear, simple and adapted information; use of pictures or stories to facilitate emotional expression.

II. Adaptive Behavior: to explain the funeral rites; to adapt to changes and new routines; to explain the bereavement process; to encourage participation in rituals; to explain that sometimes it is normal to externalize emotions (in some cases we find that having internalized social norms associated to emotional control in a rigorous and strict way can hinder emotional and sentimental expression in situations of grief).

III. Participation, interaction and social roles: to minimize secondary losses (abrupt changes in daily life stemming from the death of a loved one or close friend who depends on some form of support); to encourage, without forcing, conversation about the loss; to include this person in the bereavement shared with others; to give support to interpersonal communication; to encourage the emotional processing of the loss in natural contexts; to support the family in normalizing the theme of death and loss in the family environment so that the person with intellectual disabilities can share more easily her/his feelings and concerns; if the person with intellectual disabilities, who has suffered the loss, is employed, it is important to establish communication channels between the figure of support and the co-workers of the person with intellectual disabilities to provide guidance on how to normalize the situation in the workplace.

IV. Health: to identify symptoms of pathological mourning after a period of three or four months; to refer, if appropriate, the bereaved person to clinical specialists; to guide families and report physical symptoms that may appear in the grieving process; to intervene with peers, friends or partner; to explain to the one who has had the loss, if necessary, the physical symptoms that may occur during the grieving process.

V. Context: to encourage the expression of feelings of guilt; to encourage a coherent response of the support institution (consensus resulting from the coordinated work of the entire professional team); to plan the transfer of information between professionals and peers of the person who has suffered loss so that a normal environment prevents the emergence of suspicions, rumors, etc.; to make more flexible and adapt the training plan to the needs arising from the bereavement situation; to identify a professional or reference guardian that accompanies the person who has suffered the loss during the bereavement process; to consider possible mental health disorders that may hinder the healthy working through the loss.

In relation to the educational intervention prior to the loss, the diversity of ideas, beliefs and attitudes about death guides the formative intention not only to the development of a proper idea or attitude, but also to the development of the concept of death itself and self-constructed conceptions of death, which also promote the personal and social maturity of the person with intellectual disabilities. The resources identified in Rodríguez Herrero, Herrán and Izuzquiza (2013b) –film forum, service learning, life cycle, literature, partial deaths or news media– can help support the educational potential of death. Death can be educational, from a deeply pedagogical perspective, and it can be part of inclusive education to improve the quality of life for people with intellectual disabilities.

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