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## The Experience of Alzheimer's Disease as a Learning Situation

### Abstract

The author shows Alzheimer's disease as a learning situation, from the andragogic perspective and in the context of experience analysis of three family carers. She describes this learning as an informal process. She also points to the dramatic aspect of accompanying the patient on their journey as an important background to this process. She emphasizes "maturation in a process" as a particular dimension of this learning which deepens the existential development of the carers. She stresses the importance of support for people suffering from Alzheimer's disease by adult education and geragogy specialists, which enables carers to experience the disease as a process of broadening their self-awareness.

**Keywords:** Alzheimer's disease, learning, family carers, analysis of experiences, andragogy.

### Doświadczenie choroby Alzheimera jako sytuacja uczenia się

#### Abstrakt

Autorka ukazuje, z perspektywy andragogicznej, w kontekście analiz doświadczeń trojga rodzinnych opiekunów, chorobę Alzheimera jako sytuację uczenia się. Opisuje to uczenie się jako proces nieformalny. Wskazuje na dramatyczność towarzyszenia choremu w jego drodze jako istotne tło tego procesu. Uwypukla też „dojrzwianie w drodze” jako szczególny wymiar tego uczenia się, pogłębiający egzystencjalny rozwój opiekunów. Akcentuje znaczenie wsparcia osób w sytuacji choroby Alzheimera przez andragogów i geragogów, które może pozwolić opiekunom doświadczać tej choroby jako procesu pogłębiania samoświadomości.

**Słowa kluczowe:** choroba Alzheimera, uczenie się, opiekunowie rodinni, analiza doświadczeń, andragogika.

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## Introduction

Alzheimer's disease is an individual life experience, occurring particularly in old age, diagnosed most frequently after the age of 65. It is a physical, mental, and spiritual experience related to dysfunctions of orientation in the surrounding world as a result of disturbances of cognitive processes, in particular memory processes; an experience which means a change in the sphere of emotions, behaviours, and personality, making independent everyday functioning more difficult (cf. Zająć-Lamparska, Leszko 2017).

Alzheimer's disease is, however, not only an individual but also a social problem (Trafiałek 2002). It arouses common and strong fear, not only in individuals at risk of the disease, but also in family members of people possibly suffering from the disease and in society, which does not understand the disease and is afraid of its burden. The authors of one American guidebook write:

We all know that 'the wave of old age' will soon flood our civilisation but we are not ready for it. Even after the death of President Ronald Reagan, memory disorders cause embarrassment. Many families try to hide or deny those disorders until, in the end, they become bankrupt – in the financial, spiritual, and emotional sense. Alzheimer's disease cannot be satisfied with one individual... it claims whole families (Shankle, Amen 2012: 6).

The Alzheimer's disease experience is becoming increasingly common. A increasing in the incidence rate may be observed. The disease mainly affects ageing people after 65 and worsens in the following decades of old age. At present, 350,000 people are suffering from the disease in Poland. In 2050, there will be over a million of them, i.e. three times as many. And 44,000,000 people are suffering from the disease all over the world at present. As predicted by WHO, in 2050 there will be 115,000,000<sup>1</sup>. The statistics are frightening, considering the fact that, at present, society is not able to cope with a smaller population of patients.

Alzheimer's disease, as a neurodegenerative disease connected with dementia, is a medical and health issue affecting individuals living in well-developed societies, where the average life span is increasing. In that context, it is also a geriatric issue related to diseases connected to the ageing process. Being a disease, it is associated with a diagnosis, therapy, and prevention. The health care system becomes involved in the process of supporting an individual suffering from Alzheimer's disease, along with other social services, including social workers. In Poland, the support of a patient with Alzheimer's disease falls mainly to the patient's family. Informal family carers, often with no knowledge of the disease, overwhelmed with its surprising and difficult course, try to cope with that task of providing care

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<sup>1</sup> <https://www.focus.pl/artykul/polacy-coraz-czesciej-choruja-na-alzheimer> [accessed: 7.10.2019].

with various results. Their negative experiences in that area often become a long-term trauma. The image of the disease in society, coloured by such experiences, is very often extremely negative. The disease arouses fear and is associated with social misunderstanding and rejection. However, is it always like that? Is it possible to experience Alzheimer's disease in a different way? Is it possible to gain positive experiences from the disease? These are questions asked in this paper by an andragogy – geragogy specialist. The situation of Alzheimer's disease is treated here as an andragogic problem, as it is also seen as a situation of learning understood widely as increasing awareness and self-awareness, as becoming someone greater in the face of a situation which is existentially difficult. On the other hand, the situation of Alzheimer's disease is associated with the question of how to support a patient with Alzheimer's disease, how to “accompany them in their journey” (Dubas 2019) to make that an experience which enriches participants in an existentially difficult situation and contributes to their development and internal maturation.

This paper is an attempt to look at Alzheimer's disease as a learning situation to show that it is not only a danger, but also an opportunity for development. At its empirical level, the paper is based on the experiences of three informal family carers of patients with Alzheimer's disease, i.e. a wife, a husband, and a daughter. Two communications have already been published (Beaudoin 2002; Lallich-Domenach 2002). The third one contains the personal experiences of the author<sup>2</sup>. Those experiences refer only to informal learning and, as a result, the paper concerns that dimension of learning.

## Method

The method used in the study is contents analysis (“study of recorded human communication”) (Babbie 2008: 358) as an example of a non-reactive method, with no influence on the analysed existing communication. The study included three analysis units, i.e. statements of informal family carers of people suffering from Alzheimer's disease, that is to say statements of a wife, a husband, and a daughter. Two communications (those of a wife and a husband), translated from French, have already been published in a Polish local gerontology journal for Polish gerontology researchers and practitioners acting for elderly people as well as students, in particular on pedagogical courses. The third communication (that of a daughter) comes from the “diary of the researcher”, author of this paper and, at the same time, a patient's carer.

The selection of the research sample was intentional; the researcher has consciously chosen three statements of informal family carers which show

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<sup>2</sup> The quoted experiences of the author are marked with ED.

the developmental nature of experiences they gained in the situation of Alzheimer's disease. That was a conscious effort as a result of the need to show Alzheimer's disease in the manner different to the stereotypically negative one, which is common in society. It is an attempt to overcome that stereotype by presenting the different experiences of those three carers.

The contents analysis was directed by two main analytic categories which conceptualised the studied issue, i.e. Alzheimer's disease as a tragic situation and Alzheimer's disease as a learning situation. The former "imposed" the contents of the carer's statements; the latter one is a theoretical category adopted at the beginning by the researcher. The first category, as it turned out, described the situation of Alzheimer's disease in an important manner; only against that background was it possible to read the context of learning in the situation of that disease more fully. Detailed categories, which are disclosed in the presented analysis, resulted from the contents of the carers' statements and had not been determined by the researcher beforehand. The analysis of the statements' contents was qualitative ("qualitative assessment of material") with no quantitative analysis (Babbie 2008: 367) and it aimed at finding, in the subjects' statements, contexts related to learning in the situation of Alzheimer's disease which are not always obvious, but are important.

Therefore, the analysis of the contexts of communications, directed with classic questions in communication studies, focused, most of all, on answering the question: "What does the author of the communication say?" It is also possible to find the answers to the remaining questions in the communication studies:

Who is speaking? – informal family carers, also with positive experiences of Alzheimer's disease; one person is associated with the Alzheimer's movement – France Alzheimer Rhone in Lion (Lallich-Domenach 2002), the second one – with gerontology research and participation at the Third Age University in Canada (Beaudoin 2002), and the third one with andragogy and geragogy research in Poland (the author of this paper).

To whom are they speaking? – to researchers and practitioners dealing with elderly people suffering from Alzheimer's disease. The statements may be useful for families taking care of patients with Alzheimer's disease. They may be useful for possible carers of such patients and all others interested in that disease in the context of widely understood support.

Why are they speaking? – out of the need to share their own experiences with others, increase social knowledge about patients and their carers in the disease situation. That communication is a result of the need to support others by sharing one's own experience. To a certain extent, it is written to raise the spirits of others.

How are they speaking? – the communications are very detailed and, most of all, deeply emotional.

What is the result? – the author of the paper does not know the result of the communications; it has not been studied by her. The author of the paper may only

speak about the influence which the other two communications had on her reception of the disease, about experiencing the community of experience, and the need for sharing her experience with others after reading both texts.

Below, I present the analysis of the texts according to the adopted two main analytic categories.

## **Alzheimer's disease as a time of tragedy**

To understand the complex context of learning in the situation of Alzheimer's disease using the analysed communications of family carers, it has to be underlined that the disease is a time of a certain tragedy. A tragedy as understood by Tischner:

And what is a tragedy? That term points to an individual. An individual lives in a manner which makes them take part in a tragedy – they are a tragic being. They cannot live in a different way. Their nature includes tragic time and two openings – an intentional opening to a stage and a dialogic opening to another individual. To be tragic being means to exist in a specific time and to open oneself to others and to the world – the stage – in a specific way. (...) The opening to another is dialogic. It differs much from the intentional opening. Owing to the intentional opening, the world of things is present in front of us; owing to the dialogic opening, you are present with me (Tischner 2012: 9–10).

The shared journey of a patient and their carer as well as other people accompanying them is difficult, critical, and tragic. Everyday life with multiple problems seems impossible to bear. You lack knowledge, support, understanding, and physical and mental strength. The full tragic nature of that journey is expressed with all the most important existential worries, i.e. illness, suffering, old age, loneliness, dying, and death, merging into one (cf. Fabiś 2013). It does not seem to be a journey for a human. It seems to deny humanity. And, nonetheless, more and more frequently it happens to a human, both a patient and the person accompanying them in the disease. The tragedy of that journey has its crises, accumulations of tension, and pain, but also moments of joy resulting from the meeting of two people, their communication, the exchange of meanings and feelings, hope, and a lesson, a deep existential message. The journey into Alzheimer's disease refers (may refer) an individual to fundamental human values considered in the relationship of life-death. They include being, community – family spirit, involvement, freedom (conscious acceptance of a difficult situation), love, and dignity of a human being. The awareness of that message may, to a great extent, limit the difficulties of that journey. However, how difficult it is to gain such awareness of the journey “in Alzheimer's disease”, “with Alzheimer's disease” ...

The statements of three family carers of people suffering from Alzheimer's disease presented below show the tragedy of that journey, i.e. non-average (not usual) difficulties of everyday life, physical and mental exhaustion, the need to make hard decisions, the confusion of mainly negative strong emotions, the experience of loss, the excessive experience of life hardships:

I am devastated by problems<sup>3</sup> (...) There are a lot of things about which I have never thought before (Beaudoin 2002: 98)

This disease is a true curse. (...) The pleasures which are gone will not come back. What is more, new losses are in view. (...) What counts is doing everything possible to make the present moment bearable (Beaudoin 2002: 101.)

Patients with Alzheimer's disease are as though imprisoned in a dungeon by their own powerlessness and we who serve them are in that prison along with them (Lallich-Domenach 2002: 90).

You have to make a decision (...), when at home problems arise which exceed our possibilities or our tolerance threshold (...) But what fear and what guilt do you have to accept when deciding to entrust him to a stranger? It is hard to "move" the person you love. You have the feeling that you burden others with the problem you are unable to solve. You are worried about the patient, that he will be alienated, lost in strange places, afraid of new faces, new customs, unexpected food, a different rhythm of life. You are anxious about yourself due to the organization of your own life which was organized around the patient. The feeling of emptiness and discouragement arises on top of guilt (Lallich-Domenach 2002: 89).

You would have to be me to understand and feel how important it is never to abandon her. If there is anything that sends shivers up my spine, it is the thought that I could witness her coming to her end in an institution of some kind. How could I ever do anything like that to her? (Beaudoin 2002: 102).

A person with a mental illness (...) takes us from a loss to a loss, to subsequent periods of despair, and the memory of him when death comes is very painful. (...) Regardless of the reason, that moment is sacred through its secret. (...) And Alzheimer's disease may mean flirting with death for a long time; this is exhausting for us. (...) We lived through subsequent little deaths, but Death, real death, is something completely different. (...) What we wished for in the end is to see the end of that situation and to find peace. (...) In each case, you have to try to ensure his comfort and dignity until the end. (...) To die with dignity does not mean to die in good conditions. It means to die surrounded with affection and human solidarity, in love which accompanies the other person in their own journey. What counts is our eyes resting on them (Lallich-Domenach: 92-93).

Suffering in itself does not give anything and has to be fought with all strength (ibidem: 91).

Undoubtedly, that was a difficult time. It required good organization of time and multiple additional activities, e.g. to keep the house orderly. To

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<sup>3</sup> The underlining by the author of the paper puts an emphasis on the tragic experiences of Alzheimer's disease.

cope with the requirements of the disease, you have to take care of yourself even more: of a good sleep, food, physical fitness, rest, peace of mind, development of hobbies. Religious practices were a support which could not be overestimated. We all lived like before, pursuing our current activities, including professional work and hobbies. Therefore, we had an escape from the disease and support for our bodies and souls. I do not see that disease as a tragedy, a curse, a catastrophe; it was simply a difficult life situation, which was easier, in my opinion than e.g. human suffering during the Nazi occupation, transportations to Siberia, hell in Stalin's labour camps. Our generation, without wars, simply has Alzheimer's disease (ED).

Despite the enormous suffering, the quoted statements show the developmental aspect of the life situation brought about by Alzheimer's disease, the developmental aspect of the tragedy triggered by carers themselves who, driven by love and a certain mission for the patient, open themselves to that difficult experience, gain awareness of the deep meaning of their fate, and overcome themselves:

We have to find internal freedom, internal strength to survive and, I dare to say, to live (ibidem: 90).

What can make us resistant if not trust that life exceeds us, that it exists before and after us, and that love I give and receive draws circles around us. Suffering in itself does not give anything and has to be fought with all strength. But it is an opportunity to reflect on yourself and on life if we do not drown in martyrdom, if we try to come out of it; then suffering opens the door to a new understanding of life (ibidem: 91).

Our generation, without wars, simply has Alzheimer's disease. It seems a kind of a background is always needed as an opportunity to experience understanding of the essence of the sense of human life. I would not like to go through that again but if it was necessary... There is no fear and anxiety in me anymore. I know that you have to organize everything well, you have to be active, give up part of your egocentrism, and... you have to survive. After all, it is always a temporary situation (ED).

Alzheimer's disease as a particularly difficult life situation, which may be interpreted as e.g. a borderline situation (Wrona, 2015)<sup>4</sup>, a biographic turn<sup>5</sup> etc., may therefore, as shown in the statements above, become a background for the personal development of carers and a foundation, a circumstance favouring learning. What learning is that?

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<sup>4</sup> Cf. the synthesis of meanings close to the notional categories described together as "borderline situations". They include a key borderline situation (after Carl Jaspers) as well as a critical event, critical occurrence, critical phase, critical period, critical situation, crisis, social life turning point, turning point, nuclear episode: experience of the top and experience of the bottom, crystallizing experience, transforming event (Wrona 2015).

<sup>5</sup> The expression "biographic turns" is related, among other things, to the terms passages – transits – transitions etc. (cf. Dubas, Gutowska 2019: 8).

## Alzheimer's disease as a learning situation

A disease, a serious disease is recognized in andragogy as an educational situation. Examples confirming that thesis include studies of educational biographies of women suffering from breast cancer (Mazurek 2013). Alzheimer's disease may also be a learning situation; however, it is most often informal learning (against the background of life), going on in the privacy of one's four walls (or rather, as the carer quoted above wrote "imprisoned in a dungeon"), where the carer and the patient, who are often left only to themselves, experience the disease. Non-formal education may, on the other hand, take place in various forms of adult education, including organized special groups, supporting patients with Alzheimer's disease as well as their carers and families. However, that education pertains only to people who were lucky enough to receive social institutional support. Alzheimer's disease is also the subject of formal education, in particular medical education in the area of psychiatry and geriatrics.

Alzheimer's disease is a situation stretched over a long time as it lasts for many years. It is a situation exceeding a single dimension of time; it combines all its spaces: present, past, future, and even eternity (transcendence). Learning is helped by high or sometimes even very high dynamics of changes resulting from the gradual course of the disease and, in particular, from the emotional factor with which the disease is saturated. (The situation of a relative *constans* in the disease occurs when the symptoms stay at a similar level and the behaviours of the carer may become rituals for a certain time.)

What do informal carers of patients with Alzheimer's disease learn? The informal carers of patients with Alzheimer's disease who share their experiences in this work gain new knowledge pertaining to the disease itself, its course, stages, the patient's behaviours and personality, which are changed. That knowledge enables them to look "differently" at the patient and not to treat them as a malicious and disobedient person but rather to interpret their behaviours as an effect of the disease. That makes it easier to "carry" the burden of care. The knowledge of the disease enables them to understand the patient to a certain extent. They also gain knowledge about institutional treatment of patients as well as institutions of support for the disease and, very often, knowledge about the impotence of those institutions with regard to the needs of patients and their families. They learn the environmental map of assistance in the disease. They gain knowledge about the disease from other carers of patients with Alzheimer's disease. They share their experiences with others who are in the same situation. The disease broadens their perception of the world; it enables them to observe its dimensions which have been hidden, unconscious, unappreciated, or rejected so far, but which still exist and affect us particularly painfully when we are surprised by them. That knowledge also makes them more resistant to similarly difficult existential experiences; it makes them accustomed to similar experiences when they occur, adapts them to life with difficulties.



They gain new practical skills related to taking care of the patient's hygiene and cleanliness of their surroundings, making them able to perform many care procedures which become increasingly difficult along with the development of the disease and the patient's disability. They gain skills helping them in communicating with the patient in a manner different from before and with healthy people, as well as skills helping them in communicating their situation to other people in their environment. They gain skills of organizing their life in a difficult situation and their family's life in the circumstances of the disease. They gain skills of coping with their own emotions, with the patient's emotions, and with the emotions of their family members. They appreciate the meaning of humour in the relationship with the patient and people from the group of family carers. They learn how to start communication and how to behave to relieve a tense atmosphere, which indisputably leads to aggression and deterioration of the patient's emotional condition, by directing the patient and themselves to positive emotions, e.g. by referring to past positive biographic experiences, which are important to the patient.

They learn many new social and existential attitudes or develop such attitudes in themselves more intensively than before. They learn tolerance and respect for another person. They deepen their spirit of family community and the relationship with the patient. They learn humility to fate/life. They become accustomed to death. They appreciate little things and give meaning to minor everyday joys; they take the attitude affirming life "such as it is".

Below, selected examples of statements are presented showing the listed areas of learning:

There are a lot of things about which I have never thought before (Beaudoin 2002: 98).

*What they have to offer to us is learning respect, tolerance, and affection* (Lallich-Domenach 2002: 89).

This is a school of humility if we are able, if we can take those deficiencies upon us. (...) We are not omnipotent with regard to our lives and with regard to his life... (ibidem: 91).

We have to learn anew (after death; note by ED) how to manage our time, learn to be flexible and to plan projects anew (ibidem: 92).

I think this is a great lesson of life; we can learn something new almost every day. That concerns many dimensions of our functioning at the same time. This is a long lesson, which takes place in stages, along with transformations of the disease. Changes caused by the disease make us change. That learning is an adaptation to the disease and to the patient, but it is also our change or even transformation. We learn many specific things, such as how to take care of the patient, manage time, and efficiently take care of cleanliness, as well as more general ones, e.g. how to feel the moods of the patient, organize social relationships, define oneself in a new situation, cope with the suffering, understand death *etc.* Others support us in that learning, suggest answers, explain, give advice, and share their experiences. The essence of that learning is

the observation of ourselves and the patient, frequent reflexions on the situation and ourselves, thinking about the same events many times, analysing them, drawing conclusions. The effects of that learning are useful during the disease but also afterwards. They may influence our other lifestyle, life's foundations after the disease are other than before. Minor teaching of the patient over the years is also possible, e.g. getting them accustomed to certain places in the flat, activities, presence of other people *etc.* (ED).

The accounts of family carers presented above show informal learning occurring in the situation of a disease. In that process, action is present first, as it is necessary to do many activities related to the patient urgently, necessarily, continuously, and during the whole day. The action may be accompanied with observation, but that often does not happen immediately and only after having adapted oneself to the situation and getting accustomed to it. However, emotions are present always and they are most often negative, as it is difficult to remain indifferent to incomprehensible challenges beyond one's strength. And finally, what is also important is motivation, the will to cope with the situation at hand and face up to it, combined often with deep reflexion referring to higher values (e.g. love to the patient) and the transcendent dimension (in view of the closeness of death). All the four fundamental learning activities proposed by David Kolb may be found here, i.e. feeling, watching, thinking, and doing (Kolb, quoted after Grajewski 2005: 29), although their order may be different. Doing combined with feeling is often the first. Reflective observation and abstract conceptualization come later. Learning in the situation of Alzheimer's disease occurs every day, in various changing situations resulting dynamically from the disease. The expected effects of the learning depend, to a great extent, on the positive emotional relationship of the carer and the patient which was present before the disease and which is maintained intensively and sometimes even heroically during the disease. Love, community solidarity, and responsibility make the background of that process. Then, it is possible to learn in the positive meaning during the disease. Another important condition of learning in the situation of Alzheimer's disease is a deep existential reflexion of carers and/or possessing existential wisdom which enables one to open oneself to discovering meanings, finding optimum solutions, and finding and understanding the sense of the existing situation. By learning in that manner, in such circumstances, one may "mature during the journey", although it is a very difficult challenge for a modern individual due to the excessive focus on their own needs, on the need of self-fulfilment understood in an exceptionally self-centred manner.

Analysing the process of learning in Alzheimer's disease, one may also find all three dimensions there specified by Knud Illeris, i.e. the cognitive, emotional, and social dimensions (Illeris 2006: 24–25). The overwhelming presence of the emotional dimension has to be emphasized, as in the case of strong negative emotions it may make learning more difficult. Therefore, negative emotions have to

be recognized, labelled, mitigated, and transformed through finding positive references for the existing situation. That already means a certain process of learning which consists in forming emotions through, among other things, recalling and maintaining positive feelings from the past in the relationship with the patient from before the disease. A good “memory of the heart”<sup>6</sup> cannot be overestimated here. The social dimension of learning is obvious, as forming references to another individual, the patient, family members, and people around, is its fundamental space. That dimension of learning means overcoming barriers and social stereotypes concerning Alzheimer’s disease and building relationships in the family in the situation of the disease. The social dimension of learning is limited through remaining in social isolation with the disease/the patient, which begets loneliness. In the cognitive dimension, it is not only learning that means an increase in the knowledge about the disease and about oneself in the situation of the disease but, most of all, it is also deepening of existential self-awareness and opening oneself to transcendence.

Learning of the patients suffering from Alzheimer’s disease in the aspect of informal learning is almost never discussed because it is very slow if it ever occurs. But it does occur. Patients with Alzheimer’s disease try to cope with the disease in their own way, in particular in the initial stage (e.g. making notes to remember, to know what day it is *etc.*). When staying in a new place e.g. after having moved to the carer’s home, they learn over time, get accustomed to the specific rhythm of a day, everyday activities, the presence of people and furniture. They can learn positive reactions and behaviours which they have not shown before and which may be a result of the influence of a friendly environment. They may change their mood and messages they send to positive ones, also with the influence of such an environment. The disease leads to negative changes of personality; however, friendly “company during the journey” by carers may change their direction to the positive. What is more, those changes may concern earlier negative habits or even all life experiences from before the disease, ones which are perceived in a negative manner. Thus, you may teach a patient with Alzheimer’s disease not to be critical or pessimistic which they were before the disease, based on losses of biographic memory, on the benefits of forgetting. The mechanisms of the biographic memory are an important factor useful in the learning of patients with Alzheimer’s disease, in transforming negative behaviours from before the disease into positive behaviours during the disease. If you know the patient’s biography, you may refer

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<sup>6</sup> That term is well-known in gerontology, popularized by Olga Czerniawska, and related to the term “invisible environment” used after Helena Radlińska (Radlińska 1961: 33; Czerniawska 1997). It is used e.g. in the context of the memory of childhood: “...childhood as a niche, «memory of the heart», makes our life richer, regenerates the invisible environment, teaches the relationship with children and grandchildren in the next generation” (Czerniawska 2000: 99); or the memory of school: “It is, therefore, affective and vivid memory, which is called «the memory of the heart» in gerontology studies (Czerniawska 2007: 125).

to their positive memories and avoid negative associations. However, it is worth emphasizing, in the aspect of non-formal learning, the meaning of Montessori's geragogy method for the teaching of elderly people, including patients with dementia. The geragogy methods according to Maria Montessori are based on the assumption that learning is also possible in the event of dementia. It is organized using various teaching aids which stimulate all the senses, in an educational situation in which learning gives joy, which strengthens the feeling of self-confidence, and which makes one stronger spiritually (cf. Gutowska 2017: 495–497). What is also important is maintaining the thinking processes, recalling good memories. Speech disturbances which may occur in that disease and, in general, in old age and which speech therapy tries to eliminate are studied by geriatric speech pathology (Zych 2018). Learning anew how to speak and communicate is also a sign of learning in a patient with Alzheimer's disease. In the learning of patients with Alzheimer's disease, the role of people accompanying them during their journey (carers, geragogy specialists, educators, teachers *etc.*) should be particularly emphasized, those who are empathic, respectful, know the biography of patients, respect their individual learning needs and possibilities, and, most of all, treat learning as fun.

### **Maturing during the journey as a dimension of learning in Alzheimer's disease**

A relationship with a patient with Alzheimer's disease, understood as accompanying them during their journey, creates favourable conditions for maturing personally, despite many difficulties, tensions, frequent lack of knowledge, and uncertainty. That concerns the carer and other people surrounding the patient on condition that they show courage, bravery, and involvement to see a developmental situation in that difficult situation. In that relationship, personal maturing is stretched over time, which is a burden, as it drags on (the disease lasts for at least several or even more than ten years) and, on the other hand, creates a space to return to reflexions related to the disease many times over. It may also take place after the death of the patient. Personal maturing related to Alzheimer's disease takes place on many interpenetrating temporal layers and is biographic. It occurs in stages, like the disease, and marks subsequent stations of the way travelled together. From the observation of the first clearly alarming behaviours, through the shocking diagnosis of the disease (which is usually surprising) and coping with increasing pathological changes for many years, to coming closer to death and finally the death of the patient itself. The time after the patient's death may be another period of personal maturing, i.e. "settlement" with the disease and with oneself in the disease, recognizing its meaning from a longer temporal and biographic perspective. In the most general meaning, that maturing concerns

recognizing and understanding the sense of humanity. It has a definite existential dimension. It forms a personality which is brave and full of humanity, managing the difficult challenges of fate, fearless of challenges, trustworthy, coming to the defence of human love and dignity.

Below, examples are presented confirming the fact that accompanying in Alzheimer's disease is enriching:

#### painful journey – difficult journey<sup>7</sup>

It is an infinitely painful way which we have to travel (...) a long way covered with pain and uncertainty but also with enriching meetings. (...) A difficult way, yes, really difficult (Lallich-Domenach 2002: 85).

#### journey consisting of stages

First, I am going to tell you about the beginnings of the disease and the period after the diagnosis. Then, I am going to consider the need to adapt and the difficulty in making decisions when the disease gets worse. I will recall the way which a family has to travel. At the end, I will say a few words about the death of the patient (ibidem).

#### acceptance of the disease

(...) a moment comes when you decide to accept the reality and to organize the situation which has been imposed on you as well as possible. You decide to "act together", i.e. recognize the reality, organize yourself, accept help, share the new life project with the rest of the family (ibidem: 87).

#### accompanying during the journey

Accompanying means to be next to someone, not to lead or overtake. It means to be at someone else's disposal, to help them, sometimes to direct them (ibidem: 90).

You have to travel from the hope for the patient's recovery to accompanying the patient (ibidem: 87).

#### new experience – changing experience

I often think that the disease suffered by my husband which, in a sense, chained me to one place and deprived me of external adventures, provided me, however, with an opportunity to become involved in an internal adventure which bound me to him in a way different from before (ibidem: 90).

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<sup>7</sup> Selected analytical categories of "accompanying in Alzheimer's disease".

It is difficult for me to imagine who I would be if I had not experienced that disease. It has given me a depth of life. I have observed that today I look quite differently at e.g. homeless people in the street, a beggar in front of a church etc. I can talk to them, I am not afraid, I have a smile for them. I avoid judging people, I have a greater tolerance of unconventional behaviours. My perception of elderly people has also gained depth, which has strengthened my gerontology theory very much. It made my relationship with my mother more orderly, as I understood the matters which I saw differently earlier. Now, I am able to go to the cemetery out of love and not only through an obligation. It has made our family stronger, brought in more feeling and gentleness. When I think about the disease as a past event, it is more and more difficult for me to recall difficult things; only the good has remained. Time makes the good more visible. I am writing about that for others so they do not break down, so they know that it is possible to come out richer even from difficulties. You only have to show courage... (ED).

What explains the transformation of the torment of the disease into the benefit of development understood as going up, improving oneself, is a particular attitude taken by carers towards the disease and the patient at the same time, when they are able to observe the disease from the angle of the patient. That attitude may be described as “accompanying during the journey”. It is an example of a geragogy relationship (Dubas 2016; Dubas 2019)<sup>8</sup>, but also a relationship with each individual who requires existential support, not only an elderly person. The motif of a journey is often present in the carers’ narrations. To be with the patient means to be with them on a journey, which is long and not easy. A relationship in Alzheimer’s disease has several dimensions and rules: the dimension of a person with the rule of respecting the patient as a person, the dimension of emotions with the rule of arousing and maintaining positive emotions, the dimension of the community with the rule of building the spirit of community in the family and the social environment of the patient, and the dimension of communication with the rule of maintaining communication with the patient (Dubas 2019: 181–188) as well as in the family and social environment. Realization of such a relationship, based on a deep reflexion and, on the other hand, on a deep relationship with the patient before the disease (love, attachment, empathy, affection, care for their interests, responsibility), makes us able to experience the gift of development in a tragic situation.

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<sup>8</sup> “Accompanying on a journey” as a geragogy relationship is an enriching, but also educational relationship with the Other – an elderly individual treated subjectively as a person, often in their difficult everyday life defined by existential cares (cf. Dubas 2016: 297 and further). “Accompanying on a journey” is analysed as a social relationship, as a relationship with the Other, as a relationship in the perspective of personal-existential pedagogy, and as a “to be” relationship (Dubas 2019: 175–179).

## Conclusion

Based on the experiences of three family carers of patients with Alzheimer's disease, including my own experiences, the "educational" dimension of the disease has been presented. In the situation of Alzheimer's disease as in other difficult existential situations, one may learn, i.e. expand one's knowledge, skills, and acquire new attitudes. That learning is, most of all, existential<sup>9</sup>, which clearly includes a social, axiological, biographic, or even happiness-related meaning of learning. It expands awareness and self-awareness. It means cognition deepening the present understanding of life, including understanding of humanity, which also includes the presence of existential cares. It means a return to the autobiographic memory, which contains recollections of experiences shared with the patient and, using that opportunity, learning from one's own and from the shared biography. It also means learning from biographies of Others, including those who participate in the situation of the disease and those who want to share their experience of the disease<sup>10</sup>. The patient themselves may also be the Other – the teacher of life, most frequently with no awareness of the fact. That may also be learning how to find joy in a difficult situation, how to find and summon humour which helps to mitigate the tragedy of the disease. However, such learning in the situation of Alzheimer's disease is still a challenge. The disease, which is nowadays more and more frequent due to human life being longer, is still not well known with regard to its aetiology, not to mention the values it may offer society. The disease raises fears and anxiety. It is not accepted socially and is associated with negative stereotypes concerning the patients and members of their families. It is rejected, as difficult situations are rejected. And it is understandable, as suffering only for the sake of itself is pointless. Suffering may have a sense if there are some values behind it. Experiencing Alzheimer's disease is precisely about discovering values, also when, and most of all when, we notice an educational situation in it, i.e. the situation which supports development of an individual and strengthens the community. Such an understanding of Alzheimer's disease is a challenge for andragogy and geragogy specialists who popularize knowledge about learning against the background of life, during the performance of tasks given to individuals by difficult everyday life, where suffering is present as well. It is hard to prepare for suffering. However, you may become sensitized to it without denying its existence, to be able to become accustomed to it when

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<sup>9</sup> A reference to the theory of existential learning by Peter Jarvis: "Learning is a combination of processes during which people construct situational experience and transform it into knowledge, skills, attitudes, beliefs, values, emotions, senses, and meanings, and integrate them within their own biography" (quoted after: Malewski 2010: 104).

<sup>10</sup> Cf. learning from one's own biography, learning from biographies of the Others (Dubas 2011; Dubas 2017).

it appears and to use it as a developmental opportunity. The experience of Alzheimer's disease may be "a great lesson of life" and humanity if we show the courage of being<sup>11</sup>.

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<sup>11</sup> A reference to Paul Tillich: "Courage as a human act, as something which is subject to assessment, is an ethical term. Courage as a common and significant affirmation of a certain being is an ontological term. Courage of being is an ethical act where an individual affirms their own being contrary to those elements of their existence which oppose the fundamental affirmation of a human" (Tillich 2016: 36).



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