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"Accompanying on the way" as a relationship in Alzheimer's disease

Keywords: Alzheimer`s disease, "accompanying on the way" as a relationship, dimensions and principles of this relationship

Abstract
The author shows Alzheimer`s disease as an example of existential struggles constantly present in human life, especially in the context of family carers. In this article, the relation in Alzheimer`s disease is described as "accompanying on the way", which helps to face the great hardships of this condition. The author characterized "accompanying on the way" as several types of relations, such as geragogical, social, personal, relations with another person, "be" relation. The analyzed experiences of three family carers of Alzheimer`s disease patients, show several dimensions and principles of "accompanying on the way" relation. Those are: personal dimension (personalistic) – which is a rule of respecting a patient as a human being (person); emotional dimension – the rule of creating and maintaining positive emotions; community dimension – obligation to build community bonds within a family and social environment of a patient; communication dimension – obligation to constant communication with a patient, including understanding and conversation.

Introduction

What is "accompanying on the way"? "Accompanying on the way" as a geragogical relation[2]

"Accompanying on the way" may be understood in a variety of ways.

"Accompanying" means certain interpersonal relations based on coexistence, togetherness and thus fulfilling mutual needs to a certain degree (see: Dubas, 2016, p. 293).

As suggested by Anna Wieczorkiewicz (1996, p. 49), the way may be understood in its topographic sense (spatial, objective, as a way prom one point to another) and

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[2] A broader description of „accompanying on the way" as a geragogical relations: E. Dubas, 2016, p. 293 -307. The text below includes fragments of the proprietary work.

metaphorically (subjectively), as a way of life, a course of life or fate. Both meanings remain within a relation – the way is at the same time a process of changes in a place as well as within a person. Moving along that path is on the one hand of a horizontal character – it takes place in physical space, within the roles and life tasks. It means the earthly life. On the other hand, however, it means a vertical movement with a perspective upwards and downwards, in connection with a symbolic content – the context of thoughts, feelings, spiritual life, transcendence: heaven – the earth (Wieczorkiewicz, 1996, p. 43). One may assume that both understandings of the way – topographical and metaphorical are manifested particularly in a variety of existential experiences of a man on his way of life. Additionally, it needs to be mentioned that understanding the path in a metaphorical perspective, as an existential situation, connected with an axiological experience as emphasized by Anna Gałdowa who treats the path as an area of spiritual and inner development, as a development towards values (Gałdowa, 2000, p. 175).

"Accompanying on the way" would thus mean presence alongside another person on their way of life, understood as an existential experience which would be a part of this person's development, particularly the spiritual one, auto-informative, understood as heading towards values. Such manner of experiencing life is also combined with the space of a physical way.

"Accompanying on the way" as a cognitive phenomenon as well as a practical one, may be applied in many scientific disciplines and sub-disciplines. Anthropology, sociology, psychology or philosophy should be pointed out here. It is impossible to omit pedagogy, social pedagogy and special education in particular. Among the many pedagogical disciplines, geragogy seems of particular importance in deliberations on senility. For Lutz Vellken, "geragogy is an introduction to senility, preparing for senility, leading towards maturity and "accompanying on the way", and the subject matter of geragogy is broadly understood education of an elderly person (Vellken, 2000, p. 88). According to Elżbieta Dubas, the range of education defined by her as "senility-oriented education" is even broader and includes three directions: education about senility (supplying gerontological knowledge), education towards senility (preparing and educating towards senility), and education at old age (learning processes in elderly people, including the processes of education) (see: Dubas, 2008, p. 45). For Vellken, geragogy means overcoming the difficulties of life, organising life and self-realisation of an elderly person. "Geragogy is a critical science about the bases and the ways of accompanying a mature adult, and the learning processes connected with that, the constant need of education, and the science about teaching gerontologists as specialist services that support self-realisation of an elderly person" (Vellken, 2000, p. 88). One may thus assume that gerontological approach combines the areas of interaction in pedagogy (educational processes) with the subject matter of gerontology research (ageing processes and senility) perfectly, in this way pointing towards "accompanying on the way" as a kind of a mutual personal and formative relation

that takes place between the participants of the path, with particular attention placed on the need to support an elderly person who is also at the same time much weaker in this relation (peregrination). This does not rule out the concern for the people supporting the elderly in institutionalized forms and outside them, particularly in a family.

Selected contexts of a relations "accompanying on the way"

The perspectives of looking at a relation of "accompanying on the way" may vary. Below there are contexts that seem of particular importance for the geragogical approach that has its roots in pedagogy and which are also to be found in Alzheimer's disease.

"Accompanying on the way" as a social relation

"Accompanying on the way" is an example of a particular social relation. A man is seen here as a being experiencing a relation. The starting point for perceiving a man in social relations may be a relational concept of man, which goes back to the ideas of Joseph Nuttin (relational theory of personality, 1968) and Hanna Świda (personality as a system of conditioning toward the world, 1974), and included by Ewa Marynowicz-Hetka into the realm of research and practices of social pedagogy. It includes the relation of relationships (two-sidedness creating a whole) of an individual with the environment, a specific "feedback" between them. "Particular usefulness of a relational concept of a man lies in the fact that such an important element for social pedagogy as social context, environment, is 'blended' in a person and their psychological system (personality)" (Marynowicz-Hetka, 2006, p. 38–39). In a social relation, the author lists at least three types of interaction: transfer, exchange and mutual participation. "Transfer is usually one-way, with a strong touch of asymmetry of a relation and clearly visible in manifestations of power"/…/ "Exchange /…/ may take the form of a contract or trade (something for something) or some kind of an exchange through gifts or giving (e.g. time, emotions, one's own privacy, individuality, oneself)". Mutual participation (*partage* – sharing life, space, time) creates the possibilities of equalizing a relation and the sense of togetherness and community. The author points out that a mutual participation is an ideal situation (rarely to be found) (Marynowicz-Hetka, 2006, p. 141, p. 135). "Assistance in development", so fundamental for social pedagogy that still assumes an asymmetric relation because assistance, support" show the weakness of the one that is not concerned and the superiority of the one who presents it", is more and more often replaced by the more neutrally formulated concept of social accompanying in including, establishing social bonds, in enabling social relations" (Marynowicz-Hetka, 2006, p. 142). The category of social accompanying refers most of all to the balance in a relation (Marynowicz-Hetka, 2006, p. 135). Seeing assistance in development from the perspective of a rela-

tion allows one to talk about accompanying in development instead of assisting in development. "(…) Accompanying in development, by being a certain dimension in development, thanks to this feature – relation, which is created through interactions with others, takes on the dimension characteristic for social accompanying" (Marynowicz-Hetka, 2006, p. 135).

First and foremost, category of "accompanying on the way" refers to such types of social interaction which, by supporting the development of an individual, respect their subjectivity and create opportunities for reciprocity in relations by diminishing their asymmetry, they strengthen the bonds between individuals, create close emotional relations between them and, as a result, they strengthen the sense of community. "Accompanying on the way" may undoubtedly be assumed as an example of a social relation that is characteristic for a man as a relational being. An elderly and ill person who remains in social relations is still a subject of a multi-dimensional exchange between people, characterized by values and "accompanying on the way" takes on a form of mutual aid in development, even though it may not be immediately understood as such, as it takes time and experience to see the progressive character of such a relation.

"Accompanying on the way" as a relation with the Other

A person who is elder and senile, often ill, ill in a "different way" which is incomprehensible, may be seen by the members of younger generations as the Other. It is senility and the process of ageing that create this difference, also seen with a naked eye, shocking, incomprehensible and raising concerns even among the "not yet old". Perceiving the difference seems of key importance when looking at the Other. Quoting the broad context of understanding the Other seems also most appropriate here. The Other understood as everyone else but me: "the Other… is every man who is not Me, regardless of the distance between us" (Dubas, 2010, p. 229; Dubas, 2011, p. 5). Three types of relations are possible when discussing the Other: the Other as an enemy – "war" between Me and the Other, the Other as a stranger – a "wall" between Me and the Other, the Other as my neighbour – a dialogue between Me and the Other (see: Kapuściński, 2006; Dubas, 2010, 2011; Walczak, 2006). These relations are revealed in a common existential situation which is not always approved of or understood. Following the mutual path, sometimes out of duty, sometimes because of the granting of fate, may occasionally be the only chance to learn from each other. A relation with the Other may be of an educational character, which depends on how I perceive the Other. This may mean learning from the Other, learning the Other and learning from each other not only in the context of direct experiences but also in the context of biographical memory of these experiences. The Other visualizes our separateness and difference. He becomes a challenge in learning and understanding his reality and through his reality, the universal one. The other, who is present on various paths of our life may support us as a master and mentor, he may also expect and

require support (Dubas, 2010; 2011, pp. 6–9). The relations with the Other, especially the conscious and a thought-through one, means "being" with a man, finding oneself through this relation, change oneself and improve permanently (grow in one's own development and support the development of the Other). Then it becomes possible to talk about accompanying on the way as a mutual personal relation in supporting and developing. A reflexive attitude towards the Other is a key to accompanying on the way that would be fruitful for you and the Other. This approach can be seen in the following way of thinking: there are also other people in my life, if not mostly. They accompany me on the way also through their biographies. Thanks to Others it is easier for me to find myself in this world. I am becoming aware of the role of the Other in the process of my development. I also am in the world of Others. My experience is meaningful for Others. I am becoming aware of the mutual dependencies between us on the "way" of the same existence, which is in fact the same. We all give each other "lessons" on life and our lives receive meaning (see: Dubas, 2010, 2011).

"Accompanying on the way" in the perspective of personal and existential pedagogy

Such approach of "accompanying on the way" is constructed by three contexts (see: Dubas, 2016): firstly – personalistic norm, according to which every man is a unique, specific and free person, dignified and worthy of respect. In the upbringing process (in a pedagogical relation), a man meets another man in a mutual impersonal contract between people; secondly – existential philosophy pointing to drama as a feature of human existence, the presence and entanglement of a man in paradoxes, e.g. externality and internality; thirdly – other educational ideas presented in the aspect of drama of the existence of a human being, such as a dialogue (dialogism), particularly a personal dialogue aimed at "unifying people through manifestation of feelings", existential dialogue – "the ultimate gift of existence for partners" and the approach of dialogue: "constant readiness to achieve the understanding of others through a conversation (as well as through other means), approaching them more closely and co-operation as far as possible" (Tarnowski, 1991, p. 73), authenticity (taking off the masks), a meeting that would result in permanent and principal changes within the deep "I", engagement resulting from free choice (see: Tarnowski, 1991; 1993). In understanding "accompanying on the way", the category of meeting is a particularly bearing one. A meeting has a personal dimension – we meet the fate of another person, their emotions, fears, wisdom, quirks, needs, etc. It also is of transformational character because it changes a man. Through a meeting, a man ceases to be what he used to be, he matures as a person. A meeting is also of educational character because it teaches through direct contact with a person, through reflections, frequently multiple, concentrated around a once lived situation. It broadens the awareness and self-awareness, it changes social and existential attitudes. A meeting requires engagement (openness and authenticity), respect for the other person as a

human being, a full partner in a situation, acknowledging togetherness of fate and the will to understand another person. Although understanding is not the necessary condition in "accompanying on the way", yet a meeting may create a situation leading towards it. From the point of view of personal and existential pedagogy, accompanying on the way is a personal and existential experience at the same time, something that brings us closer to the participants of this meeting on the way, characterized by mutual trust and understanding, overcoming egocentric behaviour, insecurity and existential fears (see: Dubas, 2016).

"Accompanying on the way" as a "Be" relation

Considering the objective and subjective context, accompanying on the way may also be looked into as three types of relations: "Have" relation, "Function" relation and "Be" relation (see: Buber, 1992; Gadacz, 1991). A man is undoubtedly the crux of every relation, including social ones, although these may be defined or determined differently[3].

"Have" relation is placed within the optics of possessing. It points to a subjective, instrumental treatment of another man and any bonds between them are of superficial character. From this point of view, one may "have" a carer, doctor, husband – wife, children who fulfil our needs. One may have a good treatment, a place at the social welfare home, the expected material back up, rehabilitation equipment, etc. The Other is here only a means to an end – he or she secures our "have".

"Function" relation is a type of a subjective relation located within the optics of functioning. "Functioning is an impersonal undertaking" (Gadacz, 1991). This relation is sometimes of assisting, rescuing or research character. It is of fragmentary character – it only fulfils a certain task and allows to achieve a specific objective goal. From this perspective, it may be performed (and very well, too) by, e.g. a nurse, doctor, physiotherapist, a guardian of an elderly person, etc.

"Be" relation is an example of a subjective one, a personal relation directed at a person as a whole. This is an attempt to see a Man as a whole in the Other. It is also being oneself in a relation with the Other. Tadeusz Gadacz writes that personal being means opening to a meeting, a change and conversion, opening to limitless possibilities. "Meeting" another man is meeting oneself, meeting the universe of human existence (Gadacz, 1991, p. 67). Being with the Other means being a person and it is realised when a man participates in values and realizes them (Gadacz, 1991, p. 63). Any personal relation is primarily built on love. Karl Jaspers claims that "Only when facing true love do we see a man for what he really is". We meet a person in love (Jaspers, 1993, p. 89). "Be" relation is an authentic one, not staged but true, in which we address the partner in the whole truth, we put all of ourselves into the conversation,

[3] See: "ralational concept of man" in social pedagogy (Marynowicz-Hetka, 2006) described above or "man of relations" in the humanistic and existential anthropology (Formella, 2009).

concentrate it on the content and we know how to keep silent (see: Buber, 1992). A man of such a relation "can hold real conversations" concerning "real issues" and be genuine in such a relation" (Formella, 2009, p. 364).

"Accompanying on the way" in difficult existential experiences. The situation of Alzheimer's disease

It seems particularly expected and at the same time burdening to "accompanying on the way" of the elderly in their difficult existential experiences. Senility is abundant with numerous hard situations and experiences which does not make it any easier to go through the "path" of life for the elderly or those who accompany such a person. Adam A. Zych writes in this context about, e.g. existential fears and threats of senility. He includes there also the retrospective look at one's own life (the life summary), loneliness and being alone, compromises of senility and becoming disillusioned, the road from being charmed by life to being disillusioned with it, the inevitable involution and degradation, the lack of energy, becoming weak, tired, excluded from life, experiencing the hardships, fears connected with illnesses, pain and suffering, and the inevitability of death (Zych, 2013, pp. 255–268). According to Artur Fabiś, three main existential concerns are particularly burdening: death, suffering and loneliness (see: Fabiś, 2013, p. 40). At old age, they frequently appear together. They are all connected with strong fears, although the one particularly difficult for a man is thanatophobia that is connected with death, dying and passing.

Throughout their life, people come across suffering and their attitude towards it is shaped. People learn suffering – a way of life is as if "a school" of suffering. "Accompanying on the way" is in fact, accompanying in suffering: protecting them from suffering, mitigation of pain, carrying the suffering of the Other, rationalizing the suffering, etc. Our childhood is mainly constructed on not noticing suffering due to the poorly developed cognitive and spiritual skills of a child and their little social and cultural awareness, and the ability to make conscious comparisons. Loving and caring parents protect their child from suffering, making the world full of fun and carefree. The burden of suffering, if it touches a child at all, deforms their personality often for their whole life, leaving a trauma and painfully accelerating the process of becoming an adult. Youth favours seeing suffering in idealistic categories, in the context of tensions connected with intense personal growth at this time. On the onset of adulthood, having cognitive, emotional and social skills at our disposal, taking difficult and responsible duties connected with social roles, a man begins to see suffering more and more clearly. Further stages of adulthood bring more personal experiences of suffering placed in the reality of our own life. And then old age (late adulthood) is the time of the increase in existential thoughts, which is provoked by the process of ageing and the multitude of illnesses, deaths of the closest ones and a close perspective of our own death, coupled with other existential concerns. It is also advanced personal maturing in suffering, understood

as transcendence of oneself through suffering. Such systematic life-long education in suffering and through suffering in a company of other people allows to embrace suffering, i.e. accept it as an integral universal component of human life and personal experience, understand suffering or at least try to do it, i.e. find its sense and experience it more consciously, finally – mature in suffering by acknowledging it as an element of spiritual growth and gaining the fullness of humanity. Undoubtedly, personal maturity of a man is connected with their attitude to suffering and how they have "reflected" on life suffering "lessons".

The situation of Alzheimer's disease (Mace, Rabins, 2005; Jóźwiak, 2007) is an example of a nexus of all most relevant existential concerns experiences particularly by people caring for the ill (it is difficult for those touched directly by the disease to objectively make any statement, although their experiences must be of deeply existential character and their suffering immense). The disease is associated with a multifaceted suffering: in the bodily context of the disease as well as psyche and the spirit, but also in the context of loneliness, dying and the actual death. Which particular aspects describe the relation of accompanying in Alzheimer's disease? Which aspects of that relation may mitigate the difficulties and suffering in this disease? These are some of the main questions that come to mind when reflecting on "accompanying those touched by Alzheimer's on their way".

Main dimensions and principles in relations in Alzheimer's disease

While describing a relation in Alzheimer's disease, one may qualify it as a geragogical relation because most frequently it refers to the elderly and old who are touched by this condition. Their carers, particularly spouses and siblings also usually belong to the elderly generation. This relation, however, goes beyond one generation and includes an intergenerational reference, e.g. between the ill parents and children, grandparents and grandchildren. It presents a character of a complex social relation that goes also beyond the micro-social system, e.g. a family. It also touches people from the local community and, what is also important, is present in the public opinion that has a global reach. The universal features of a geragogical relation described above also include more general interpersonal relations in illness. Below there are listed some of the most crucial principles (also the most fundamental ones) of a social relation in Alzheimer's disease. Their form is the result of an analysis and reflection over personal experiences of two carers of elderly people touched by Alzheimer's disease, already previously published (Beaudoin, 2002; Lallich – Domenach, 2002) and personal experiences of the author of this text[4].

[4] The author's experiences quoted here were coded ED.

Personal dimension (personalistic) – the principle of respecting the ill person

The deep humanistic relations of "accompanying on the way" is a relation that maintains the subjectivity of the patient, including a personalistic norm. This means treating the patient as a person despite the signs of limitations or even lack of consciousness and awareness. Respecting human dignity in the patient creates a chance of their well-being and allows the carer a much better condition in which they will accompany the patient. The patients is still seen as a grown-up person, someone who still has a once granted autonomous identity. Such a new situation of this person is acknowledged as yet another important, although difficult and hardly possible to understand stage in their life.

My wife is not a case. She is a person and she is different from all other cases that you (the carer – note by ED) have had. (Beaudoin, 2002, p. 97);

It had never come to my mind to address my Mother anything else than "Mummy". She has always been my Mother; she is as if in a different form now, but it is still the same. (ED)

Respecting him for what he has become means also not to treat him as a child, which we sometimes are inclined to. (Lallich-Domenach, 2002, p. 87).

This relations also requires something incredibly difficult, i.e. respecting (within limits) the freedom of the patient, allowing them to be active, participating and engaged.

What helped me personally each time I was forced to look after my husband, was that I tried to make that necessity an occasion to meet him. In that way he could have been at least a subject of his own life, if not the organizer. (Lallich-Domenach, 2002, p. 88).

In this relation, the person's dignity is maintained and the person is treated respectfully. It is particularly important to maintain the right to intimacy (within the accepted limits) and still acknowledge their sexuality. We see a "teacher" in the patient, the teacher of life.

/…/ those ill men and women, hurt totally in its all essence, still remain men and women in full understanding of the word, and they have something to teach us until we are parted by death, if we can listen to them even when they are silent and stop talking altogether (Lallich- Domenach, 2002, p. 85);

Mother felt a woman almost until the very end. She liked to comb her hair, arrange it, do her scarf extremely solemnly. She would also use her lipstick. (ED)

The older generation are people who did not use to strip themselves in public as it is now. They did not use to see the naked bodies. They were raised in modesty and bodily restraint. That is why the problem in Alzheimer's disease is, e.g. nakedness in a bath, changing clothes, taking their clothes off. These activities must be done in such a way so that they do not embarrass the patient. These activities are best done by the person whom the patient trusts. It would be best if that person was remembered as a loved one.

Otherwise the mood of the patient worsens rapidly. A success in Alzheimer's disease is measured primarily by how long the positive mood of a patient can be maintained. (ED)

Dimension of emotion – the principle of arousing and sustaining positive emotions

Alzheimer's disease creates a situation that is extremely difficult emotionally. Negative emotions dominate here, particularly at the beginning of the disease and during the period connected with the diagnosis, but also when the symptoms become worse or when there is a prolonged time of the disease, finally during the dying phase. Most often these emotions are overwhelming for the carer. They also worsen the condition of the patient. The trick here is to break them and find positive emotions and feelings in a situation that, in the eyes of the majority, does not present any occasion for such experiences. The carer's work with their emotions "pays off" immensely. It is their emotional state that resonates with a double force towards the emotional condition of the patient. Alzheimer's disease is, in a way, a condition of emotions and it is precisely in the process of "ennobling" these emotions that we may find the key to handling this disease. It is only the carer who can undertake work on emotions and it is only him / her, from this point of view, who creates an emotional atmosphere in this relation. Emotional atmosphere that is at home (in the surrounding of the patient) is the foundation of success when struggling with the disease. It is the main background of accompanying each other "along the way". It is the treasure of this relation. And love is of particular value here; basing on the memory of happy moments, it gives strength and adds spirit. It protects from becoming discouraged. It reveals the sense in what may seem senseless. It means gentle care until the last moments of life – it allows to endure till the end. It leaves the experience of Alzheimer's disease as a positive memory. This principle emphasizes the necessity of work with and on emotions, care for the positive emotions, create the atmosphere of emotional warmth that would surround the patient and as a result, it fosters creating a situation of emotional support so imperative both to the patient and the carer, but also to other people who are close to the patient.

When you really manage to establish a connection with the patient, you may have moments when you exchange ideas and emotions that are so important that you never forget them. Even when my husband could not speak, he looked at me in a way that expressed his love for me (Beaudoin, 2002, p. 88).

The patient is sensitive to mental state of the person who looks after him / her. He or she needs trust to his carer, to others and to life. It is important to provide him with the sense of security, manifest their importance to us and that today they are loved for what they are.(Lallich-Domenach, 2002, p. 87).

The time of her staying with us, over five years, changed Mother drastically and for the better, which is a phenomenal case in this disease. From a person that used to be fearful

and permanently anxious, with autocratic tendencies, not very willing to open to close relations, hugs and complaining, she became more benign, she laughed more often and very frequently showed us signs of her love, thanked us or praised. She did not treat us as her enemies. On the contrary, e.g. I would hear every day that I was an angel. I am convinced that the atmosphere of positive emotions at home is passed on to the patient. When they feel loved, they also feel safe and are in a better mood. There are no grounds then to trigger off aggressive behaviour (ED).

Dimension of a community – the principle of building a community spirit in a family and social surrounding of the patient

Social context of Alzheimer's disease is obvious and multi-faceted. Firstly, it is plausible that the illness may be created as a result of a person's "oversaturation" with bad social relations or exorbitant social expectations. Elżbieta Trafiałek writes that "Becoming lost in the constantly changing reality, helplessness, sadness or poverty generate stress and this in turn most frequently leads to depression that triggers off various psychological conditions" (Trafiałek, 2002, p. 82). Escape into oblivion that is made possible because of Alzheimer's disease, breaks free from these burdens and becomes in a way, a salvation for an overloaded person. Secondly, the patient lives in a social environment which is obliged to accompany him / her on the way, care for them and provide support as is the case with any other illness or difficulty. Finally thirdly, Alzheimer's disease creates a certain situation of a community growth – it may become a factor that binds a family, makes it stronger, although that does not happen automatically but is an outcome of certain approaches (see above) towards the patient with Alzheimer's and towards people – family members who remain in that relation. Alzheimer's disease stands up for the family to a large extent and familism is raised to the leading rank in human life.

There are many forms of being different in Alzheimer's disease. The patient with Alzheimer's is treated as Different. Also family members are different. Those who are outside the family system are different (doctors, friends, colleagues, social carers, etc.), although they are in the direct contact with the situation of the disease. Finally there are Others, those who create and receive social opinion, who easily reach out for clichés. Alzheimer's disease requires a deeply humanistic understanding of dignity, where "Everyone who is not me, regardless of the distance between us, is the Other", and yet, at the same time, "The Other is my twin" (see: Dubas, 2010,p. 229), a companion on my life path. In this sense, we are all Others. Such a difference, however, requires openness, understanding and empathy, a deep sense of union of fate, mutual support. One has to learn such a difference.

When we understand "accompanying on the way" in a relation in Alzheimer's disease, the Others become extremely important. They should not be strangers or enemies but they should support or serve, offer help and care. Others are present and understanding in this relation. They treat the patient as well as their family subjec-

tively, as people of no less value now – stricken by an illness than it was before. Being associated with the disease becomes a school of life for them. It builds up their personality, strengthens pro-social attitudes, deepens spiritual life as well as understanding the world and themselves. Such relations of respect and trust concern all Others and should be of mutual character. This also concerns the relations between a family member and a carer.

In a way, Alzheimer's disease is a challenge to contemporary loneliness. The patient who is left to his own devices dies quickly. He / she needs social community to survive. Does contemporary society need a person with Alzheimer's? Perhaps it is thanks to them that the Others may see how important another person is for us and how valuable the quality of relationship for our existence is. How much a man needs relations based on love and emotional warmth. Relations that became instrumental kill humanity in a man. Alzheimer's disease creates an opportunity to maintain humanity both in the patient and those who accompany them on the way.

Admittedly, this illness requires great social solidarity "…not only when dealing with the effects of the condition that degrade the organism, but also when searching for its sources, in mitigating the symptoms, in creating a friendly environment for the ill but also for those who care for the patient" (Trafiałek, 2002, p. 82).

The whole family should take the responsibility for the disease as it is also the condition of mutual relations (Lallich-Domenach, 2002, p.88).

We were always together in this illness. /…/ Mum's illness strengthened our family relations, taught us to be even more trustworthy. And when Mum was gone, we stayed that way. (ED).

Social responsibility also needs to be recognized. The patient is a burden and they interfere in society. (Lallich-Domenach, 2002, p. 88). Familiarity, respect and mutual trust are a benefaction for the patient and all of us gain from that (Lallich-Domenach, 2002, p. 90).

Life would be easier if I learnt to ask for help and turn to others. In this way, a safety net is created around us, when you know you are surrounded by people who pay attention to what you are saying, to how you behave. /.../ having said that, I realise that some friends have disappeared because they had no role to fulfil (Beaudoin, 2002, p. 96).

Dimension of communication – the principle of maintaining communication with the patient

It is indispensable to communicate with the patient with Alzheimer's disease, although it is also extremely difficult to perform. One needs to communicate with the patient but one also must be aware of our levels of communication – they are not congruent. It is difficult to expect "understanding" from the patient. Verbal communication must be enhanced with a non-verbal message that is received by the patient who

uses their other, more accessible senses. Thus, communication, including the non-verbal one, must be characterized by emotional warmth so as it would not provoke anxiety in the patient but rather sooth them and create the sense of security. It is worth holding "natural" (provoked by natural activities) and directed (initiated by the carer) conversations with the patient about things that are associated well by them when they have something to say and enjoys sharing these pieces of information.

Communicating our experiences with Alzheimer's disease to the environment is yet another question. The subject of "Alzheimer" is, as are some other, shameful diseases, including psychological disorders, still taboo. This raises the loneliness of family carers and results in them being social outcast. What is so shameful about this disease that we do not want to or we are even afraid of talking about it? Is it the fact that it "distances" the patient from "humanity"? It is us who described the character of that disease and its drama in that way. Thus it is us who can look for a different meaning of it, find some sense in it. The conspiracy of silence around this issue must be broken. It is worth doing it as, in fact, it concerns the *conditio humana,* so as to become more familiar with a man and understand each other better.

/…/ how could they understand if I say nothing (Beaudoin, 2002, p. 98)

I had a school of hard knocks /…/ that her behaviour makes some sense./…/, that it signals something, something that I can comprehend or not. /…/ in fifty percent of cases I cannot understand what's going on, but what counts is that I've learnt not to treat her gestures as meaningless right at the first impulse (Beaudoin, 2002, p. 100).

One may and should "talk" with the patient, but one does not necessarily must want to understand everything. Our world and the patient's world are not congruent most of the time. They may, however, overlap, have something that once was common. That is why just the memory of those events, places and people from the past is so important. That is why it is easier to talk to the patient when the carer is someone who knows them. We may try to tune to the patient and the conversation then becomes a little meeting with the recalled good past. (ED).

The carer should (and that concerns also the nursing personnel) learn to observe the patient, listen to them positively, communicate with them verbally, even when they do not answer, with gestures, touching, facial expressions and bahaviour (Lallich – Domenach, 2002, p. 87).

The disease must not be denied, neither the patient should be lied to, they must be told the truth but this should be done at moments of peace and intimacy, and some room for hope always should be left, of course the life would be different, but not totally negative. The patient must also be informed about what is happening in the family (Lallich – Domenach, 2002, p. 88).

Conclusion

In summation, "accompanying on the way" (see: Dubas, 2016) in its broadest approach, i.e. spatially-metaphorical is a personal, social, existential, axiological, universal and mutual relation on the level of experiencing the phenomenon of life as a common human fate, and at the level of experiencing values that favour discovering the context in which we may find the sense of this fate, also from the perspective of an individual. This relation is placed in everyday situations in which we make our choices and undertake actions, we think and experience emotions and at time that goes beyond the objective calendar dimension. Frequently, it is a relation founded on difficulties. "Accompanying on the way" is an educational relation as it favours the process of learning in its broadest context and thus also favours personal transformations. "Accompanying on the way" as a "Be" relation is a process that takes place based on a variety of challenges of various existential situations as well as values that become a reference point for them, connected with human possibility and need to broaden their own consciousness and self-awareness in relations with Others, including the elderly who are experienced with illnesses and suffering.

"Accompanying on the way" in Alzheimer's disease should fulfil the above assumptions. It is not an easy task for the carers and people from their own environment, yet it is possible, the evidence of which can be seen in the quoted fragments received from the family carers. Does this narration come from the spiritual heroes, aristocrats of the spirit or simply from the people who love their closest ones and who show respect to each other, and are responsible for the core values? The values listed here build up a relation in Alzheimer's disease and in fact, can be shortened to just a few basic and universal needs and values that describe humanity: respect for the dignity of every single person, positive emotions and communicating with people, the need of community. Alzheimer's disease very clearly claims these values and creates the opportunity to "practise" realizing them, to exercise our humanity. A relation in Alzheimer's disease in undoubtedly a difficult one. However, there is no lack of narration about experiences that present this illness also in a positive light, as a consciously created relation, the one that favours achieving values precious to the participants of this relation. Doubtless, this is "accompanying on the way" understood in a deeply humanitarian way, strengthening family relationships and when the patient is gone, allowing to still feel their presence.

References

Beaudoin, P. (2002). *Perspektywa współmałżonka*, „Zeszyty Naukowe Wyższej Szkoły Humanistyczno-Ekonomicznej w Łodzi", zeszyt: Gerontologia Ludzie starsi jako jednostkowe siły społeczne, No. 7 (27), pp. 95–102.

Buber, M. (1992). *Ja i Ty. Wybór pism filozoficznych*, Warszawa: Wydawnictwo PAX.

Dubas, E. (2008). *Edukacyjny paradygmat badawczy w geragogice* [in:] Edukacja do i w starości, M. Kuchcińska (ed.), Bydgoszcz: Wydawnictwo Kujawsko-Pomorskiej Szkoły Wyższej, pp. 45–65.

Dubas, E. (2010). *Uczenie się od Innego – w andragogicznej perspektywie* [in:] *Edukacja jako czynnik rozwoju społecznego* (materiały I Ogólnopolskiego Zjazdu Andragogicznego – Kraków, 23–24 czerwca 2009), T. Aleksander (ed.), Radom: Wydawnictwo Naukowe Instytutu Technologii Eksploatacji – PTB, tom 1, pp. 225–240.

Dubas, E. (2011). *„Uczenie się z biografii Innych" – wprowadzenie* [in:] Biografia i badanie biografii. Uczenie się z biografii Innych, tom 2, E. Dubas, W. Świtalski (eds.), Łódź: Wydawnictwo Uniwersytetu Łódzkiego, pp. 5–11.

Dubas, E. (2016). *„Towarzyszenie w drodze" jako przykład relacji geragogicznej* [in:] Starość – poznać, przeżyć, zrozumieć, M. Halicka, J. Halicki, E. Kramkowska (eds.), Białystok: Wydawnictwo Uniwersytetu w Białymstoku, pp. 299–313.

Fabiś, A. (2013). *Człowiek stary wobec trosk egzystencjalnych*, „Edukacja Dorosłych" 2, pp. 39–46.

Formella, Z. (2009). *Zakończenie* [in:] Jak rozmawiać z uczniami o końcu życia i wolontariacie hospicyjnym, J. Binnebesel, A. Janowicz, P. Krakowiak (eds.), Gdańsk: Biblioteka Fundacji Hospicyjnej, pp. 363–365.

Gadacz, T. (1991). *Wychowanie jako spotkanie osób*, „Znak" 9/436, pp. 62–68.

Gałdowa, A. (2000). *Powszechność i wyjątek Rozwój osobowości człowieka dorosłego,* Kraków: Wydawnictwo Uniwersytetu Jagiellońskiego.

Jaspers, K. (1993). *Uwagi o wychowaniu*, „Znak" 460/9, pp. 81–90.

Jóźwiak, A. (2007). *Senior z zaburzeniami psychicznymi w środowisku* [in:] Senior w domu. Opieka długoterminowa nad niesprawnym seniorem, J. Twardowska-Rajewska (ed.), Poznań: Wydawnictwo Naukowe Uniwersytetu im. Adama Mickiewicza w Poznaniu, pp. 85–111.

Kapuściński, R. (2006). *Ten Inny*, Kraków: Wydawnictwo „Znak".

Lallich-Domenach, D. (2002). *Rodzina i chory na chorobę Alzheimera. Trudna droga do wspólnego przebycia*, „Zeszyty Naukowe Wyższej Szkoły Humanistyczno-Ekonomicznej w Łodzi" 7 (27), zeszyt: Gerontologia Ludzie starsi jako jednostkowe siły społeczne, pp. 85–93.

Marynowicz-Hetka, E. (ed.) (2006). *Pedagogika społeczna podręcznik akademicki*, tom 1, Warszawa: PWN, pp. 38-39, 135, 141–142.

Mace, N. L., Rabins, P. V. (2005). *36 godzin na dobę. Poradnik dla opiekunów osób z chorobą Alzheimera i innymi chorobami otępiennymi oraz zaburzeniami pamięci w późnym okresie życia*, wydanie polskie, Warszawa: Wydawnictwo Medipage.

Tarnowski, J. (1991). *Człowiek – dialog – wychowanie. Zarys chrześcijańskiej pedagogiki personalno – egzystencjalnej*, „Znak" 436/9, pp. 69–78.

Trafiałek, E. (2002). *Choroba Alzheimera jako problem jednostkowy i społeczny*, „Zeszyty Naukowe Wyższej Szkoły Humanistyczno-Ekonomicznej w Łodzi" 7(27), zeszyt: Gerontologia Ludzie starsi jako jednostkowe siły społeczne, pp. 75–84.

Walczak, A. (2006). *Koncepcja rozumienia Innego w kategorii spotkania* [in:] Pedagogika społeczna. Podręcznik akademicki, tom 1, E. Marynowicz-Hetka (ed.) Warszawa: PWN, pp. 430–439.

Wieczorkiewicz, A. (1996). *Antropologiczne sensy drogi*, „Kultura i Społeczeństwo" XL/4.

Vellken, L. (2000). *Geragogik: das sozialgerontologische Konzept* [in:] Handbuch Altenbildung. Theorien und Konzepte fur Gegenwart und Zukunft, S. Becker, L. Vellken, K.P. Wallraven (eds.), Opladen, pp. 87–94.

Zych, A. A. (2013). *Przekraczając „smugę cienia". Szkice z gerontologii i tanatologii*, Katowice: „Śląsk" Wydawnictwo Naukowe, wydanie drugie.