

Agnieszka Smrokowska-Reichmann* 

A Senior as an Individual in the Situation of Dementia. Tom Kitwood's Person-Centred Care Model and the Philosophy of Dialogue

Abstract

Seniors suffering from dementia are always exposed to a reductive approach and depersonalization due to the specificity of that disease. The subjectivity of a senior is neglected or even completely negated. What remains unnoticed is the fact that, despite their disease, a senior is still a person – with the rights and needs of a person – and not just a helpless patient. The paper presents a break that has been made in the understanding and care of seniors with dementia thanks to the work of Tom Kitwood, a British psychologist. In Kitwood's Person-Centred Care model, a person is defined as a relational, feeling, and historical being. At the same time, being a person is only possible in the interpersonal context. Hence the author's suggestion to read Kitwood's concept from the angle of the philosophy of dialogue, which is always an affirmation of subjectivity and an opposition to tendencies that reify human beings. In the author's opinion, Kitwood translated the main postulates of the philosophy of dialogue into the language of psychology, gerontology and senior care by operationalizing the indicators of the well-being of a patient with dementia.

Keywords: dementia, personhood, subjectivity, dialogue, relationship.

Senior jako Osoba w sytuacji choroby demencyjnej. Model Person-Centered Care Toma Kitwooda na tle filozofii dialogu

Abstrakt

Seniorzy cierpiący na demencję, ze względu na specyfikę tej choroby, narażeni są zawsze na podejście redukcyjne i depersonalizujące. Zaniedbywany lub nawet całkowicie negowany jest wówczas wymiar podmiotowości seniora oraz to, że pomimo

* University of Physical Education in Kraków.

choroby pozostaje on nadal osobą – z prawami i potrzebami osoby – a nie jedynie bezradnym pacjentem. Artykuł przedstawia zwrot, jaki dokonał się w rozumieniu seniorów z demencją oraz opiece nad nimi dzięki pracy brytyjskiego psychologa Toma Kitwooda. W modelu Person-Centered Care osoba definiowana jest jako istota relacyjna, czująca i historyczna. Jednocześnie bycie osobą jest możliwie jedynie w kontekście interpersonalnym. Stąd wynika propozycja autorki artykułu, aby koncepcję Toma Kitwooda odczytać przez pryzmat filozofii dialogu, będącej zawsze afirmacją podmiotowości i sprzeciwem wobec tendencji reifikujących człowieka. Zdaniem autorki, Tom Kitwood, operacjonalizując wyznaczniki dobrostanu pacjenta z demencją, przetłumaczył główne postulaty filozofii dialogu na język psychologii, gerontologii i opieki senioralnej.

Słowa kluczowe: demencja, bycie osobą, podmiotowość, dialog, relacja.

Towards the rainy autumn of life

In well-developed communities, the average human lifespan is increasing. That is also true for Poland, where the lifespan of men has increased by 7.9 years and that of women – by 6.5 years. On average, men live to be 73.8 years old, and women – 81.6 years old (GUS, Statistics Poland, 2016). People live longer and longer, which means that old age is a growing part of human life. A longer old age may bring many benefits, in particular if it is lived in an active and positive manner. A long, cheerful autumn of life, unlike any other period in human life, creates favourable conditions for, among other things, developing wisdom, both in the pragmatic (practical) and spiritual (transcendental) dimensions¹. A perfect old age, i.e. long, healthy, and experienced in an optimum manner, may be understood as savouring the fruits of the whole of a long life, understanding oneself and the sense of life better and better, reducing fear of death, and increasing spiritual maturity. However, that vision of old age is one-sided, even utopian.

Unfortunately, along with the increasing human lifespan, the probability of the incidence of various diseases, mostly chronic and degenerative ones, grows. Among those, various types of dementias come to the fore (Alzheimer's disease, vascular dementia, frontotemporal dementia, or dementia with Lewy bodies). Age is the main risk factor in dementias: in people over 85, the incidence of such diseases is app. 30%, while in people below 74 it is only 5% (Barcikowska, Bilikiewicz 2004: 26). Therefore, dementia may seem to be the price for a long life. A high price if one considers its multiple symptoms, incurability, and progressive nature. Those disorders have an effect on all levels of human life, i.e. the cognitive (memory, thinking, and understanding disorders; disorientation), emotional (low spirits,

¹ More about the wisdom of elderly people in the dimension of life practice has been written, among others, by Straś-Romanowska (2007). The issue of the spiritual wisdom of seniors is, on the other hand, reflected in the theory of gerotranscendence, ref. to in particular Tornstam (1989, 1999).

hyperactivity, aggression), behavioural (self-isolation, loss of self-control), and physiological (incontinence, neglect, Parkinson's symptoms). Speaking about a certain totality of dementia (Iliffe, Drennan 2001) is justified, as it seems that it does not spare any dimension of being a human. As a result, questions of existential meaning arise: is it possible, despite all, to remain oneself in the situation of dementia? Does the totality of dementia mean that an elderly person suffering from the disease is, most of all, an object of care, which is, out of necessity, as total as the disease? How should we understand the subjectivity of an individual, how should we see an individual as a person in confrontation with such an inexorable and overwhelming neurodegenerative pathology?

Those questions become increasingly important for us, as the process of ageing of society goes forward more and more quickly. It is estimated that in 2025, the share of people over 60 in Poland will be 28% of the population, while by 2035 it will have increased to 32% (Statistics Poland 2016). That translates into the huge numbers of 10 million and 11.4 million people respectively. Many seniors will suffer from dementia and will require specialist care. That, on the other hand, means that we have to take up the task of not only developing appropriate medical and nursing procedures, but also taking anthropological, axiological, and ethical reflexions, which are no less important.

“Disappearance of a person” vs. subjectivisation of a patient

It is easy to succumb to the pessimistic and deterministic vision of patients with dementia. It is easy to say that the slow loss of memory and cognitive competences, in particular, means a slow goodbye to oneself as a creature of the *homo sapiens* species. Tom Kitwood, a British psychologist, has objected to such a reductive approach to dementia sufferers. He has questioned the current understanding of dementia only from the biomedical perspective and started to emphasize the interpersonal and processual context of dementia. In cooperation with the Bradford Dementia Group, he has revolutionized the conceptualization of dementia and dementia sufferers. As a result, Person-Centred Care, which is a special model of care for seniors with dementia, where the central place is taken by a senior recognized as a person was developed (Kitwood 1997).

Kitwood accused the traditional biomedical perspective of dementia most of all of leading to “the almost complete disappearance of a person” (Kitwood 1993: 451). In my opinion, that observation may be construed in two ways. Firstly, the diagnosis of dementia has become more important and more worthy of attention than the patient diagnosed with the disease. Secondly, the focus on the symptoms of the disease has made the patient a helpless and powerless individual rather than a person. Kitwood took quite the opposite perspective and emphasized that a patient with dementia must still be recognized as a person. Kitwood defines

a person as a feeling, relational, and historical being who still wants, and is able, to influence their world. (Kitwood 1993: 451) Personhood is a status bestowed by other people; therefore, it is possible only in the interpersonal context. A person has their worth, dignity, and rights; they require respect and demand the satisfaction of their needs. Depersonalization of dementia sufferers means taking them out of the interpersonal context and depriving them of the properties of a person. A depersonalized patient is decontextualized and defined only through their deficits and problems (Kitwood 1993: 452). Being a person is also possible in the situation of dementia, but only on condition that other people are present around a patient and bestow the status of a person upon them.

It is worth underlining that the theoretical, and often very subtle, concepts of Tom Kitwood are well-grounded in empirical studies. Kitwood with his team conducted thorough research on the behaviour of people with dementia in their various environments (in family homes, all-day care centres, day care centres). He was always interested, most of all, in whether the attitude of the surrounding people to a senior with dementia has an influence, positive or negative, on the patient's behaviour. The results of the studies led Kitwood to make a famous differentiation between "malignant social psychology" and "benign social psychology" (Welling 2004: 6–7). Those expressions refer to medicine, which divides tumours into malignant and benign ones, rather than to the character and good (or bad) will of carers of a person with dementia. Malignant social psychology means focusing on the deficits and regression of a senior with dementia, denying them the right to be a person, and objectifying them, which makes their condition worse and accelerates the course of dementia. Benign social psychology helps to maintain the relatively good quality of a senior's life despite their having dementia by reinforcing the patient and accepting them as a person in their dignity and subjectivity. It was that motto, i.e. maintaining a relatively good quality of life despite dementia, that was the fundamental goal of Tom Kitwood's work. All his studies and publications aim to show that the well-being of a patient in the situation of having a serious and incurable disease depends directly on the status of a person being bestowed upon them.

Research conducted in the life environment of seniors with dementia, and a conceptualization of those observations, has enabled Kitwood to define the fundamental signs of malignant social psychology with regard to seniors suffering from dementia. They include:

- Infantilisation – suggesting that a patient with dementia has the mentality of a child;
- Treachery – deceiving a patient, manipulating them, not for their good, but for the carer's interests;
- Stigmatisation – treating a patient as if they are not a part of normal life, as if they have no value, stigmatising them in particular by verbal labelling;

- Disempowerment – not allowing a patient to do what they are still able to do, though slowly and clumsily;
- Intimidation – verbal threats, actual physical abuse, using one’s own advantage over the patient;
- Outpacing – providing a patient with information or instructions at a rate which is too fast for them to understand;
- Invalidation – ignoring or disregarding the emotional states of a patient, in particular confusion and stress;
- Objectification – treating a patient as a case, number, task, object; which is washed, dried, measured, moved *etc.*;
- Banishment – removing a patient from the human community either in a physical or psychological sense;
- Ignoring – speaking about a patient in their presence, as if they were absent, no reaction to a patient’s attempts at communication;
- Condemnation – blaming a patient for their behaviour, ascribing maliciousness or bad will to them, although dementia is the reason;
- Disruption – interventions breaking something which is good, proper, or satisfying for a patient at the moment concerned (Kitwood 1997; Morton 2002).

Most of the studies concerning the situation of seniors with dementia were conducted by Tom Kitwood in the 1980s and 1990s. It is, among other things, the Person-Centred Care concept that caused fundamental changes in the attitude to care of seniors with dementia, although many aspects of malignant social psychology identified by Kitwood are still present. The items explained above show how depriving a senior with dementia of the status of a person looks in practice. Kitwood has rightly observed that it is not dementia itself that depersonalizes a patient, but, paradoxically, people taking care of the patient.

Benign social psychology, on the other hand, nurtures and reinforces the fact of being a person in a senior with dementia; the more advanced dementia is, the more carefully it is done. Others become allies of a senior in the confrontation with the incurable and inexorable disease. Maintaining the status of a person in dementia, and often despite dementia, requires effort, but is possible and achievable. Kitwood believed that the success of such work is proven by the personal well-being of a senior with dementia, which may be identified and operationalized using the following 12 indices of well-being: communicating wishes and needs, relaxation and stress relief, sensitivity to emotional needs of others, sense of humour, creative expression (e.g. singing, painting, moving along to music), readiness to help, showing initiative in interpersonal contacts, showing feelings, respecting oneself, accepting other seniors with dementia, feeling pleasure, and readiness to be active (Kitwood, Bredin 1992: 281–282).

Needs of a person and the practice of interaction with a person suffering from dementia

What is characteristic of Kitwood is constructing well-thought-out and convincing typologies. The Person-Centred Care concept consists in putting a senior with dementia, perceived as a person, in the centre of the therapeutic process; and since it is all about a person, one should think what basic needs a person has, and how they can be satisfied if that person suffers from dementia. So, Kitwood's other typologies emerge, i.e. the six-item catalogue of a person's needs and twelve-item set of techniques used to transfer the theoretical assumptions of the model to care and therapeutic practice. Below, a general description of that positive vision of interactions with a senior with dementia is presented.

Needs of a person:

- The need to experience love, which is the most important, and around which other needs are focused; experiencing love as being accepted by another, regardless of one's health and fitness;
- The need to experience comfort; understood as a passing of the feeling of security, and the empathic reception of the difficult situation of the person;
- The need to experience a relationship, which is particularly important for people lost in the surrounding world;
- The need to join a community, i.e. the need of affiliation owing to which the person does not feel lonely;
- The need to have something to do, as a constitutive property of each person is their orientation to do something and search for tasks which give them the sense of meaningfulness and satisfaction;
- The need to experience identity, which is the awareness of who one is and what one's value is, experienced not only in the cognitive but also the emotional dimension (Welling 2004: 7–8).

Techniques of positive interactions with a person suffering from dementia:

- Recognition – treating a senior with respect, greeting them and saying goodbye to them politely, listening to their words carefully, maintaining eye contact;
- Negotiation – learning the wishes and expectations of a senior and determining, together with them, which wishes and expectations can be met and how, giving a senior the feeling that they have at least a minimal control over their situation;
- Collaboration – doing something together with a senior and shaking them out of passiveness;
- Play – interacting creatively together, spending time together pleasantly, stress-free activity which is not oriented to results;

- Timalation – a neologism created by combining two words, the Greek *timalao* (acts expressing appreciation and respect for a person), and Latin *stimulatio* (stimulating, mainly in the sensory dimension). Timalation means stimulating a senior with positive sensory stimuli, with no reference to the cognitive sphere, emphasizing the importance of a senior;
- Celebration – being together with a senior which eliminates borderlines drawn by the disease, in the atmosphere of spontaneous joy, free from tensions and suffering;
- Relaxation – refraining from excessive actionism (in particular the therapeutic) and simply being with a senior, doing nothing together as a factor stabilizing a senior emotionally and providing them with a feeling of security;
- Validation – the term known in psychotherapy, here: receiving and accepting the subjective reality of a senior, making patient attempts to understand their world, recognizing their emotions and experiences as important and real for them;
- Holding – creating a safe space in the actual and symbolic meaning, close contact with a senior also in the literal meaning (like holding a child);
- Facilitation – supporting a senior, but doing things for them, helping when they feel helpless and refraining from helping when a senior acts on their own again, which shows them that they still have certain competences and a certain scope of control;
- Creation – catching and developing moments when a senior becomes active out of their own will and wants to initiate something in the dimension of human interaction;
- Giving – noticing and maintaining situations when a senior makes attempts to reach out to others, and tries to refer to their needs and help them (Kitwood 2005: 133–137; Morton 2002).

The Person-Centred Care concept and the philosophy of dialogue

When we look for the inspirations and contexts of Tom Kitwood's Person-Centred Care, what comes first to mind is the Person-Centred Therapy concept developed by Carl Rogers. That has been noted many times by authors commenting on Kitwood's works. Indeed, the connection between Kitwood and Rogers seems the most obvious. Rogers initiated a turn in humanist psychology which is similar to that achieved by Kitwood in the care of seniors. Rogers proposed psychotherapy focused on a patient, whom he called "a client" to emphasize their dignity and equality with the therapist. The therapeutic process has been presented by Rogers from the angle of the relationship between the therapist and the client, where the client, despite their problems, is an independent party with equal rights rather than a submissive executor of the specialist's instructions (Janus 2016).

Therefore, the compatibility between Rogers's attitude and Kitwood's approach can be seen at first glance. However, a deeper reflection also points to a different tendency, which is more speculative than Roger's humanist psychology, but, at the same time, equally related to Kitwood. That is the philosophy of dialogue, which is also called the philosophy of a meeting, in particular in Martin Buber's approach.

The name of philosophy of dialogue/philosophy of a meeting indicates that that direction of philosophic thought focuses on the analysis and explication of relationships and related subjects, i.e. people who meet and start a dialogue. The philosophy is based on the dialogic principle, which says that an individual does not become themselves until they meet another individual in a source experience called a dialogue. Not each conversation or communication meets the criteria of the dialogic principle. What is more, a dialogue within the meaning of the philosophy of dialogue may involve no words whatsoever. A true dialogue is only a contact which makes the other person a subject, which proclaims the sovereignty, non-repeatability and dignity of the other person, and which, at the same time, recognizes that a single individual is not self-sufficient (Gadacz 2009: 507). That is why, Martin Buber, one of the most eminent representatives of philosophy of dialogue, writes about a silent dialogic relationship which connects people entangled in the joint, often difficult, situation of being human (Buber 1993: 92) The fundamental fact of human existence is neither an individual (a single person) nor a community (a collective). It is only a relationship of a person with a person which enables "the direct cognition of essence of a human being, that which is typical only of a human being" (Buber 1993: 93).

Therefore, a meeting of two people becomes an event which creates humanity in both parties to the meeting. In Martin Buber's philosophy, that meeting is present between I and You; in Emmanuel Levinas's philosophy, on the other hand, the concept of meeting with the Other appears. Regardless of the detailed differences between those and other philosophers of dialogue, all of them unanimously underline that you may meet only a person and you may establish a relationship only with a person. Therefore, the philosophy of dialogue is, on the one hand, an affirmation of subjectivity and, on the other hand, an objection against all tendencies to reify a human being. Treating an individual as a person rather than as an object means that they are recognized as "a partner in a life event (...) What decides is not-being-an-object" (Buber 1992: 140).

In modern philosophic anthropology, applications of developed theories are more and more often sought, sometimes highly speculative and sophisticated, but concerning an issue which interests us very much, i.e. the issue of humanity. What does it mean to be a human being? What is a person? How can one become oneself, and is it possible? What does the relativity of human existence consist in? How can a human be a human in a world which is not only human? Those and other

important questions asked by philosophic anthropology may be answered not only in the further development of philosophical theorems, but also in the achievements of detailed sciences. Tom Kitwood's Person Centred Care, which concentrates many of the most important demands of philosophy of dialogue, is a clear example of that.

Firstly, Kitwood demonstrates that discovering a senior with dementia as a person rather than a case or an object requires that they are perceived in the relational context (Kitwood, Bredin 1992: 269). The perspective of an isolated individual is useful for the purpose of purely medical studies and procedures; however, it is not successful in the context of care which preserves relatively good quality of a senior's life through respecting their dignity. Therefore, a purely neurological approach to dementia is different from a psychological one – and that is how it should be.

Another innovative and bold idea of Kitwood, which has become a keystone of his care model, was questioning the dualism present in the care of seniors up till then, i.e. normal, fit, competent, and professional carers on the one hand, and tedious, problematic seniors destroyed by dementia on the other. That dualist approach resulted in neglecting the aspect of a relationship in contacts with a senior with dementia. Of course, Kitwood never denied that a certain asymmetry between a patient and their carer is a fact. However, he emphasized that such an asymmetry should boil down only to purely technical aspects (i.e. reduced functionality as a result of the disease means that the carer must help the patient in many dimensions or even do things for the patient). However, in no circumstances may one assume that people with dementia are people to a less extent than healthy people. What the best professionals share with the most disorientated seniors with dementia, for Kitwood, is a community of humanity, which does not allow any asymmetry in that relationship. A patient and a carer need one another and may not be perceived without one another.

One of Kitwood's most popular demands is the following: we should stop speaking about "a person-with-DEMENTIA" and start speaking about "a PERSON-with-dementia" (Welling 2004:1). By developing the catalogue of the needs of an individual perceived as a person, working on techniques of satisfying those needs in a person with dementia during everyday contacts, and operationalizing indicators of a patient's well-being resulting from such techniques, Tom Kitwood translated the main demands of the philosophy of dialogue into the language of psychology, the language of gerontology, and the language of care and nursing practice. Kitwood's subjectivisation of seniors with dementia and putting them in the context of interpersonal relationships is a reassuring example of the fact that being a person and becoming oneself is possible, not only in old age, but also in old age lived in the shadow of an incurable and progressing neurodegenerative disease. A dialogic relationship joining people may exist without words.

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