

A body without memory? How to relate to someone with Alzheimer?

Um corpo sem memória? Como se relacionar com alguém com Alzheimer?

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We know that an estimated 46.8 million people worldwide are living with dementia in 2015 and that this number almost doubles every 20 years, arriving to about 50 million in 2017, and is predicted to arrive to about 131.5 million in 2050.¹

In terms of cost of caring for people with dementia: about US\$ 800 billion is spent globally per year and that by 2030 the cost is foreseen to reach to about US\$ 2 trillion.²

There are existing risk factors, however, like low education level, loss of hearing, hypertension, obesity, smoking, depression, physical inactivity, social isolation, and diabetes, that may be modified through proper and early intervention.²

Yet, in the face of this existing situation, how can we meet this challenge?

Is there a possibility of the arrival of new therapy for Alzheimer?

As to date, the Food and Drug Administrations have not yet approved any new pharmacy following its last approval in 2003.²

Therefore, in view of the lack of new therapies, the health system is at a risk of being overloaded by the future cost of assistance. In this regard, the importance of non-medicinal therapy is to be underlined. For the treatment of agitation and aggressiveness, for example, social contact or activities result to be more useful than antipsychotic drugs, which can provoke important collateral side-effects.

In order to emphasize the significance of non-medicinal therapy, it is thus necessary to examine the identity of a person with Alzheimer.

Oftentimes, there is a shared vision of dementia as a pathology that cancels the perception of what has subsisted in one's life, conveying the person to live in an eternal present, without a past, without a future. Not only is this vision unacceptable from the ethical point of view of life, but it is also contrary to many results of studies, in which dementia does not exclude the possibility of finding significance in one's life condition, if the person is supported by interpersonal relationships and by a care process. Certainly, the loss of knowledge of one's self is a cause of suffering for the sick person and the caregivers, worsening the

symptomatic expression of the disease. It is undeniable that the cause of such is correlated to the cerebral damage, but it also depends on the environment, be it physically, and above all, relational.

With regards to pharmaceutical therapies for dementia, as above-mentioned, that as to date the Food and Drug Administration has not approved any new pharmacies since 2003, even if there are various on-going experimentations.²

If today it is not yet possible to positively influence the neurological damage, it is however possible to modify the relational context in order to reduce the suffering of the sick person and, partly, also to lessen the worsening of functional deficits.

Therefore, attention must be given to other factors that influence profoundly on the daily lives of those affected by dementia. This consideration allows the psychological aspects of the person to be enhanced, sustaining the person's identity.

THE PROBLEM OF PERSONAL IDENTITY

The progressive deterioration in the level of the cerebral organ and the resulting functional impairment determine substantial modification in the patient's personality.³ The family members suffer due to the difficulty in bringing ahead the affective relationship, which can constitute in itself a true and real sense of loss. Parallel to the progressive functional impairment of memory, a situation of spatial disorientation is verified, such that the patient no longer recognizes the environment in which he or she is in, temporary disorientation, phenomena of misidentification (e.g. Exchanging their family members for other people, even for strangers). This generates in the patient, from the initial onset of the disease, serious psychological sufferings: from anxiety for the future connected to the fear of dependency and loss of autonomy and decision-making ability, to the existing disorientation due to the progressive difficulty in "recognizing one's self" and "recognizing others". Personal identity is therefore a problem peculiar to Alzheimer's disease. Several questions arise:

- ✓ What is known about the identity of patients affected by dementia?
- ✓ What skills are missing and which ones are intact?
- ✓ Do people with advanced dementia still have desires and wills?
- ✓ Does the absence of emotional behaviours mean that they do not have emotions?
- ✓ Are there still some ways of interrelationship?
- ✓ If the capacity of verbal expression is lost does it mean that all capacities of expression are also lost?
- ✓ In the advanced stage of dementia can one presume that no type of will still exists?

In the attempt to give some answers, the fundamental assumption consists in the assessment of all the dimensions of the person.

Personal identity is a complex concept, multidimensional, that includes emotional aspects, behaviours, cognition, values.⁴ Besides the traditional methods of assessment, evaluation should be done from the subjective point of view in order to determine the interrelations between biological changes, personality factors, and psychological aspects. Furthermore, the level of impairment presents an ample individual variation, independent of the severity of the disease.⁵

In the absence of knowledge and of a complete sharing on the part of the professional operators and the members of the family regarding the identity of a person with dementia, one runs the risk of making the patient experience even

more acutely the depersonalisation, the loss of independence, as well as their social and political rights.

In this regard, it is necessary to take into consideration that which is defined as “irreversible deterioration”: an expression that indicates the percentage of disability not directly correlated to the neurofunctional damage, but more towards the interaction between the patient and the environment.

The improvement of the environment of life – even if it does not have a probable influence on the biological duration of the disease – certainly prolongs and improves the quality of life of the patient and their family members. Therefore, this has to be taken into consideration as one of those few existing therapies with verifiable results.

However, it happens so often that whenever the operator finds himself or herself in front of the patient’s difficulty in communicating, he or she attributes this automatically to the disintegration of the logical process, strengthening the conviction that the person with dementia is incapable of expressing not only needs, discomforts, desires, but also sentiments and emotions. And from here stems forth the consideration of the demented as a “non-person”, an “empty shell”, in which the possibility of any form of interaction no longer exists.

THE INFLUENCE OF RELATIONSHIPS

It is a widely diffused conviction by now that the alteration of the sense of one’s self, the disintegration of the personality, is not only the result of the inevitable degeneration of the cerebral organ, but also of the type of environment – physical and relational – that surrounds persons affected by dementia. This conviction still dates way back in the early ‘90s, from researches conducted by Tom Kitwood,⁶ an English psych gerontologist, considered as one of the first to look into the topic of dementia not departing from the pathology of degeneration, but from the person. Under the term of “malignant social psychology” he describes the various types of undermining and stigmatizing interactions in the care relationship, which may threaten the psychological aspects, and more so the profound identity of persons. Although oftentimes unintentional, it happens quite commonly, notwithstanding the profound damage that they inflict in the curative context. This occurs primarily remarkable with persons who have difficulty in following verbal contents: the elaboration of such messages through a non-verbal level, particularly conditions the quality of life of the patient due to the surrounding negativity of the atmosphere.

The premise in evading a negative climate in the care environment consists in the consideration of the personality, not as exclusively correlated to the cognitive function only, but more as a “status” conferred by others to a human being in the context of determining relationships and social rules: it therefore requires acknowledgement, respect and trust. Personality may be defined as “socially constructed through the interaction with the environment”.

The influence of relationships on the personality has been studied successively by others, who have then developed further the prime intuition of Kitwood. In particular, it is underlined that even in persons with advanced dementia; there are existing episodes that reveal the awareness of one’s self, above all in the presence of “involving” relationships with the family members and professional operators.⁷ Vice versa, relationships that are task-centred, with difficulty in care relationship, increase psycho-behavioural disturbances, which become present in about 80-90% of the patients with dementia. These various types of non-cognitive symptoms are: hallucinations, psycho-motor agitation, verbal

and physical aggressiveness, alteration of the wake-sleep rhythm, etc. Their presence or variation in frequency and gravity can represent the “non-verbal” manifestation of the patient’s unease.

Besides neurobiological (neurochemical and neuropathological) alterations and psychological aspects attributable to pre-existing personality traits, these disturbances are also often due to social aspects, such as a change of environment and interactions with the caregiver.

Difficulty in communication becomes more evident with the progression of the disease: the person may be incapable of expressing his or her needs, language disturbances and sensory deficits become existent. Considering the various communicative channels, it is known that the verbal part is the least representative of language, whereas the one related to the body has dominance over tone of voice. The two linguistic forms: verbal and corporeal, are inevitably linked between them. It may happen that the coexistence of the two languages may not coincide in a harmonious relationship; rather, at times one may contradict the other. An important strategy in making communication efficient is to render its various levels pleasant.

THE DECISION-MAKING CAPACITY

In the ethical perspective of care, it is a fundamental objective of the therapeutic relation to promote autonomy in the different stages of the illness, sharing with the patient and the family decisions regarding the cure, which is also based on desires, values and personal convictions. The respect for autonomy is considered universally as a fundamental ethical principle. The challenge is to assert this universal principle in every single situation; in particular, taking into consideration what remains of the possibility of determining one’s life for a person living for years in the substantial impossibility of deciding, as is generally the case for those with cognitive impairment. There is an increasing interest in research and clinical practice towards the centrality of the patient’s desires with regards to therapeutic choices, and more generally with regards to life choices, even for patients with dementia.

As regards to the assessment of dementia-related decision-making aspects, a major contribution has been made by neurobiology:^{8,9} also with the help of functional neuroimaging techniques, it could be demonstrated that mental images are a documentable biological phenomenon. The biological substrate consists in the functional activation of specific neuron groups in response to the recall of certain mental images. The evocation of these images has also been documented in the decision-making process, pointing out that the mental image is associated with the activation of brain areas directly or indirectly linked to the perception of emotions.

Therefore, there is good reason to affirm that the decision-making ability of a person depends heavily on the emotional process.

Even if the person is unable to understand the content of a form of consent when informed, the person with limited cognitive capacity can at times still be able to express choices and preferences coherently with his values of reference.¹⁰ The therapeutic and relational needs are also expressed through gestures, posture, mimic, volume and tone of voice, and disturbances of behaviour. In order to understand them it is necessary to be able to adjust communication to its functional level. From this need derives the importance of a specific formation not only for the health operators, but also for the support administrators and tutors, oftentimes consulted in the decision-making process, which should promote the good of the patient.

THE BODY COMMUNICATES

The relationships of care are intrinsic to corporeality, therefore it is necessary to pay particular attention to body expressions, especially when assisting persons with dementia. The French philosopher Merleau-Ponty affirms that the body lived – *le corps sujet* – is the only access to the external world, the only way to be in the world (*être-au-monde*).¹¹ This idea of a body lived has been explained lately with the metaphor of “body like a text” to be interpreted.¹²

If the unity of mind and body is considered as the ontological characteristic of a human being, then, these two entities, mind and body, cannot both and completely disappear. In other words, although the body of a person suffering from severe dementia, at least apparently, functions progressively on its own, it still remains a living body. The body is certainly the product of nature, but at the same time of culture, it has the innate capacity and experience that is deposited in the “body memory”.

If in a person affected by dementia the cognitive capacity has been lost, it does not mean that bodily knowledge developed in the course of life is also lost.

The past is manifested above all in the body, it talks in one’s face, in one’s gestures, in one’s way of sitting, eating, in one’s gait, words, and voice. Also the body lives with the memory. There is no better proof of this than one’s habits, which are no other than a form of conserving the past.

When a relationship becomes difficult verbally and emotionally, could the body be a mode of communication?

Could the defensive movements of a person affected by dementia be interpreted as a communicative mode of “bodily autonomy”, a remembrance of what was once a “rational autonomy”?

Through bodily communication, there is then the possibility of knowing and interpreting the preferences of persons with advanced dementia. Moreover, non-pharmaceutical therapies are generally based on this conviction.¹²

By means of bodily communication, the preferences, approvals, and refusals, in persons with severe dementia could be known and interpreted. In addition, psychosomatic methods, music therapy, the practice of sense stimulation through music, lights, perfumes, bodily contacts are based on these convictions. If the defensive body movements are interpreted as significant expressions of a person unable to manifest his or her desires in other ways, the question still remains, however, of whether to respect these desires or not. In first approximation, if one perceives that the benefits of a particular intervention that causes defensive movements are not clearly resolute and therapeutic, the said intervention could be suspended.

THE ROLE OF CAREGIVERS

Care that is centred on the person, rather than on the illness, is a holistic and integral approach that aims at maintaining the well-being and improving quality life of the sick. Even the results of a recent study, based on a systematic review and meta-analysis, provide further evidence of the effectiveness of such an approach, demonstrating a reduction in agitation, neuropsychiatric symptoms and depression. Therefore, one needs to remember that the behaviour of a patient with dementia reflects the mood of the people beside him or her.

However, an educational strategy that promotes the learning and development of communicative skills for formal and informal caregivers of persons with dementia is necessary.¹³ The care centred on the person does not consist in what is said or done, but on how it is said and done.

The results – following communication training strategies – besides an improvement of quality life and well-being of patients, also consisted of an increase in positive interactions in various care settings, as well as a positive impact on the same caregivers.¹⁴

Nevertheless, the consideration that each operator assigns to those who have a cognitive impairment remains crucial: the value of life in perturbed conditions inevitably determines the behaviour of those who are assisting.

SPIRITUAL ASPECTS AND DEMENTIA

It has been said that personal identity includes emotional, behavioural, cognitive, values, and therefore, also spiritual aspects. It is noted that people who are not supported in this aspect of the cure, experience a spiritual anxiety.

It is important, therefore, that in assessing the needs of the patient, the spiritual aspects must also be included, which may be identified by trying to know the convictions and values of the person or by asking information from family members. However, in order to be able to support the spiritual or religious convictions of the person, not only a personal but, also a shared approach with every component of the multidisciplinary team is required.¹⁵

What relationship could one hypothesise between loss of identity, spirituality and dementia? Can the spiritual identity be threatened by the dementia process?

It has been observed that while cognitive abilities decline, the ability to experience feelings and emotions remains.¹⁶ For those patients who have been going to church in the past, offering them the possibility of participating in religious rites can be a reminiscence therapy, a multi-sensorial approach, favouring in them a sense of belonging. Religious symbols can elicit thoughts, memories, and experiences that give consistency and unity to the person's life by reinforcing the identity of the ego.

Therefore, it can be said that spirituality and religion are categories that do not vanish with the dementia process, but deserve to be cultivated with respect of the person. The balance of spiritual needs should not therefore be considered optional, but rather an important strategy in a global plan of cure.

CONCLUSIONS

Based on the above, it is shown that personality is the product of relationships with others and can be improved or worsened based on how it is valued or depersonalized.¹⁷ Trying to understand the complexity and quality of these relationships adds further insights into the lives of people with dementia.

If personality is not influenced in a one-way direction only, the same people with cognitive impairment become active agents in the care process, showing some degree of awareness.

A person remains a person even when he or she cannot express externally his or her vital spirit: pathology does not destroy – it can perhaps obscure – the psychological and spiritual components that characterize the human person.

People with dementia think, communicate, remember, understand and express feelings and self-awareness, convey an interpretation of life, a personal narrative history.¹⁸

Through a new cognitive and emotional reorganization, the person searches for a new way of existence, a new plot of self, a new memory that gives continuity to what remains of his or her identity. For this reason, respect for his or her subjective experiences, perceptions and inner world is required.

It is important to respect and to promote the *continuity of each person's identity* by ensuring the freedom of verbal and non-verbal expressions, recognition of desires, re-appropriation, though transient and illusory of significant experiences of the past.¹⁹

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