

## Life quality and the self: A person-centered case study of Alzheimer's disease.

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### Abstract

Alzheimer's is a neurodegenerative disorder that manifests itself physically, cognitively, emotionally, behaviourally. Despite that AD influences all aspects of life of the sufferer, treatment focuses on the biological and cognitive aspects, fact which is problematic, both theoretically (as cognitive abilities decline, it is thought that the self is gradually lost) and practically (aspects that should be targeted are neglected). The result is that AD is approached differently from other neuropsychiatric disorders and there is no focus on the individual's actual well-being. A Person-Centered Approach recognizes and targets all aspects of the person. The model approaches the core of the self and its goal is to promote the holistic well-being of the person, leading to a life with quality despite the disorder. The importance of the PCA is made apparent through a case study of an 84-year old man with AD. The interaction with the man began with sessions of cognitive reinforcement only, as requested by the caregivers, yet the spherical needs of the person and his low life quality lead to the PCA being applied. The treatment plan became more personalized (atuned to the preferences and mood of the man), more engaging (allowing a sense of agency, including the person in the process and the goal) and elements that allowed the expression of the self (roles, character) were added. After some time, a therapeutic alliance was developed and the man became more stable emotionally and cognitively, learned to manage life with his existing skills, and his subjective well-being increased, as reported by the caregivers, the man himself, and as revealed through questionnaires. A PCA in AD allows the person to maintain a sense of self, and a quality of everyday life, because it approaches individuals as persons and not as manifestations of disorders.

**Keywords:** Alzheimer's dementia, Self, Selfhood, Personhood, Person-centered approach, Intervention, Psychotherapy, Therapy, Treatment, Art, Art modalities, Case study, Greece.

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### Introduction

Alzheimer's disease is a condition almost as old as mankind: ancient civilizations, such as the Greeks, the Romans, the Egyptians, recognized that old age often came along with problems in memory, in judgement, in concentration [1]. In the recent years, individuals with Alzheimer's (AD) represent a growing population: in Europe more than 7.3 million suffered in 2011, and more than 160 thousand individuals in Greece alone with the numbers moving solely upwards, and expected to triple in the upcoming decades [2]. According to the statistics of Alzheimer's disease International, in 2017 there were approximately 50 million individuals living with AD, and in 2015 the global cost of care for AD reached 818 billion dollars.

These facts lead to a growing need to treat AD effectively, and improve the life of the individuals who suffer. AD is a neurodegenerative disorder of the brain, which manifests itself cognitively, emotionally, behaviourally, and physically. In order to treat AD effectively all the aspects that the disorder influences, therefore all aspects of the person, should be targeted [3].

The Person-Centered Approach (PCA) in Alzheimer's allows a focus on all aspects that the disorder influences, thus all aspects

of the self, in order to improve the quality of life (QOL) of the individuals, as was revealed through the case study of P.

### Literature Review

It used to be widely accepted that individuals with AD experience a 'loss of self': as the disorder progresses the self gradually diminishes until it is lost. In this view the self is approached as a cognitive entity, relying on cognitive and metacognitive skills alone (such as autobiographical memory). Therefore little to no attention was paid to the self in AD experimentally and clinically: few studies had addressed this issue, and of those who had, most supported the above argument [4]. Similarly, it used to be widely accepted that individuals with AD cannot have a life of quality: their QOL gradually decreases as the disorder progresses and cognitive symptoms take over [5]. Both concepts (self and QOL) therefore tended to be linked to cognition alone.

When it comes to AD, the focus, aside from the practical care, is the disorder not the person suffering from it. This is manifested in reality: on the one hand, the general public and caregivers within it are not adequately informed about AD and do not know how to interact with a person with AD [6]. Caregivers often grieve about their loved one while he/ she is

still alive, because they believe that a part of them (their self) is gone, and the QOL of both the person and the caregiver is perceived as low [5]. In Greece, there are many clinical settings for individuals with AD (specialized or general mental health clinics, care units, day-care units), yet most of them do not offer any kind of intervention programme (they only offer practical care). From the few that do offer, most focus on cognitive reinforcement, meaning conducting exercises (verbal, mathematical, orientation, etc.) that target the symptomatology of AD. This is the only systematized approach in the treatment of AD in Greece [7]. Other interventions tend to be scarce and non-systematic.

Overall, as mentioned, little research has addressed the issues of self and QOL in AD, and few clinical interventions have focused on them (most of them in the US and the UK, and none of them in Greece). Most interventions are highly symptom-specific and target several aspects of cognition. The self-used to be perceived as 'gone' in AD, and QOL was perceived as low 'by default'.

This though is problematic both theoretically (and philosophically) and practically. In theory, the self was seen only in relation to cognitive abilities, neglecting aspects such as the emotion, the behavior, the physical reality. The person with AD still interacts with the world around him/ her, and they 'react to, engage with, and co-create a life- world' [5]. Moreover, if the self does not persist in AD, what is 'left'? Accepting this premise would lead to an 'ontological nullpoint', where the individual is perceived as a 'non- person' [5]. Similarly, QOL was seen as an objective measure of the behavioral competence of the person, neglecting the quality and meaning of the subjective experience. Individuals with AD, even in the latest stages, still experience emotion and exhibit behaviors that indicate the quality of their moment- to- moment experience- is this not indicative of their QOL? [5]. Accepting that both concepts (self and QOL) are linked to cognition only would mean that the person cannot have meaning in his experience of living (with AD). Practically, these premises lead to a problematic and incomplete care, both by the caregivers and by the health care professionals in clinical settings [8]. Denying that individuals with AD have a sense of self and can have a QOL leads to lack of meaning of care for the caregivers, and a demoralized and generic care in clinical settings, which deprives individuals of their dignity and agency, while failing to engage them in the process of their own treatment [8]. The treatment that is offered is highly disease-oriented, it fails to target all aspects that the disorder influences, and it fails to engage individuals in the day-to-day basis [5,9].

Overall, it was widely accepted that the self is lost, and there was no clinical focus on the self in AD, little focus on the subjective QOL of individuals, and both were replaced by symptom-specific and disease- oriented objectives.

In the recent years, the above premises have been challenged: it has been argued that the self appears to be 'lost' in the cases that conceptualize and assess the self as linked to cognitive and metacognitive skills- thus results are a matter of operational definition [10]. Indeed, the construct of the self is a highly abstract and complex one. A new line of researches indicates that the self can be conceptualized as complex and

multifaceted (composed of many different aspects) and dynamic (incorporating the changes of time). The self can 'manifest itself' through cognition, emotion, behavior and through the physical and sensory experience, all of which compose the unique entity that each person is, which does not cease to exist despite the presence of AD. Moreover, the self is 'growing' along with the person, learning from experience and adapting to the abilities, needs, and shortcomings of each age (Millet, 2011). Through this lens, the self appears to be maintained in AD [10]. Several studies support this argument, through slightly different (yet similar in their approach) assessments of the self [10,11]. Extending this, the sense of self can be enhanced in AD through an intervention. According to a systematic review, few efforts have been made to enhance the self (only 10 studies met the final inclusion criteria, and most of them managed to enhance the sense of self without that being the primary goal). What was found to be effective in these studies was the use of the arts, the focus on the narrative of the person, and a focus on the existing skills [12].

Similarly with QOL, it is a matter of definitions: when the QOL is linked only with objective factors of competency and functionality, it is perceived as low in AD. Researches though that have conceptualized QOL in AD as both subjective and objective argue that it can be maintained in high levels. Lately many efforts have been made to both assess and target the QOL in AD. Many questionnaires have been devised and revised for this purpose, in an effort to adjust to the needs of the population [13]. Furthermore, many non- pharmacological therapies have emerged that aim at improving the QOL through several different methods and approaches [14].

To link the two, it appears that the concepts are connected, and it has been argued that maintaining a sense of self in AD could lead to improved QOL [10]. Still there is no systematized intervention that targets the self (and all its aspects) in order to improve QOL, even though some are working 'around' those terms [12].

This is theorized through the Person- Centered Approach (PCA) in AD, an approach devised by Tom Kitwood in the 1990s. It is a highly individualized approach, instead of a symptom- specific one, and it has the person- centered rational at heart. The PCA focuses on the self of the person with AD: according to Kitwood, the self is maintained in AD, and there should be a therapeutic focus in all aspects of the self- as this proceeds throughout the disorder. The overall aim of the PCA is to improve the life of the person, by targeting everything that makes us 'ourselves' [15,16]. The benefits of the PCA are many. Since the multidimensional self is the 'target' of the treatment, all aspects that the disorder influences can be addressed: cognitive reinforcement can be included, along with emotional expression, behavioral competence, and physical engagement. The focus on the individual allows the process of treatment to fit the exact needs of the person, instead of the generic needs of the disorder [9]. It provides the opportunity for caregivers to communicate meaningfully with the person and to find meaning in caring, since they can still relate to the present of the person, and it promotes dignity, respect and individualized care in clinical settings. Most of all, it allows the person to find meaning in the experience of living with dementia: the person can be

active in the process of treatment, and can find importance in what is being done. In extend, the person can be active in his/her life despite having AD [15].

## Case Study

The PCA emerged as a need in the case study of P. He was an 83 year old man, who had a diagnosis of AD for five years. P. came from a large rural family; he moved to Athens to study in college, and later worked as an executive of a company where his job was highly demanding. He had lots of friends from his hometown and his work environment, with whom he went out and travelled a lot. He married his wife and had two daughters- he was responsible for all of them- a traditional patriarchic family. He had a lot of hobbies, such as the arts (reading poetry, going to the theater) and sports (he loved swimming, diving and hiking).

His wife and daughters who are his primary caregivers had noticed the cognitive deterioration, and asked for sessions of cognitive reinforcement in order to delay the progression of the disorder. Interestingly, the caregivers had not informed the person about his diagnosis, and asked me to do the same (fact which raises several ethical issues) [9].

Upon meeting the man, a 'brain professional', specializing in the way the brain works (because terms such as 'psychologist', or 'psychotherapist' could be perceived negatively by the elderly) [9]. "I asked him whether he was facing any trouble- he was entirely aware of his cognitive problems, and he stated that he had troubles in recalling and concentrating, he often felt sleepy and lost. P. asked 'Can we reverse these problems?' I told him we could not, but we could stop them from growing. In this way, the desire of the caregivers was respected, while there was no deception towards the man. We decided to set as a common goal to 'exercise the mind' and began our sessions of cognitive reinforcement twice a week."

Before we began, P. was assessed with a Mini Mental State Examination (MMSE) and a Geriatric Depression Scale (GDS), along with an informal assessment of aspects of his cognition (for example autobiographical memory), his emotion, his daily activities, and his overall QOL. Moreover, the caregivers were assessed informally, and were asked to elaborate on aspects of P's cognition, emotion, his activities and his QOL. P. scored 15/30 in the MMSE, a score indicating middle stages of AD, and 10/15 in the GDS, a score indicating the existence of geriatric depression. Both P. and his caregivers indicated that his emotional state was not good, his daily activities little and his QOL was not satisfying.

### Initial sessions

In the initial sessions P. was presented with cognitive exercises that targeted specific symptoms (for example verbal exercises for aphasia). P. answered politely, but he was not engaged. As he got more comfortable, he said he did not want to 'exercise the mind'- instead he wanted to talk about what troubled him. He increasingly changed the subject of the exercise into something that was in his own mind. The same themes kept emerging: cognitively he was relatively steady, but his emotional state was negative, he was experiencing sorrow, hopelessness, and found no meaning in his life. Behaviorally he was often agitated

and 'took it out' on his wife. He said he felt trapped and lost. At the same time, I tried to focus on the cognitive exercise of each session, in the hope that it would 'take his mind off' these issues- fact which was not true.

### The session of change

One day, three months later, this situation reached a peak.

"I was contacted by P's wife (who was in tears), and informed that he was extremely agitated, he was in a state of shock, and she could not calm him down. I arrived and found P in a very tense state: he was screaming, he yelled he wanted to die, and he was trying to leave the apartment. With a lot of effort, we sat down to talk, and for the first time, I gave him the room to do so".

P. began talking in an entirely rational manner, and stated his problems logically. He spoke with cohesion and flow, which were maintained for over one hour (our session that day lasted one hour and twenty minutes). This was very surprising since AD was manifested in P with quite intense working memory troubles. He said:

"I do not want to live anymore because nobody treats me like myself, and I feel like I am losing myself. What is happening to me?" He elaborated by explaining that he was not allowed to do anything on his own (from zipping his own jacket to going out alone), he spent all day at home (when he used to be a very social person), people kept lying to him and hiding things from him and he understood that things were said 'behind his back' (since his family tried to 'hide' anything negative that would occur), and everyone treated him as a 'fragile baby', when he used to be the 'head of the family' (in his own words). 'I have no control over my life, I am a burden to my family, I am no longer myself! This is why I want to die!'"

Indeed, everything that he described was true. P, despite having AD was able to comprehend his problems clearly. He desired to feel more like himself, and to improve his day- to- day life.

"I suggested we should shift our target, and make our first goal to improve his daily living (his QOL), and maintain as a secondary goal to exercise the mind. He liked the idea, so we proceeded with the PCA."

### Person- centered approach in P.

The PCA was utilized through two main practices: engaging P. in the process of his treatment and presenting him with structured activities that target all aspects of the self.

P. was engaged in the process of treatment, and was made active in it in an effort to increase his sense of autonomy and agency, and improve his self-esteem [9]. This was done in three ways. The sessions with him; despite that the caregiver would have the final saying,

"I am coming back again on Monday, is this ok with you?."

Also we chose the task of the upcoming session together; P. would be presented with two activities and he would choose what he preferred. Finally, a printed copy of the activity that we would be doing. It would be printed in large and clear font (so he could read it effortlessly), and had gaps to be completed based on what was said during the session. What was being

done and why was clearly stated. In this way we were able to maintain a file and indicate the importance of what was being done, while he was actively involved in the process.

"I was also able to 'keep track' of his cognitive performance, and emotional states."

P. was also presented with structured activities that target all aspects of the self in order to address all aspects of AD as well [3]. Each activity had a cognitive, an emotional and a behavioral (and sometimes a physical) component. Each activity was linked to the self (in the past, present and future), and, drawing from the existing literature, the arts were used and there was a focus on the narrative of P, and on his existing skills [12].

For example, we would read a poem (drawing from the art modality that he preferred) by the Greek poet K.P. Kavafis entitled 'As much as you can' (try for your life). We would pick words from it and create sentences with them (cognitive reinforcement), discuss its meaning (cognitive component), discuss what it made him think about or feel (emotional component), and whether he liked it or not, or whether he agreed with the meaning of it (linking the activity to the self).

"Then I would ask whether he thinks he was following the meaning in the past, and now (link to past and present), and what could he do to follow it- thus try as much as he can (behavioral component)- finally I might ask him to 'show me' how he could follow a behavior (engage him physically). In the beginning of every session we would get oriented in the here and now and discuss his current mood and overall state, and in the end we would discuss the activity (sometimes there could be homework), and chose the activity of the upcoming session. Each time he knew what to expect from the process, even if he did not recall precisely [17]."

#### ***Assessment after the use of the PCA***

Concerning the activities, P. claimed to enjoy the different stimuli and the themes discussed. He was more engaged in the sessions, and said he was interested.

P. was assessed every five months. The initial assessment occurred before the beginning of our sessions, and the second about two months after the shift of our goal. In the second assessment, and from then on, P. scored a steady 18/30 in the MMSE. What had changed was the orientation aspect- he was more oriented in the 'here and now'. He also scored 2/15 in the GDS- a score indicating a great difference from the initial one. He continued mentioning that he has abandoned many of his past activities and that he is often bored (where the scoring 2 derived from). His answers and scores are steady and similar in all the assessments so far.

From that point on, the self was assessed with the I- AM test (asking individuals to complete ten sentences starting with 'I am'). He was able to provide all ten answers in a relatively short time and his answers were specific, true and with positive affect (except one answer where he said time after time 'I am old'). Moreover, his answers were stable and similar from assessment to assessment. Finally, the self was assessed through informal interviews with the caregivers and with P. himself. Both the man and his caregivers indicated that he felt and acted more like

himself. More specifically, he exhibited qualities of his character (such as his sense of humor, his tendency to 'tease' others, his active care for his family), interests (such as a renewed interest in the arts), and maintained the same preferences and beliefs. All argued that he was adapting to living with his existing skills. P. claimed to feel more 'active', 'alive' and 'himself', despite not being always able to specify further.

Similarly, QOL was assessed through informal interviews with the three caregivers and P. Again, all of them indicated that his QOL had improved a lot: he was less emotionally tense, he was less agitated behaviorally, and was relatively stable cognitively, while having learned to act based on the skills he had (and not on the skills that were affected by AD). All these were supported by my own observations.

#### ***P. in the Present***

"P. and I are still working together, for over two years now. We have developed a therapeutic alliance that works towards the same goal. He is currently looking forward to our sessions, and so do I."

#### **Discussion**

In the past it was widely accepted that the self-deteriorates until it is 'lost' in AD, and that QOL tends to be low due to the disorder. In the last few decades these premises have been challenged: the self is approached as dynamic and multifaceted and appears to be maintained in AD, and QOL is seen as both subjective and objective, and seems that it can be high in AD. A theoretical focus on the self and QOL comes from the PCA. In the case study of P. the PCA was used through engaging the man in the process of treatment and through activities that target all aspects of the self. This individualized version of the PCA allowed the treatment to become spherical and address all aspects that the disorder influences. The case study of P. allowed a glimpse of Alzheimer's 'from the inside', since the experience of the man was at the heart of the approach.

The qualitative and quantitative assessment of P supports that the self is maintained in AD, and that a focus on it can lead to improved QOL. The self is an abstract construct, which is difficult to assess with precision. It is multidimensional, with dynamic properties. As the person proceeds through life, the self-adapts to the new needs and capabilities that come with each age. Thus, the self can adapt to hardships such as AD [5]. The fact that P was able to learn to live with his existing skills, and did not rely on the ones that were affected by AD, indicates the dynamic property of the self [18]. On the other hand, the stability of certain qualities (such as personality traits, preferences and beliefs) indicates that a 'core' of the self remains the same. Cognitive symptoms and their progression do not alter some qualities, as research has indicated in the past- for example art preferences remain the same throughout dementia [19]. Focusing on this 'new- old' self (the one with the remaining skills, but with the same qualities) can allow the person to live a life of quality, since there can be meaning in the experience of living (with AD). The individual is able to remain active in his/her life and treatment, and can find importance in both [9]. The PCA allows mental health professionals to adapt to the needs of the individual, thus provide them with the

meaning necessary [16]. Overall, the case study of P revealed that the self may adapt to the changes due to AD, but it is not gone, and targeting it could improve the QOL of the person, fact which is in line with previous research [10,12]. The PCA can be applied in different settings (such as one- to- one sessions, groups, clinical settings, etc.) and since it adapts to the needs of each person, be effective in all of them [9]. The PCA can be applied both as a systematized approach, and as a point of view in the caring for AD, where the person is approached with respect and as an individual [20].

The current case study brought forth several implications. The MMSE assessment indicates a link between QOL and self and the 'here and now'- the person lives in the present, which was revealed by the change in the orientation aspect [9]. The GDS assessment indicates that geriatric depression in AD is not similar to clinical depression, and that it reflects the state of the person in the present, instead of generally, and that it may also be linked to QOL [21]. The fact that the qualitative assessments of P and his caregivers were similar indicates that the person can provide valid and reliable data even in the middle stages of dementia, and that a combined assessment may be useful [22]. Moreover, the case study indicated the need for flexibility by mental health professionals: when something does not 'work' professionals should be able to recognize that and alter their approach in an effort to attune to the person's needs [9]. Finally, claiming that the self persists in AD, despite the disorder is something which could be theoretically and experimentally generalized to neuropsychiatric disorders in general: the self is not composed only by the disordered aspects, but has a 'core' that remains the same in spite of them [5].

Still there were some methodological limitations in the current case study. The PCA was not applied initially but three months later, and the constructs self and QOL were assessed mainly qualitatively (since the I-AM test also provides many qualitative information). This is due to a gap in the literature: quantitative assessments of QOL and the self-do not exist in a Greek version.

Future research could aim at translating questionnaires about AD in Greek, in order to allow professionals to address more issues regarding the disorder. Moreover, future research could focus on linking more precisely and in a large scale the concepts of self and QOL in AD and other neuropsychiatric disorders [10].

## Conclusion

The case study of P indicates the need for a more individualized and wholistic approach in the psychosocial treatment of AD. There should be more experimental and clinical focus in the construct of the self, and an effort to grasp the essence of the construct.

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