

Why is research involving people with Alzheimer's disease difficult?

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Summary

The article reflects the reasons for the scarcity of patient-inclusive projects in Alzheimer's disease psychosocial research. Among the prejudices concerning research methods the authors identify and examine:

1. the expectation to obtain rich data while involving as little means as possible,
2. the belief that investigating experiences of AD patients poses specific challenges to the researcher and
3. the conviction that the scientist's role is abused by such challenges. The attitude towards involving people with AD in research is also shaped by fear and stigma connected with the disease. The need to apply a metaclinical perspective is suggested.

Alzheimer's disease / dementia / research / ethical aspects

INTRODUCTION

In a text published by Cotrell and Schulz in 1993 [1], the authors point to the fact that our understanding of Alzheimer's disease (AD) has become increasingly biomedical and the experience of people with AD tends to be attributed solely to the disease process. What is more, "in the majority of research on AD, the afflicted person is viewed as a disease entity to be studied rather than someone who can directly contribute to our understanding of the illness and its course" [1]. Since the time of Cotrell's and Schultz's publication, the need to include patients with Alzheimer's disease as equal participants in research as well as to allow them to speak about their experiences and needs has been underlined many times [2, 3, 4, 5]. Practical approaches to dementia

care, developed in the last two decades, have taken into consideration models of caregiving other than the organic model or "the standard paradigm" as Kitwood calls it [3]. Such frames for interventions perceive the process of developing an empathic, supportive relationship as an end in itself [6, 7]. However, academic research within such patient-inclusive approaches still remains scarce. Even in the field of clinical trials of new drugs, the involvement of patients with AD is insufficient: in the UK, less than 1% of people with this condition are involved in trials of experimental therapies. [8] *This number is far below the average percentage of cancer patients participating in clinical trials. Still, there are even fewer people with AD engaged in research concerning their psychosocial situation.* Recent research agendas on neurodegenerative diseases, such as *The European Dementia Research Agenda*, still stress the need for combining both approaches – the biomedical and the psychosocial one – in order to provide better care.

Although psychosocial research in the field of Alzheimer's disease has been developing for several decades now, there still remains a lot to dis-

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cover and many questions demand an answer. There is also an unexplored area of the questions that have not yet been asked. Among these an especially neglected area of research is the experience of people with AD [9, 10]. Personal meanings give us knowledge and understanding that cannot be obtained through second-person accounts or triangulation methods. Therefore, it is the person with AD who should be asked: how does cognitive loss impact him/her? How does he/she perceive the change brought by the disease? How does he/she cope with his/her disabilities?

In order to answer the title question – why is research involving people with dementia so difficult? – this paper will pinpoint the tacit assumptions about Alzheimer’s disease held by researchers and healthcare professionals that impede including people with AD into research. We seem to know what issues need to be considered, but we have not posed the crucial question: why have they not been yet?

Scientific research is an action, which has its premises in the will to act and in the judgments concerning the aim and the motive of the act. [11] We should then consider both the reasons of the unwillingness to involve people with Alzheimer’s disease in research and the presuppositions that such attitude stems from. Firstly, however, the obstacles in including patients with AD into research have to be summarized.

OBSTACLES IN AD RESEARCH

First of all, one of the most obvious obstacles in psychosocial AD research seems to be the cognitive impairment of the patients, especially in the advanced phases of the disease. As states de Boer et al. “For long it was assumed that data collected from people with dementia themselves were unreliable because of their cognitive impairment, and therefore unusable” [12]. The fact that communication with people with AD is considered hampered in comparison to that with healthy people leads to strong objections to the validity of the data. On speaking with an AD patient, one asks himself whether the questions were properly understood and the responses adequate and logical. In case of people with a neurodegenerative disease, the impairment of reasoning, judg-

ment, decision-making and language too often prompts the listener to deny any logic and reason in the interlocutor’s statements.

Secondly, there are serious ethical doubts in research involving AD patients. They are strongly connected with cognitive impairment of the subjects – if there is no mutual understanding, the influence on the vulnerable research participant is considered to be more harmful. One of the most vital ethical concerns is the eligibility of AD patients to consciously consent to research participation. This issue has been discussed in many places and the use of decision-making surrogates’ consent or continuous verification of agreement has been suggested [13].

Thirdly, data collection within AD patients is difficult due to specific requirements of the researched group. The researcher has to apply an individual approach to every patient adjusting not only the design and setting of the data collection but also his/her emotional attitude towards the subject [9]. As with any clinical population, access to the potential participant is limited and one has to take into consideration the expectation of the patient to get something in return for his or her contribution – at least some professional advice. What is more, important obstacles also lie in the financial and socio-cultural conditions of the patient’s country. Access to the patients is strongly linked to the development of professional dementia services and the knowledge general practitioners (GPs) possess. In the countries where dementia care is poorly developed, as in Poland, information and aid for AD patients is difficult to access and is limited to the largest cities [14]. Therefore, a lot of potential research participants remain undiagnosed and deprived of medical and psychosocial aid and often they and their families are left alone. Not being able to receive an aid and the lack of development of such aid harm both the patient and the research on the disease; it’s a vicious circle.

The fourth group of obstacles in AD care derives from the diagnostic difficulties concerning the illness. Not only are the diagnostic facilities hard to reach, but also the diagnosis of Alzheimer’s disease itself leaves significant doubt. Several factors contribute to this state [9, 15]:

1. During the patient’s life the diagnosis is only probable, never definite.

2. GPs often have little knowledge about the diagnostic criteria.
3. GPs assign the first symptoms to "memory problems" of normal aging.
4. Patients may be denying the existence of symptoms thus hindering the discovery of the disease.
5. As a consequence of the above points, the diagnosis takes place late in the progress of the illness, often at a stage when verbal communication with the patient is severely disturbed.
6. Patients informed about the disease may be denying its existence as a natural coping mechanism.
7. The reaction to the diagnosis of Alzheimer's disease involves strong negative emotions.

Having the diagnosis revealed may cause considerable distress and conducting research at this moment raises the question of the balance of benefits and potential harm to the patient [16].

There is also the problem of anosognosia co-occurring with Alzheimer's disease. Even if the patient was informed about the diagnosis, he or she may be at some point unaware of the illness [17], in which case investigating their experience of Alzheimer's disease may be difficult, as the issue would be perceived only by the researcher, not the participant.

However, these obstacles are due to certain assumptions we have about Alzheimer's disease and the possibilities of their scientific investigation. The presuppositions or prejudices (as Gadamer understands the notion [18]) that underlie our attitude towards involving people with AD in research are worthy further consideration.

PREJUDICES UNDERLYING THE OBSTACLES

In general, our prejudices towards the research in question can be divided into those concerning the specificity of Alzheimer's disease and those resulting from methodological scientific requirements. Interestingly, it seems that it is not the subject but the method that limits researchers more in their quest for knowledge on the experience of having Alzheimer's disease.

Among presuppositions concerning research methods are the following:

1. The expectation to maintain "economic" balance, i.e. to obtain rich data while involving as little means as possible,
2. The belief that investigating experiences of AD patients poses specific challenges to the researcher,
3. The conviction that challenges mentioned above abuse the role of the scientist who should remain unengaged with the studied subject.

Let us carefully consider each of these prejudices:

1. The first mentioned obstacle, cognitive impairment and the following communication difficulties, seems to be an objective hardship in involving AD patients in research. But is it really so? Beuscher and Grando point to the need of collecting larger samples of data and a more thorough analysis, as well as multiple data collection sessions and careful adjustment to the respondent's demands [9]. Nygård [19] emphasizes the benefits of conducting research interviews in a natural context, which will enhance recalling memories and limit distractions. What is more, AD research often requires a multi-method approach. As Cotrell and Schulz state: "The combination of data derived from proxy reports, behavioral observations, and clinical assessment is likely to provide a better indication of excess disability than any one method alone" [1]. It is then not the question of the impairment itself, but of the means to take it into account because the time and cost spent on research involving Alzheimer's disease patients exceeds that spent on studying subjects not suffering from a neurodegenerative disease, such as the patient's caregiver. Perhaps the cause of scarcity of research with AD patients is the convenience of researchers? This is not restricted only to the financial or logistical aspect, but entails also the psychological comfort of the investigator. After all, contact with a patient suffering from AD may not be a pleasant one: the respondent may behave irrationally, have emotional outbursts, repeat answers or slow down the procedure. In addition, when speaking with a person with AD, we usually tend to perceive his or her impairment and illness symptoms more vividly than the as-

pects of the interaction we consider “normal”. Thus, being more sensitive to misunderstanding than to understanding, we may exclude potentially valuable data too hastily.

2. Next, there is the issue of personal qualities needed to study AD patients. Nygård points to two important features of the researcher’s personality which are required in investigations concerning neurodegenerative diseases: “flexibility and the ability to improvise” [19]. Because of the ethical considerations mentioned before, both the project and the researcher are also required to commit to high ethical standards. Maybe withdrawing from AD patient research is just a “safer way” of investigating Alzheimer’s disease? Isn’t it an approach which does not test the value and skills of the scientist as much as talking to the patient would?
3. Moreover, the researcher is challenged by getting involved in a relation with the informant, which happens for example when a multi-stage research – advised in the study of AD patients – is being carried out [19]. On the one hand, the participant is more eager to engage in a study with a person he/she knows, on the other hand – this contradicts the expectation that the researcher should not connect with the subject personally. But is it really so? Maybe our expectations towards the role of the scientist in psychosocial AD research should be reconsidered?

In fact, the methodological procedures scientists are committed to – especially those working within the positivist, nomothetic paradigm – tend to exclude people with Alzheimer’s. The notions of validity and reliability need to be reconsidered, as research on patients with neurodegenerative diseases has shown significant instability of their responses over time and the tendency to answer question in a way that would satisfy the researcher [4]. Idiographic approach and qualitative methods seem to be more flexible as for the adaptability to the needs of AD patient research [10]. Nevertheless, it has to be highlighted that this problem is only a vivid example of more significant methodological issues like: what comes first – the subject or the method? What do we gain and what do we lose trying to fulfill method-

ological standards in a clinical population? What do we want to discover in a particular AD research project – the common norms and rules of behavior or the unique personal experiences?

Nevertheless, it is not only methodology that hampers involving people with AD in research. Understanding the prejudices we hold against Alzheimer’s disease itself is crucial to finding a way to overcome the difficulties in leading investigations including AD patients. As members of society and people who might potentially be affected, researchers too are exposed to stigmatizing beliefs on neurodegenerative diseases. Two features of our attitudes towards Alzheimer’s disease seem to be essential:

FEAR

Stigma

Although these two presuppositions seem to be related, such a distinction allows a more thorough consideration of impediments in AD research:

1. Perhaps what underlies most of the concerns in research involving AD patients is fear. Kitwood asks: “Is it that people with dementia were considered to have no experiences? Is it that their subjective world was assumed to be so bizarre and disordered that it could not be discussed in the categories of rational discourse? Is it that they were no longer deemed to be persons, and thus not worthy of consideration? Whatever argument is given for this flight from intersubjective engagement, it bears the marks of a rationalization of fear” [3].
2. A specific stigma is connected to Alzheimer’s disease and the social construction of the affected patients is sometimes compared to those of “zombies” [20]. Firstly, it is so because of the insufficient knowledge we have about this illness. The problematic behavior of people with AD and other diseases involving dementia may “challenge social norms regarding appropriate conduct” [21] – we come across unexpected, irrational reactions and encounter communication difficulties. Yet, what we know is that “Alzheimer’s disease is a pro-

gressive and disabling illness leading to dependence and a need for constant support" [22]. We can only be sure it will get worse. Secondly, the experience of multiple and progressive loss of memory, social status and identity or the so called "death before death" seems horrifying to people that come across this kind of disease [23].

It is a state we cannot and fear to imagine, an experience totally strange to a healthy individual. The stigma described above dehumanizes people with Alzheimer's disease and, by doing so, contributes to their preclusion from research participation. It is also reflected in the aversion towards naming the patient's condition: "Alzheimer's disease" and "dementia" bear a strong negative value [23]. When talking to people with AD or their caregivers, these terms are often replaced by the expression "memory problems". Is it possible to eradicate the fear surrounding Alzheimer's disease, at least within the academic research context? If we realize what we fear, will this emotion disappear? Is the developing research minimizing the anxiety towards AD?

THE CLINICAL AND THE METACLINICAL PERSPECTIVE

The prejudices described above contribute to a specific perspective on Alzheimer's disease research that eliminates the person from

the picture, leaving the researcher focused on the illness itself. Victor Frankl's (1950) distinction of the clinical and metaclinical perspective shed light to the situation in question [24]. [Tab. 1]. The clinical perspective in AD research results in a reductionism of the kind that identifies a person with the diagnosis given to him/her. Such a process Frankl calls "nihilism" [25]. If the researcher is focused on obtaining information he/she seeks and which may be considered reliable; if such information is to be used in planning further actions, e.g. therapy, then a logical consequence is overlooking people with advanced Alzheimer's disease as those not providing reliable information. It seems that current AD research is limited by such a narrow clinical perspective.

On the contrary, the metaclinical perspective allows and encourages researchers to involve people with Alzheimer's disease into research because it encompasses more than only seeking for scientific results. The relation, emphasized in the metaclinical perspective, is not a means to an end, but is a value itself. Metaclinical research is not an action defined by its aim, e.g. curing, but is due to a principle. Such an approach in AD research is founded on a personalistic treatment of the subjects or patients, who – as persons – cannot be reduced to what they have (e.g. cognitive impairments). This perspective is related to the well-known framework of person-centered care, but it is rather a challenge for researchers

Table 1. The clinical and metaclinical perspective – comparison

	Clinical perspective	Metaclinical perspective
Focus of research	Removing symptoms of the illness	Understanding the person
Aim of research	Description, explanation and prognosis of phenomena based on the change dynamics and their determinants	Understanding; transcending what is given towards what is not given (the metaclinical), i.e. sense and meaning
Research subject	The psychophysical organism and its functions/dysfunctions along with their enhancement/relief	The person as a physical, psychological and spiritual entity; reducing the person to an illness and focusing on the dysfunctions is considered unethical
Actions undertaken	Diagnosing, discovering symptoms dynamics, their explanation, prognosis and curing	Establishing a relation with the ill person; not only communicating
Role of the researcher	Observer of a predefined research subject	Participant of the research
Research procedure	The research subject is supposed to provide the researcher with information which is then evaluated by the researcher as reliable or not reliable, based on acknowledged criteria	The research shapes the attitude of persons involved in the procedure; outcomes are not subject to evaluation based on the amount and quality of gathered information

and their attitudes than a policy or guidelines for application.

The difference between a clinical and meta-clinical perspective clearly illustrates an example from a research project of Polish family caregivers of people with Alzheimer's disease of one of the authors:

Krzysztof, whose mother-in-law has AD, said: „lekarz powiedział, że to nie rozmawiasz z matką, ale rozmawiasz z chorobą, z chorym, z Alzheimerem praktycznie rozmawiasz. [The doctor said that you're not talking to mother but you're talking to the illness, the ill, you're practically talking to the Alzheimer's.]". The mentioned practitioner applied a clinical perspective to the situation and reduced the person with AD to her illness. He also transferred his understanding to the patient's family. The doctor's attitude had been, however, shaped by his academic education and professional experience. Prepared to cure the disease, he omitted the person.

Within a metaclinical perspective, the main focus would be to acknowledge the value of the person, not forgetting to treat the disease. Perhaps this perspective is to be learnt from family carers. Alina, a granddaughter of a person with Alzheimer's disease from the mentioned study said that what she wanted to do was to: "Zrozumieć i pokochać. To tyle. (...) Zrozumieć chorobę i pojąć to, że tego to się już nie da już (...), a pokochać babcię, bo ona tego świadoma nie jest do końca (...) [Pokochać ją] pomimo tego, co robi i co ta choroba robi z nią. [To understand and love, that's all. (...) To understand the illness and comprehend that it cannot be changed (...) and to love grandma, because she isn't quite conscious of that (...). [To love her] in spite of what she's doing and what the illness is doing to her." The metaclinical point of view emphasizes that behind the symptoms there is a human being, a physiological, psychological and spiritual entity.

Involving people with AD in research is an important contribution to shape attitudes, not only of researchers themselves but also to all the recipients of their research. Scientific inquiry influences the social perception of people with Alzheimer's disease, and is thus capable of reducing the stigma of their illness and the fear experienced in encounters with people with neurodegenerative diseases. The metaclinical perspective

seems to be the one worth consideration in order to overcome the shortcomings of Alzheimer's disease research.

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