

Some Potential Benefits of Creating Research Partnerships with People with Alzheimer's Disease

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Abstract

Studies of elementary cognitive functions in people with Alzheimer's Disease (AD) do not reveal a variety of intact remaining abilities. Elucidating the subjective experience of such persons is fundamentally important in (1) having a more informed understanding of the effects of AD on persons, and (2) finding ways to enhance their quality of life regardless of where they live. Advantages of engaging people with AD as research collaborators include (1) what we can learn about psychosocial aspects of their subjective experience, and (2) how, by supporting aspects of their selfhood, we can enhance the quality of their lives.

Introduction

For more than three decades, researchers have studied the effects of Alzheimer's Disease (AD) on elementary cognitive functions such as aspects of memory, attention, information-processing, restricted aspects of language use, sensory and motor function and the like by employing 'traditional' investigative strategies. Thus, we have come to understand AD in terms of its effects on cognitive functions that are usually, according to experimental designs and neuropsychological tests, studied independently of one another. Researchers often use 'group' data wherein the average scores for people with AD are compared, statistically, with those of a normal control group. Often, there are statistically significant differences between the group averages, the AD group average being worse than that of the normal group. Thus, we find that in the areas of word-finding ability (Appell, Kertesz and Fisman, 1982), other aspects of language function (Hutchinson and Jensen, 1980; Bayles, 1982; Martin and Fedio, 1983; Hier et al, 1985) explicit episodic memory (Heindel et al, 1989), confrontation naming, learning to recognise new faces, maintaining vigilant attention (Freed et al, 1989), processing of emotional cues (Allender and Kaszniak, 1989) and the like, people with AD are 'deficient' relative to age-matched normal control subjects.

Such research can be quite useful with regard to testing the effects of drugs and it would be sophomoric to ignore its value. Still, it is clear that there is much left to learn and the question of how we go about learning more is what is at issue here. What remains to be learned? Let us first return to the idea that traditional approaches to understanding AD have been focused upon a limited range of cognitive processes. What we don't come to know about at all are the people with AD, their hopes, dreams, fears, what they need,

what they don't like, what provides them with purpose, meaning, pride, peace, enjoyment, and how they go about navigating the social world in which they live each day. That is, we don't learn about the subjective experience of people with AD and this is precisely what we need to know if we are interested either in having a more developed understanding of the effects of AD on persons, or being able to enhance the quality of life of such people, whether they live at home, in assisted living residences, or in nursing homes.

Another aspect of traditional investigative strategies that must be acknowledged is that by using the 'group data' approach, we often create stereotypes such as the false notion that there actually exists the 'average person with AD' or the 'average elderly minority group member'. On the basis of such mythological thinking, we may assume, incorrectly, that each member of said group has the presumed characteristics of the mythological average person. It is blatantly clear from the data of so very many studies that not all members of a group behave as the average, that there is a good deal of variation, often overlapping with the variation in the control group's performance. So even in the case of studies in which researchers have focused on elements of cognitive function such as language, memory, attention, and the like, the data themselves reveal the wide variation among people and that all people in one or another group do not show as the average (Sabat, 2001).

To summarise, then, when we study this or that cognitive function quantitatively and as defined operationally by one or another test or task or collection of tasks, and collapse the data thereby gained into group numbers and perform statistical operations on those numbers comparing one group of elderly with another, we risk both creating stereotypes which obscure individuality and having

a paucity of information regarding issues which are of great import to the elderly themselves and to those among us who are carers. What then to do?

One choice is to omit from our research those aspects of psychological life that do not submit to quantitative assessment. After all, to do otherwise would be time consuming and would leave us open to the criticism that we are venturing into the subjective realm: a realm often regarded as being 'merely' subjective, and, as R.D. Laing (1965) once commented, we rarely if ever hear the term 'merely' used in connection with the term, 'objective'. Another choice is to venture boldly into that realm which does not submit readily to translation into numerals, the realm that includes aspects of life such as meaning, purpose, and pride so as to understand more fully the everyday socially based experience of another person. In such an effort, one does not approach the person with AD as an instantiation of this or that operationally defined cognitive function or observable characteristic or diagnostic category, but rather as the subject of study - a living person who attempts to encounter and interact with the world as best as he or she can. Such an approach is exemplary of what Luria (1987) called Romantic Science.

The hallmark of Romantic Science is not to analyse the subject of study into elementary components and seek to formulate general laws as does Classical Science, but rather to preserve the living reality of the subject of study. Therefore, rather than trying to understand the effects of AD on a variety of cognitive functions taken one at a time and studied via the use of standard neuropsychological tests or experimental designs and obtaining group averages there-from, the approach of Romantic Science is to study the person as a whole in the natural social world. In so doing, we come to understand a person who manifests a variety of cognitive functions as he or she interacts with others from moment to moment in a rich, social world, and the person 'comes alive' as it were, in ways not possible through the use of Classical Science's methods. Although there are no standard tests through which to examine aspects of psychological life such as pride, purpose, meaning-making ability, natural conversation, and selfhood, these aspects of life are central to being

human and can be studied through the techniques of Romantic Science. It is not too much of a stretch, I think, to say that a 'person-centered' approach to understanding and treating people with AD is a reflection of Romantic Science.

Subjective Experience and Goal Seeking Behaviour

Some years ago, while administering a battery of language tests to a man with AD, I heard him say, 'Doc, you've gotta find a way to give us purpose again.' Clearly, the man would not have uttered this sentence if he felt as though there were purpose in his life. Thus, despite his struggle to find the words with which to frame his thoughts, what was most important to him to convey was that he was lacking purpose and wanted desperately to change that state of affairs with my help. This poetic moment served, and still serves, to illuminate a great deal for me. One of the fruits we can reap from this example is that we can examine - what a person says and does - to help us understand aspects of AD for which there are no quantitative measures. That is to say, we can use natural conversation to help illuminate a variety of intact highly complex cognitive functions, such as the need for purpose, for meaning in life. How interesting that the man who could articulate his desire to regain a sense of purpose was also describable as being severely afflicted with AD according to standard neuropsychological measures. When we consider the realm of purpose, we can think of having purpose as being linked to having goals in our lives. Most of us, for most of our lives, have delineated and pursued goals - going back to the childhood goal of walking, for example. Thus, for an elderly person whose life has been populated by goals, purposes, to find him or herself bereft of purpose can be overwhelmingly and appropriately saddening.

By examining the discourse of persons and by applying ideas put forth by William Stern (1938), we can come to appreciate that people with AD can display intact goals which Stern called Autotelic and Heterotelic goals. Autotelic goals are those that involve the maintenance and development of oneself. Thus, as I have reported in the literature (Sabat and Harré, 1994; Sabat et al, 1999; Sabat, 2001), if a person with AD attempts to avoid

embarrassment or attempts to avoid humiliating situations or treatment, that person is attempting to maintain his or her social standing according to local norms and is thus displaying autotelic goal-seeking behaviour. This sort of behaviour requires that the person be able to attend to and evaluate the situation, interpret its meaning in terms of social norms, and proceed to act accordingly. Such behaviour can exist despite striking deficits in a variety of elementary cognitive functions as measured by standard tests. It is, however, the heterotelic goals that may be of equal interest to us given the subject of this article. Heterotelic goals are those that go beyond oneself and extend to the larger community. So, for example, doing something to help others is a heterotelic goal that also, when reached, could have as a byproduct, the enhancement of one's own development.

For example, one person with AD, Mrs. D, with whom I was associated for more than two years, and who attended a day care centre, would work to help cheer up other participants, to bring laughter to their moments (for a full examination of this person's case, see Sabat, 2001). This, despite the fact that she could not recall the day of the week, the date, the season and displayed obvious sensory-motor and word-finding problems as well as problems with the recall of recent events. Indeed, she was 'the life and soul of the party' at the day care centre. On the surface, we can appreciate that she had found some purpose in her days - being a source of good feelings, of cheer for others. Her role went beyond this, however, for the staff at the day care centre asked that she help to integrate new participants into the group - she was outgoing and warm and she took on this job with great pleasure. At the day care centre, her identity was not confined to being an Alzheimer's patient or someone with dementia but, rather, she was the life of the party, and liaised between the staff and new members of the group. She had purpose and she exulted in it, often hurrying her husband to take her to the centre because she didn't want to be 'late for work' - in her words. Her husband initially thought that she had developed a delusion, for to his knowledge she was unemployed. In this process, however, she gained a measure of self-worth by being of help to others, thereby achieving a heterotelic goal.

She could not have found such purpose if the day care centre staff members had not recognised her remaining skills and encouraged their use. Thus, in this case, it was the cooperative interaction between the person with AD and the staff members that allowed Mrs. D to have purpose, achieve autotelic as well as heterotelic goals, and enhance her feelings of self worth despite the deficits stemming from the neuropathology of her illness and her sadness about those deficits. Therefore, it was through cooperative, mutual efforts that a person with AD was able to construct the social personae, 'the life and soul of the party', and 'Ambassador to new participants' through which she could help others - something she wanted very much to do - and through which she could find purpose. The Director and social worker at the day care centre commented that the woman behaved almost as another staff member, for they could rely on her to help others to feel at ease and enjoy themselves while there.

The staff members understood that the woman's abilities in the areas of social interaction and humour and caring for others were intact despite her other AD related problems, and then proceeded to encourage their use so as to benefit her as well as many of the other participants. It is important to recognise that Mrs. D came from a show business family, that she was always a gregarious person who loved to tell jokes and sing songs and that this aspect of her personality was quite intact despite her losses in other functions due to AD. Thus, her life-long inclinations, and her personality were still very much intact and when she was given the opportunity and encouragement to bring them to the fore, she did so with enthusiasm. At home, however, where she received no such encouragement, she was often sullen and silent.

Social Dynamics and Aspects of Selfhood

Let us reflect for a moment on the social dynamics involved when the staff members gave Mrs. D a 'job' to do at the day care centre: They asked for her help in an effort to help others. For many people with AD, it is increasingly rare to be asked to help another person. Indeed, the majority of their social interactions may be confined to 'physician-patient' relationships in which there is

precious little opportunity to realize any sort of autotelic or heterotelic goal or to find some avenue through which to experience enhanced self-worth, for the focus of such social interactions is, most often, the person's behavioural deficits. Likewise, in relation to family carers, the person with AD is often positioned as being, and is thereby confined to the social identity of, the 'burdensome, defective patient', in which the main focus of others is upon his or her AD related deficits which, themselves, are anathema to the person with AD because they so often constitute a source of embarrassment, depression, anger, frustration, torment, and shame (Sabat, 2001).

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Such a social dynamic hardly affords the person with AD an opportunity to construct and experience a more worthy social identity. The life-long valued inclinations and dispositions of people with AD are rarely called into play and, as a result, the sense of being purposeless grows and there can be a striking lack of meaning in their lives. Is it any wonder that many people with AD experience depression? Who among us would not feel depressed if we were to see ourselves as being without any purpose and meaning in life - if there were no goals save to avoid the embarrassment of being looked upon and treated as if we were defective or burdensome? Often, in order to avoid embarrassment, persons with AD retreat from social interactions whose focus is on their defects and the outcome of such withdrawals is that they are labelled as being 'apathetic' or 'reclusive' or 'uncooperative'. Such labelling has been termed a form of 'malignant social psychology' (Kitwood, 1998; Kitwood and Bredin, 1992) which constitutes an assault on the afflicted person's feelings of self-worth, of personhood, and which leads to him or her being depersonalised.

Social construction theory (Coulter, 1981; Harré, 1983, 1991) offers a useful heuristic with which we can understand the relationship between aspects of one's social identity and the behaviour of others. According to this framework, a person's social personae (Self 3 in social constructionist terms) are *constructed* through the mutual, cooperative interaction of persons. Thus, one person can have a number of different social personae such as 'devoted parent', 'demanding professor', 'loving spouse', 'generous friend', 'good neighbour' and

the like. Each of these personae involves particular patterns of behaviour, which may or may not be manifested in other social personae - so that the ways in which we behave with one person (one's spouse) may bear little resemblance to the ways in which we behave with other persons (one's students, neighbours, children).

One of the key points in the above paragraph is that (Self 3) social personae are *constructed* by a person only with the cooperation of others because one cannot construct successfully the social persona of 'loving spouse' if one's spouse does not cooperate. Likewise, one cannot construct the social persona of 'demanding professor' if one's students do not recognise and treat one as their professor; one cannot construct the persona of 'loving parent' if one's child refuses to acknowledge his or her parent as being his or her parent. In this sense, the person with AD is extremely vulnerable, for as long as others position (Harré and van Langenhove, 1999) the person as 'the patient', or the 'burdensome patient', or 'the defective patient', or 'a shell of the person he or she was', or 'demented', the person with AD will not gain the cooperation necessary to construct healthier, more worthy and desirable social identities. In such cases, the person with AD is as much a prisoner of dysfunctional treatment as he or she is of the neuropathology of the disease. There is a striking difference between these two 'prisons', however, for the prison walls defined by neuropathology are not yet able to be broken down, whereas those defined by dysfunctional social treatment are eminently open to being breeched.

One way to help the person with AD construct a worthy, valued, social persona is to engage said person as a collaborator in research efforts of which there are many types. For many years, people with AD have been participating in drug studies thereby allowing some (Sabat, 2001) to gain a measure of self-worth by working as subjects in major research centres. Although some people with AD have gained a sense of purpose through their participation as subjects, the process is itself defined by the administration of standard neuropsychological tests and the limited types of knowledge that derive there from. For other people with AD, such participation is eschewed, for it serves to highlight the deficits caused by AD and

the venue in which their participation occurs is generally a hospital clinic or research facility that is unfamiliar and often threatening. At the outset of this paper, I indicated that there is a need for more research focused on the subjective experiences of people with AD so that we can come to understand more fully what the disease's personal and social effects entail. It is through such research efforts that we may find some pathways not only toward providing people with AD another means by which to construct worthy, valued social identities, but also toward the unearthing of new knowledge and perspectives about the nature of AD and its cognitive and social effects. It is this possibility that I should like to address in the next section.

Toward an Enhanced Understanding of Subjective Experience

In only little more than the past decade have there been increased efforts to understand the subjective experience of people with AD and the cognitive functions that remain intact despite losses in other areas. Previous efforts of the Classical Science variety focused on quantitative analysis of elementary cognitive functions, and formed a large part of the basis upon which persons are characterised as 'mildly', 'moderately', or 'severely' afflicted (Reisberg et al, 1982). It has become increasingly apparent however, that a variety of highly complex cognitive abilities can exist in some people with AD, despite the fact that they can be categorised as being in the moderate to severe stages of the disease. Among these complex abilities are: the desire and ability to maintain and enhance self-worth, the ability to assess situations as being embarrassing and to respond accordingly, to set and achieve autotelic and heterotelic goals (Sabat, 2001), to function as a semiotic subject whose behaviour is driven by the meaning of social situations (Sabat and Harré, 1994), to employ politeness strategies in conversation (Temple, Sabat, and Kroger, 1999), and to compensate for the loss of verbal fluency by using extralinguistic means of communication (Sabat and Cagigas, 1997). The aforementioned abilities were unearthed through the use of discourse analysis of the spontaneous natural conversation of people with AD. The relationship between the interlocutors was of the person-to-person variety,

with one person being a researcher who had made it clear that the person with AD was needed as a collaborator and, as such, was essential to the process of gaining knowledge. In this way, the person with AD received the necessary cooperation required for him or her to construct a social persona of 'research collaborator' and gain a measure of self-worth as someone who was making a valuable contribution to society, and thereby fulfilling a heterotelic goal.

To be able to strive toward and realise autotelic and heterotelic goals, to have the need for meaning and purpose in life and to be able to discriminate between what is and what is not meaningful are highly complex cognitive functions which require intact brain systems involving attention, working memory, language, concept formation, abstract thinking, to name but a few. Such behaviour can be found in natural social situations in which people are engaged as people and not as one or another form of guinea pig or patient. Indeed, one person with AD with whom I was associated was quite direct in asking me if he was, in our association, a guinea pig, for that was a position that he would find objectionable (Sabat, 2001).

Subjective experience is, by nature, private until made public. It is impossible for anyone to know first-hand the experience of another person. Thus, in order to understand as best we can what life is like for people with AD and which higher order, non quantifiable, cognitive abilities remain intact, it is necessary to engage such people in conversation, to encourage them to be open about their beliefs, feelings, reactions to situations, their values, hopes, fears, and the like, and to provide a non-threatening atmosphere in which such openness is possible. Whether persons with AD live at home, attend a day care centre, or live in a nursing home, those who wish to enhance their lives must understand how situations affect them for better and for worse. That is to say, it is necessary to understand the private experience of the person with AD. By doing so, it is possible, for example, to understand his or her reactions to programmes in day care centres and nursing homes, for it is in the interests of people with AD as well as professional carers that the programmes and activities available be well-suited to the clients involved.

In terms of adding to our understanding of programme development, an example from the experience of another day care centre participant (Dr. B) may be instructive (Sabat, 2001). Dr. B was a retired academic who attended a day care centre two to three days per week and who had been diagnosed as being moderately to severely afflicted with probable AD. When I asked him about a particular activity going on in an adjacent room, he had a very cogent response. The activity in question was a game, called 'Trivial Pursuit' - a game involving information rightly regarded as being trivial - but more importantly, it requires the use of retrieval from memory via recall, which is notoriously difficult for AD sufferers, a difficulty which is compounded by the fact that the game involves recalling information which is not necessarily of value or import to many people. As a result, many would be unable to succeed at what is essentially a confrontation recall task. His response to my question, 'what do you think about what is going on in the room?' was, 'It's filler. I don't necessarily need what's in the room. I wish I could...make it break.' It was clear that he took no pleasure in such games and, had he not been working with me, he would have had to sit in the room and endure the game, much to his chagrin. By engaging a person with AD, and exploring his or her subjective experience, we can come to know far more clearly what we can do to make day care programmes more enlivening, more meaningful, for participants. In the process, we can communicate to the clientele that we value their opinions and that we want to use their knowledge to help us in the process of helping them. Thus, we can create an environment in which the clientele find enjoyment and also feel as though they are important partners in the process of creating that environment.

This dynamic has the added benefit of communicating to the person in question that he or she can play an active role in the evolution of programmes rather than being a passive participant who merely does what he or she is told to do - a situation which can lead to what Seligman (1975) calls 'learned helplessness'. The idea that a person's desires are still worthy of being understood, that he or she has a role in structuring his or her environment is one which can add to the person's sense of well-being, of self-worth, in that

the person thus feels as though his or her opinion matters and that there is the possibility of making the environment better than it might otherwise be. In the process, we engage the elderly person directly - in the way in which we would engage anyone with whom we were working to achieve some mutually valued outcome.

There is yet another aspect to the above dynamic that can be revealed through the following scenario. Suppose Dr. B, being frustrated by and annoyed with having to sit in a room and do nothing but endure the playing of this particular game, decided to take a walk in the hall. Suppose further that, while walking, he is asked where he is going, but could not say where he was going, for he wasn't going 'to' any particular place. It would not be unusual for an observer to label his behaviour as 'aimless wandering' and then to treat him as if he were, in fact, an 'aimless wanderer', for that is a 'symptom' of AD. The reality in this scenario, however, is that Dr. B's walking was hardly aimless, for it was something that was far more appealing to him than sitting in a room while others played a game that he found to be annoying, boring, and indeed, aimless. Thus, by exploring the subjective experience of people with AD, by engaging them as collaborators in research, we can come to understand more deeply the reasons behind certain reactions, certain behaviour - reasons which may be quite rational and appropriate. The discourse, the narrative, which is encouraged and revealed in such a relationship provides information that cannot be captured by rating scales or questions to which the answer is 'yes' or 'no', for we want to know not just 'that' someone feels one or another way, but 'why' as well.

A rather poignant example of the fruits of engaging people with AD as research collaborators, is provided by Robinson (2002) who was diagnosed three years prior to the publication of her comment below. In the extract that follows, she is quite direct about the relationship between developing further our understanding of AD, the role of the person with AD as a source of private experience, the construction of the social persona of 'research collaborator', and the maintenance of self-worth:

'I really think that people like myself should be encouraged to take part in any research and made to feel that their contribution, no matter how small, would be greatly valued. After all, who else would know what it's like to have the disease?...What a wealth of hidden personal experience the skilful researcher can tap into... What a hugely missed opportunity it would be if people with Alzheimer's were excluded from the very thing that could be used to gain a fuller understanding of their disease. It would be simply denying us the chance to fill in gaps that no one else can...I also know that the research I have taken part in so far will not benefit me personally, but taking part in it has lifted my morale...To know that there are many dedicated people out there, who are willing to take the time and visit us in our own familiar surroundings to listen and record our opinions, makes all the difference' (p.104)

It may seem ironic that a person who, in some circles and by some measures, would be characterised as being 'demented', could nonetheless provide such an insightful, cogent, multi-faceted, person-centred argument concerning the benefits of engaging people with AD as collaborators in research. It is growing ever more apparent that whatever 'irony' exists here is based upon the *a priori* assumptions of researchers, clinicians, and other carers who incorrectly assume that the performance of people with AD in clinical testing situations is a valid reflection of their cognitive abilities in the everyday social world. The benefits that can accrue from engaging people with AD as collaborators in research extend beyond enhancing their feelings of well being and self-worth, for they include also enhancing our knowledge about the effects of AD along with providing insights into how to provide the most supportive, humane, and enlivening circumstances to extend that well being in time. That is to say, we can enhance our understanding of the intact cognitive and social abilities of people with AD if we engage them as people, and, in so doing, ask for their help. Not only can we learn more about our own destiny in some ways, but we can also show people with AD that they still have much to give, that they still are valued, and this itself can enhance their ability to navigate through a variety of situations in everyday life. In so doing, we can

improve our understanding of their needs and thereby enhance programme development as well as further research endeavours. What we learn now about the processes of aging, through the use of as many tools of study as we can muster, will rebound not only to the benefit of those who are elderly now, but also to the benefit of those who will become elderly in the years ahead.

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