Understanding the individual with Alzheimer’s disease
Mark, R.E.

Published in:
Advances in Alzheimer’s Disease

DOI:
10.4236/aad.2012.13010

Publication date:
2012

Document Version
Publisher’s PDF, also known as Version of record

Link to publication in Tilburg University Research Portal

Citation for published version (APA):
Mark, R. E. (2012). Understanding the individual with Alzheimer’s disease: Can socioemotional selectivity theory guide us? Advances in Alzheimer’s Disease, 1(3), 77-86. https://doi.org/10.4236/aad.2012.13010

General rights
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

• Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
• You may not further distribute the material or use it for any profit-making activity or commercial gain
• You may freely distribute the URL identifying the publication in the public portal

Take down policy
If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.
Understanding the individual with Alzheimer’s disease: Can socioemotional selectivity theory guide us?

Ruth E. Mark

Department of Cognitive Neuropsychology, Tilburg University, Tilburg, Netherlands; R.E.Mark@uvt.nl

Received 22 October 2012; revised 26 November 2012; accepted 4 December 2012

ABSTRACT

Individuals often get lost behind the diagnosis of Alzheimer’s disease (AD) while widespread differences between these patients are more common than similarities. Socioemotional Selectivity Theory (SST) suggests that as we age our goals change from future-oriented (acquiring new information) to present-oriented (enhancing the emotional, especially positive, meaning of encounters). The goal of the current article is to examine whether the principles of SST might also apply for people with AD. Some aspects of SST are found especially in the early stages of AD when awareness is often intact and cognitive impairment is relatively limited. This review has clinical significance for the treatment of AD because it focuses on what is important to the individual rather than treating patients as a homogenous group. It also highlights the importance of social networks and emphasizes the role of the proxy in AD care. Lastly, it suggests that if those with AD (like the healthy elderly) have a positivity bias then positive emotional stimuli/instructions could usefully be employed in their daily treatment. I suggest that SST may be a useful starting point when attempting to address what matters to individuals with AD and conclude by providing a few suggestions for future studies.

Keywords: Alzheimer’s Disease; Socioemotional Selectivity Theory; Individual Differences; Awareness; Positivity Bias; Socialization

1. INTRODUCTION

Negative stereotypes of elderly persons are plentiful among the general public [1]. The old are typically portrayed as being lonely, as having more mood disorders than younger adults, as being “stuck in their ways”, of becoming more and more like each other and less like the individuals they are with each passing year, and of being sick and dependent and psychologically and cognitively impaired. Yet, the truth is that many elderly people live fulfilling lives and successful aging is more the norm than the exception, while at the same time individual differences in coping style, personality, cognitive functioning and motivation are widespread.

1.1. Socioemotional Selectivity Theory (SST)

Socioemotional selectivity theory (SST) [2] was initially put forward as an attempt to explain the so-called “paradox of aging” which refers to the finding that while physical health tends to decline as we age subjective well-being may be maintained or even improve [3]. Time perspective rather than chronological aging is at the heart of SST, and suggests that as people begin to realize that they are running out of time, whether due to old age or terminal illness, their goals shift towards present concerns and away from what could assist them in the future. Furthermore, SST suggests that when time is limited we begin to focus on the emotional aspects of situations and coping and prefer to spend time with loved ones rather than seek out new relationships. Elderly people are thus motivated to maximize positive experiences, minimize the negative and spend quality-time with loved ones in smaller social networks. The classic SST experiment asks participants to choose who they would like to spend time with in a variety of contexts from a predetermined list. Older adults tend to choose an emotionally close social partner while younger subjects tend to pick strangers or acquaintances especially if these social contacts can provide them with new information.

Furthermore, according to SST, a positivity bias exists for healthy elderly subjects whereby they prioritize processing positively valenced information and allocate fewer resources to negative (and therefore distressing) information. This enables older adults to optimize their emotional experiences. The positivity bias is usually ma-
nified as better attention to and/or memory for positively valenced vs negative stimuli (e.g. [4]). In many memory tasks, while older adults tend to perform more poorly overall than younger subjects, both groups tend to remember more emotional compared to neutral material, the so-called Emotional Memory Advantage (EMA) [5]. Some researchers have found a valence effect (positive > negative) in the healthy elderly while others have failed to find this effect. Whether a positivity bias is found or not appears to depend on the type of stimuli, the experimental design, the delay between encoding and retrieval, and the instructions used at encoding [6].

1.2. Alzheimer's Disease

1.2.1. Cause and Clinical Manifestations

What causes Alzheimer’s disease (AD) has been widely disputed in the literature with genetics, lifestyle, and environmental effects all mentioned. How it affects the brain is however clear with plaques and tangles being hallmarks of the disease and progressive deterioration and cell-death the result. While AD is a devastating brain disorder so much of its clinical course is behavioral, including: cognitive dysfunction (typically memory and intellectual impairment), problem behaviors (wandering, agitation), disturbed psychological states (depression, delusions), and adverse psychosocial consequences (family stress/burden, costs to society) [7]. Also, because AD is progressive the needs of the patient and caregiver will change over time.

In the early stages of AD problems with instrumental activities in daily living (IADLs) (e.g. forgetting to take medications or how to drive a car etc) become more and more apparent. In the cognitive realm, difficulties with attention, concentration, working and especially episodic memory are found early on. Later in the course of the disease procedural memory abilities involving unconscious or rote recollections also start to deteriorate (e.g. riding a bike, making a cup of tea). These may remain spared for quite a long time in AD due to their reliance on less-affected brain regions (including the basal ganglia and the cerebellum) [8]. Emotional (and implicit) memory may be spared until the later stages, while both emotional processing and facial expressions can be inappropriate or exaggerated in AD. Emotional attachments on the other hand tend to remain strong until the end when even remembering loved ones may disappear as the person retreats into themselves. Indeed, patients have been known to “shadow” their caregivers and some researchers [e.g. 9] have suggested that this may provide emotional comfort to increasingly confused patients.

As AD progresses from the early to the middle stages the person may become agitated and show more evidence of disruptive behaviours. They become increasingly confused and memory loss becomes more profound as do changes in sensory perception and problems with executive functioning [e.g. 9]. More help with everyday activities of daily living (ADLs) (e.g. washing and dressing themselves) will become necessary while patients can still perform basic, familiar tasks and remain emotionally attached to things and people that are familiar.

In the final stages both short and long-term memory declines are severe and most language abilities are lost. The patient begins to lose self-awareness often to the extent that they do not recognize themselves. At the end even basic abilities like swallowing may be difficult as the person enters a vegetative state. It has been suggested that a person with AD basically reverts back to an infantile stage, with neurological reflexes being the last to remain—so-called “reverse ontogeny” [10].

1.2.2. Prevalence and How to Diagnose AD

A recent prevalence estimate for AD stands at 35.6 million worldwide [11]. Last year new AD guidelines [12,13] appeared with the focus shifting from symptoms/diagnosis to both the early preclinical stages and to how biomarkers may aid diagnostic accuracy. AD has a long prodromal/preclinical phase lasting from 10 - 20 years before the diagnosis is made [14,15]. In the first preclinical phase, patients are asymptomatic or have subtle symptoms/complaints. Diagnosis is generally made when standard diagnostic criteria are reached, typically including gradual (episodic) memory impairment and at least one of the following (aphasia, apraxia, agnosia, executive dysfunction). Also important is a significant impairment in daily functioning [see for example 16].

1.3. Alzheimer’s Disease and SST

Despite recent calls in the literature we still know relatively little about the internal experience of those with Alzheimer’s disease (AD). This is mainly due to the fact that there is scepticism about how accurate self-assessment is in the demented and whether cognitive impairment and especially communication difficulties make finding out impossible. Mast [17] suggested some strategies for accessing the internal experiences of those with dementia and emphasised the importance of attempting to understand them as individuals.

People with terminal illnesses (e.g. younger patients with AIDS and/or cancer) [18] have been tested using SST tasks. These patients tend to behave like the elderly in that they also develop a limited time perspective, and consequently change their personal goals showing a preference for close social relationships. AD, despite people living for an average of 5 - 10 years after diagnosis, is terminal with patients typically dying from complications (lung infections, etc) rather than from neural degeneration per se. It is therefore not unreasonable to assume that those with AD should also preferentially pro-
cess positive stimuli and prefer close social relationships rather than superficial encounters with careworkers or other acquaintances. Whether this occurs in AD is obviously closely linked to how aware the person is of his/her limitations at the different stages of this progressive disease.

Whether the premises behind SST also hold for those with Alzheimer’s disease (AD) is an important question for a number of reasons. Firstly, does the “paradox of aging” also apply to those with AD? While accelerated deterioration is expected in these patients, SST would predict that subjective well-being may be maintained or even improve. Secondly, do those with AD seek out positive experiences, avoid the negative and spend quality-time with loved ones in smaller social networks (as suggested by SST in the healthy elderly)? Certainly, personal relationships are likely to become more important as the illness develops but what motivates those with AD and does this change over time? Finally, is a positivity bias found in AD? If so, emotionally positive stimuli could be usefully employed in developing new behavioral treatments which could be used alongside medication, the goal being to maintain the patient’s quality of life for as long as possible.

To summarize: do those with AD (like the healthy elderly) show a shift from knowledge- to emotion-focused social goals as suggested by SST? The main premises of SST include: a) that there is positivity bias in memory and learning in the elderly; b) that as people age, smaller, more personal social networks become important to them and c) that behavior is goal-driven and by extension, elderly people are aware of their motivations and subsequent behaviors. This article will examine each of these three premises of SST in AD and go on to discuss what the results could mean in terms of this theory.

2. METHOD

A number of search engines including Google Scholar, PsycINFO, Medline, PubMed, and ScienceDirect among others were used to search for relevant literature. The following keywords (and combinations thereof) were used: Socioemotional Selectivity Theory, social, goal, motivation, emotion, Emotional Memory Advantage, elderly, aging, relationships, Alzheimer’s disease &/or dementia, individual/patient perspective, memory (explicit and implicit), arousal, valence, quality of life, behavior, time perspective, (self) awareness, anosognosia, orientation, positivity bias, emotional processing, socialization in AD. While no studies were found which have directly examined SST in AD many of the separate premises behind the theory have been investigated in AD and these are discussed in turn below under the relevant subheadings. SST has been widely accepted for the healthy elderly [19] and whether it applies to AD (which some researchers see as extreme aging, (e.g. [20]) is, I believe, worthwhile as we move towards more individual-based treatments.

3. RESULTS

3.1. Emotional Memory Advantage (EMA) and the Positivity Bias in AD

Studies have typically shown that older adults tend to 1) be more effective at maintaining positive affect; 2) that if they do experience negative affect it tends to be short-lived compared to younger adults; 3) that they are good at regulating their emotion, and; 4) that they have a bias to remember emotional stimuli that have a positive valence above neutral and negative stimuli and that this has been observed for autobiographical events, choices, words, pictures and faces [18]. A positivity bias has not always been found however [21]. Two theories have been suggested to account for positivity biases in the elderly: the “cognitive control” [22] and the “simplified processing” [23] accounts. The first suggests that only the elderly with enough cognitive control will show a positivity bias because the usual tendency is for people to focus on the negative. The second account suggests that older people focus on the positive as a way to simplify the information they must process.

Uttl and Graf [6] have suggested however that many of the experiments conducted in this field have major methodological flaws including floor and ceiling effects making it difficult to compare young and old groups. They also note that arousal ratings are often not measured despite the claim that the effects are largely driven by arousal; that emotional stimuli used in many experiments tend to be more interrelated than the neutral stimuli so confounding semantic relatedness with stimulus emotionality; and finally, that most studies have used mixed lists and emotional stimuli tend to be more distinctive than neutral in these lists compared to ‘pure’ lists. Mathews [24] also highlighted the need to take individual differences into account, especially the effects of mood and personality on processing of emotional events/stimuli, while Isaacowitz et al. [25] focused on the need to measure the time course of emotional processing in the elderly.

There have been surprisingly few studies which have investigated whether people with AD have an EMA despite recent interest in this topic [26,27]. Some researchers have found no EMA (e.g. [26,28,29]) while some do find an EMA in AD (e.g. [30-34]). A review of the literature [Blessing et al., 35] stated that people with AD showed a reduced or blunted EMA compared to healthy elderly controls, while Klein-Koerkamp et al. [27] concluded that the EMA could be preserved in AD “under specific retrieval instructions” (p. 1). Blessing et al., also
found in a later empirical study [36] that while the explicit emotional memory system was compromised in their AD patients, the implicit emotional memory system was spared. These authors suggested that this could be explained by the heterogeneity of amygdala (and other brain) damage typically found in the, already heterogeneous AD group. Furthermore, while some researchers have found a positive advantage [37], others have found a negative advantage in their AD group [38]. Brueckner and Moritz [39] using an emotional variant of the Deese-Roediger-McDermott (DRM) paradigm to investigate false memories, found that those with mild-moderate AD showed more false memories in comparison to a healthy elderly control group and more specifically, a significant bias to falsely remember positively-valenced stimuli.

Some researchers have justifiably separated emotional memory from emotional processing and have found normal emotional ratings/processing in AD while subsequent memory may not be compromised (see e.g. [40]). Studies on emotional processing in AD have however also produced mixed findings. For example, Bediou et al. [41] investigated face processing in Mild Cognitive Impairment, AD and Fronto-temporal dementia (FTD) and found that while gender recognition was preserved, patients with mild or moderate AD had problems with expression recognition while those with FTD were impaired for both expression recognition and gaze direction. In an interesting study which assessed emotional recognition in AD patients using face, voice and music stimuli, Drapeau et al. [42] found that while the patients had difficulty in identifying the emotional facial expressions of sadness, fear and disgust, they did not differ from controls in their recognition of happy, angry and surprising faces. Furthermore, the emotional recognition of voice and music stimuli was intact in the patients.

For those who have found positivity bias in AD the suggestion has been made that these people might be attracted to positive stimuli because they are more stimulating for them while negative stimuli are avoided because they may depict disapproval or avoidance [39]. For many AD individuals, social approval is important (see following subsection).

3.2. Social Networks, Relationships and Socialization in AD

Both larger social networks and more social participation have been associated with less cognitive decline in an elderly population of both African Americans and Caucasians [43]. Intact social networks can be a buffer against physical and psychological stressors, may reduce morbidity rates in many diseases and lower mortality [44]. Remaining socially engaged may reduce the risk of getting dementia in the first place and provide other health benefits including a diminished chance of both disability and mortality. It has also been suggested that a poor or limited social network increases the risk of dementia by 60% [45]. However, other researchers have suggested that the size of the social network might not be the important factor. Rather it is the type of relationship that matters [46] with close relatives providing more benefits than neighbors or acquaintances, especially when people suffer from cognitive decline. This viewpoint is in direct agreement with SST. Some researchers are also beginning to investigate the social needs of demented individuals using for example published memoirs by writers who are living with dementia [47]. Such work recognizes that these individuals remain people (and not victims) despite their dementia.

Two studies offer some relevant information about the social goal strivings of those living with AD. Cohen-Mansfield et al. [48] asked their AD participants which of a number of predetermined role identities were the most important to them. The family role specifically that of being a parent or grandparent, emerged. Cotrell and Hooker [49] found that their AD participants valued the same domains as the healthy elderly controls, namely: meaningfulness, deepening of family relationships and enjoyment of life, even when those with AD had diminished awareness. These researchers also found that when the AD individuals reported goals related to family they (in accordance with SST) reported a more positive and less negative mood than people who did not report any such goals. Furthermore, clinical observations suggest that people with AD are happier when they can feel useful to others and that close attachment relationships are important to them [50].

It could be argued that a person who does not suffer from AD or any other disabilities has ample opportunities to have reciprocal relationships. However when faced with AD this gets more difficult with passing time and the balance in their relationships may not be optimal [36]. How dementia affects marriage is under-researched [51]. It is however reasonable to assume that a diagnosis of AD will alter the dynamics within marital (and other) relationships. The person with AD may become cast in the role of the victim with the relationship ultimately suffering a loss of shared meaning and interests [51]. Furthermore, family members may be more likely than acquaintances to a) adapt to the changing circumstances; b) use shared history; and c) adjust their relationships simply because they have more invested in the relationship in the first place [46]. It is of course important to keep in mind that people whose cognitive abilities decline are less able to participate in social situations and may therefore show a reduction in reciprocity over time [51]. Individuals with AD seem to find it difficult to maintain ties and relationships [52] as do indeed their
The identity and role of the caregiver are also important. Conde-Sala et al. [53] found that spouses tend to have a more positive view of the relationship especially when the spouse has a higher educational level and when the person with AD has more functional autonomy. These researchers also found that adult children experienced more caregiver burden especially if the person with AD was also depressed. Apathy, depression, agitation, aggressiveness and irritability are common behavioral disturbances in AD and are often quoted as the most difficult for carers to cope with especially as they often become exacerbated over time [54]. Personality also has a direct impact not only on the relationships we have but on whether they survive over time; not everyone can develop and maintain friendships for example [52]. Magai et al. [55] found no changes in personality from before the AD diagnosis until late into the disease’s progression, while Droës [56] stated that premorbid personalities were accentuated, exaggerated or even drastically changed by the progressing dementia. In a recent review, Robins Wahlin and Byrne [57] concluded that neuroticism and conscientiousness were the most likely of the personality traits to change with dementia and could be useful early markers of AD.

The living situation of the person with AD has undoubtedly a huge impact on their relationships, especially when they must move into a residential care home and are therefore removed from their familiar home environment. The last aspect which makes it very difficult for them to remain socially engaged is that their ability to communicate declines as the dementia progresses and many withdraw from social contact [58]. This occurs relatively early with reductions in both comprehension and in meaningfulness of speech [59], while at the same time it is important to recognize that there are widespread individual differences in communication abilities as is indeed the case for all cognitive and behavioral domains.

3.3. Awareness and Motivation in AD

The concept of awareness has been addressed in many different patient populations in the literature and the consensus seems to be that it is extremely difficult to measure. Awareness measurements have typically depended not only on the insights of the patient but also of the caregivers (family and non-family). Questionnaires, interviews and comparing neuropsychological performances on objective tests with subjective complaints have all been used, while the relationship between awareness and cognitive functioning is anything but straightforward. Awareness is not a unitary concept and should therefore always be discussed in the context in which it is measured. Normann et al. [60] also stated that awareness can fluctuate within an individual, while at the same time their life-long personalities and dispositions will also affect it. Clare [65] distinguishes between three levels of awareness: “on-line monitoring”, “evaluative judgement” and “meta-representation” and finds that even in the advanced stages of AD patients tend to retain the first 2 with some aspects of the third also remaining.

Absence or loss of insight (anosognosia) has however been found in many different forms in AD [60] including: memory loss, executive functioning, blindness, and/or the ability to live independently. It is entirely likely that level of awareness will also affect what motivates the individual with AD. How severe anosognosia is also varies considerably [49,61]. The degree of anosognosia may also correlate inversely with dementia severity (e.g. [62]; but see [61] who refute this suggestion). A dissociation can also exist with lack of awareness of cognitive dysfunctioning and some awareness of behavioral symptoms being relatively common in AD [63]. Edwards [64] suggested that awareness of both the dementia itself and of space and time declines as AD progresses (but see [49] who found good time orientation in their AD group). When one loses orientation for time and space, one becomes less connected with reality. SST focuses on time perspective so it is important to assess this in AD.

Some researchers therefore find a lack of awareness in AD while others say that it remains even in the later stages. Clare [65] suggested that careful interpretation of patient subjective reports is important because denial, apathy, impaired verbal expression, confusion and alexithymia are all common in AD, and all could be interpreted as “lack of awareness” when the patient actually remains aware of their developing difficulties. Research in this area is difficult but necessary because it would be worthwhile to know whether there are specific subgroups within the AD population who have different levels of insight and if so how this affects their motivation, social goals, emotional processing and ultimately quality of life (QoL): wide-spread individual differences have been reported suggesting that QoL is not always diminished in AD [49].

4. DISCUSSION

There are no studies which have so far directly examined SST in AD. This article was written in an attempt to investigate whether the main premises of SST could also hold for people with AD. With regard to the positivity bias suggested by SST for the healthy elderly some studies have found that emotional meaning can enhance memory for verbal and visual stimuli in AD [30-34], and this might be especially true for extremely arousing real-life events [30]. However, Adolphs et al. [26], Kensinger et al. [28] and Mori et al. [29] among others found no EMA in AD. When an EMA is found, whether there...
is then a specific bias for positive over negative stimuli in AD is questionable however as only a couple of studies have tackled this issue (a positive bias was reported by Hamann et al. [37] while Fleming et al. [38] found a negative bias in their AD participants). Of course, positivity biases are also not always found in the healthy elderly population; individual differences are widespread. Secondly, there are some indications in the literature that people with AD have the same social goal strivings as the healthy elderly. The family role is often the most important in their lives and contact (although it can be questioned whether this is patient-driven) tends to remain to the end with close relatives [48]. Thirdly, awareness is necessary in order to be able to form social goals in the first place. Some researchers have suggested that many people with AD lack awareness, especially as the disease progresses (e.g. [60]; but see Clare [65] who believes that aspects of awareness remain even in the later stages). A key concept of SST is awareness that time is limited. Time orientation in AD has not yet been thoroughly investigated. Nevertheless, Cotrell and Hooker [49] reported that most of their AD patients had good time orientation in that they recognized that they had a limited amount of time left.

Another issue which must be addressed is whether those with AD actively pursue their social goals or whether their social lives simply happen to them in a passive way. Individuals with AD might not take the initiative in seeking out close friends and family (as suggested by SST) either due to their cognitive impairments or due to the context they find themselves in (as behavioral symptoms increase more of these people end up in institutions making social contacts necessarily more limited). Smaller, closer social networks in AD individuals might therefore not be due to consciously or unconsciously changing social goals (as suggested by SST) but rather due to their symptoms, living context, how the person themselves, their partner, family and close friends react to the AD and the many changes which accompany the disorder over time. The question thus remains as to whether this shrinkage of the social network in AD is a passive process (over which the patient has little direct influence) or whether they do indeed have social goals as suggested by SST for the healthy elderly.

It may also be the case that SST may apply only to certain subgroups of elderly people (both within the healthy and demented populations) and only when using certain tasks. Which subgroups, individual differences, tasks etc., could all be systematically investigated. Some suggestions and recommendations for future studies are listed in Figure 1.

5. CONCLUSIONS

Knowing what is spared and what is not in AD will have important consequences for the future care of these individuals. The premises of SST can provide one approach towards discovering both what is spared and what is personally important to these people. Blessing et al. [36] concluded that the implicit emotional memory system was spared in AD and that this had implications for treatment. Specifically, while AD individuals may forget explicit information (e.g. about people and events in everyday life) they may still be influenced by the emotional valence of these interactions. Emphasising these aspects may help them cope better with everyday encounters and may even help them retain information which might otherwise be lost. A fundamental move away from the traditional palliative to a more active approach, especially in monitoring the person with AD as the dementia progresses is the one favored by this author and indeed by others in the field (e.g. [50]). A shift too towards the individual with AD and away from treating them as a patient who is impossible to test or treat is clearly required. A recent review [50] addressed the perspectives of individuals with AD and concluded that there was no support for the widespread assumption that those living with dementia are suffering. Indeed, the literature which does address the AD individual’s perspective (e.g. [47]) suggests that they do not all accept the disease passively, that both emotion- and problem-focused coping are common, that compensation strategies change as the dementia progresses and that individual differences are widespread: some cope better than others.

This review has clinical significance for the treatment of AD because it focuses on what is important to the individual with AD rather than treating patients as a homogenous group. It also highlights the importance of social networks and emphasizes the role of the proxy in the care for people with AD. It also suggests that if those with AD (like the healthy elderly) have a positivity bias then positive emotional stimuli/wording/instructions could usefully be employed in their day-to-day treatment. Individual, case-focused treatment will become more important as the population ages and AD becomes more widespread. Researchers are becoming more aware that AD is a heterogeneous group of individuals with different personalities, coping strategies, medical and personal histories, goals, wishes and disease trajectories. A single pharmacological agent, or indeed a combination, is therefore unlikely to help all individuals with AD.

To summarize, it would appear that people with AD also strive for emotional closeness and family bonds as it is indeed often the case in the healthy elderly. However it is premature to say whether SST applies to those with AD. Fundamental research is clearly required in this area with the focus on what matters to these people as the dementia progresses. Multi-level, individually-driven treatments are likely to become more commonplace in future and experiments based on the premises of SST could be a use-
Figure 1. Recommendations for future SST studies in both the healthy elderly and in those with AD (see text for relevant references and detailed explanations).

FUL starting point when attempting to: 1) investigate what matters to people with AD, in other words, the individual’s perspective; 2) highlight what may be spared in AD (cognitively and behaviorally) and how this changes over time; and 3) ultimately develop an active, individual-based approach to treatment where emotionally valent stimuli may play a crucial role. AD is a bio-psychosocial phenomenon [66] not just a “memory disorder” after all.

REFERENCES

[1] Sneed, J.R. and Krauss Whitbourne, S. (2005) Models of the aging self. Journal of the Social Issues, 61, 375-388. doi:10.1111/j.1540-4560.2005.00411.x

[2] Carstensen, L.L. (1992) Social and emotional patterns in adulthood: Support for socioemotional selectivity theory. Psychology and Aging, 7, 331-338. doi:10.1037/0882-7974.7.3.331
Diener, E. and Suh, M.E. (1998) Subjective well-being and age: An international analysis. In: Schaie, K.W. and Lawton, M.P., Eds., Annual Review of Gerontology and Geriatrics: Focus on Emotion and Adult Development, Springer, New York, 304-324.

Charles, S.T., Mather, M. and Carstensen, L.L. (2003) Aging and emotional memory: The forgettable nature of negative images for older adults. Journal of Experimental Psychology: General, 132, 310-324. doi:10.1037/0096-3445.132.2.310

Christianson, S.A. (1992) Remembering emotional events. In: Christianson, S.A., Ed., The Handbook of Emotion and Memory: Research and Theory, Lawrence Erlbaum Associates, Hillsdale, 307-340.

Uttl, B. and Graf, P. (2006) Age-related changes in the encoding and retrieval of emotional and non-emotional information. In: Uttl, B., Ohta, N. and Siegenthaler, A.L., Eds., Memory and Emotion: Interdisciplinary Perspectives, Blackwell Publishing, Oxford, 159-187.

Brody, E. (1985) Parent care as a normative family stress. Gerontologist, 25, 19-29. doi:10.1093/geront/25.1.19

Poledrak, R.A. and Gabrieli, J.D.E. (1997) Functional anatomy of long-term memory. Journal of Clinical Neuropsychology, 14, 294-310. doi:10.1097/00004691-199707000-00003

Vance, D.E., Moore, B.S., Farr, K.F. and Struzick, T. (2008) Procedural memory and emotional attachment in Alzheimer disease: Implications for meaningful and engaging activities. The Journal of Neuroscience Nursing, 40, 96-102. doi:10.1097/JNN.0b01336812355f76

Reisberg, B., Pattschuhl-Furlan, A., Franssen, E., Sclan, S.G., Kluger, A., Dingcong, L. and Ferris, S.H. (1992) Dementia of the Alzheimer type recapitulates ontogeny inversely on specific ordinal and temporal parameters. In: Kostovic, I., Knezevic, S., Wisniewski, H.M. and Spillich, G.I., Eds., Neurodevelopment, Aging and Cognition, Birkhäuser Boston, Cambridge, 345-369. doi:10.1007/978-1-4684-6805-2_21

van den Dungen, P., van Marwijk, H.W., van der Horst, H.E., Moll van Charante, E.P., Macneil Vroomen, J., van den Dungen, P., van Marwijk, H.W., van der Horst, J., Riedel-Heller, S.G., Weyerer, S., Zimmermann, T., Maier, W. and Bickel, H. (2007) Patterns of subjective memory impairment in the elderly: Association with memory performance. Psychological Medicine, 37, 1753-1762. doi:10.1017/S0033291707001122

Barnes, D.E. and Lee, S.J. (2011) Predicting Alzheimer’s risk: Why and how? Alzheimer’s Research and Therapy, 3, 33. doi:10.1186/alzrt95

American Psychiatric Association (2000) Diagnostic and statistical manual of mental disorders, 4th Edition, American Psychiatric Pub, Washington DC.

Mast, B.T. (2009) Uncertainties in dementia: What do people with dementia experience? Generations; Journal of the American Society on Aging, 33, 30-36.

Mather, M. (2006) Why memories may become more positive as people age. In: Uttl, B., Ohta, N. and Siegenthaler, A.L., Eds., Memory and Emotion: Interdisciplinary Perspectives, Blackwell Publishing, Oxford, 135-158.

Hendricks, J. (2006) Exchange Theory. In: Schulz, R., Noeller, L.S., Rockwood, K. and Sprott, R.L., Eds., The Encyclopedia of Aging, 4th Edition, Springer, New York, 720.

Powell, A.L. (1994) Senile dementia of extreme aging: A common disorder of centenarians. Dementia, 5, 106-109.

Kensinger, E.A., Brierley, B., Medford, N., Growdon, J.H. and Corkin, S. (2002) Effects of normal aging and Alzheimer’s disease on emotional memory. Emotion, 2, 118-134. doi:10.1037/1528-3542.2.2.118

Knight, M., Seymour, T.L., Gaunt, J.T., Baker, C., NeSmith, K. and Mather, M. (2007) Aging and goal-directed emotional attention: Distraction reverses emotional biases. Emotion, 7, 705-714. doi:10.1037/1528-3542.7.4.705

Labouvie-Vief, G., Diehl, M., Jain, E. and Zhang, F. (2007) Six-year change in affect optimization and affect complexity across the adult life span: A further examination. Psychology and Aging, 22, 738-751. doi:10.1037/0882-7974.22.4.738

Mathews, A. (2006) Anxiety and encoding of emotional information. In: Uttl, B., Ohta, N. and Siegenthaler, A.L., Eds., Memory and Emotion: Interdisciplinary Perspectives, Blackwell Publishing, Oxford, 191-210.

Isaacowitz, D.M., Allard, E.S., Murphy, N.A. and Schlandel, M. (2009) The time course of age-related preferences toward positive and negative stimuli. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 64, 188-192. doi:10.1093/geronb/gbn036

Adolphs, R., Tranel, D. and Buchanan, T.W. (2005) Amygdala damage impairs emotional memory for gist but not details of complex stimuli. Nature Neuroscience, 8, 512-518.

Klein-Koerkamp, Y., Baciuc, M. and Hot, P. (2012) Preserved and impaired emotional memory in Alzheimer’s disease. Frontiers in Psychology, 3, 331. doi:10.3389/fpsyg.2012.00331

Kensinger, E.A., Anderson, A., Growdon, J.H. and Corkin, S. (2004) Effects of Alzheimer disease on memory for verbal emotional information. Neuropsychologia, 42, 791-800. doi:10.1016/j.neuropsychologia.2003.11.011

Mori, E., Ikeda, M., Hiro, N., Kitagaki, H., Imamura, T. [30]
and Shimomura, T. (1999) Amygdalar volume and emotional memory in Alzheimer’s disease. *American Journal of Psychiatry*, 156, 216-222.

[30] Boller, F., El Massioui, F., Devouche, E., Traykov, L., Pomati, S. and Starkstein, S.E. (2002) Processing emotional information in Alzheimer’s disease: Effects on memory performance and neurophysiological correlates. *Dementia and Geriatric Cognitive Disorders*, 14, 104-112. doi:10.1159/000064932

[31] Kazui, H., Mori, E., Hashimoto, M., Hirono, N., Imamura, T., Tanimukai, S. and Hanihara, T. (2000) Impact of emotion on memory. Controlled study of the influence of emotionally charged material on declarative memory in Alzheimer’s disease. *British Journal of Psychiatry*, 177, 343-347. doi:10.1192/bjp.177.4.343

[32] Moayeri, S.E., Cahill, L., Jin, Y. and Potkin, S.G. (2000) Relative sparing of emotionally influenced memory in Alzheimer’s disease. *Neuroreport*, 11, 653-655. doi:10.1097/00001756-200003200-00001

[33] Schultz, R.R., de Castro, C.C. and Bertolucci, P.H. (2009) Memory with emotional content, brain amygdala and Alzheimer’s disease. *Acta Neurologica Scandinavica*, 120, 101-110. doi:10.1111/j.1600-0404.2008.01132.x

[34] Nieuwenhuis-Mark, R.E., Schalk, K. and de Graaf, N. (2009) Free recall and learning of emotional word lists in very elderly people with and without dementia. *American Journal of Alzheimer’s Disease and Other Dementias*, 24, 155-162. doi:10.1533/153317508330561

[35] Blessing, A., Martin, M., Wenz, M. and Zöllig, J. (2006) Emotionen und Gedächtnis bei Patienten mit Alzheimer-Demenz. *Zeitschrift für Neuropsychologie*, 17, 81-92. doi:10.1024/1016-264X.17.2.81

[36] Blessing, A., Keil, A., Linden, D.E.J., Heim, S. and Ray, W.J. (2006) Acquisition of affective dispositions in dementia patients. *Neuropsychologia*, 44, 2366-2373. doi:10.1016/j.neuropsychologia.2006.05.004

[37] Hamann, S.B., Monarch, E.S. and Goldstein, F.C. (2000) Memory enhancement for emotional stimuli is impaired in early Alzheimer’s disease. *Neuropsychology*, 14, 82-92. doi:10.1037/0894-4105.14.1.82

[38] Fleming, K., Kim, S.H., Doo, M., Maguire, G. and Potkin, S.G. (2003) Memory for emotional stimuli in patients with Alzheimer’s disease. *American Journal of Alzheimer’s Disease and Other Dementias*, 18, 340-342. doi:10.1177/153331750318004004

[39] Bruckner, K. and Moritz, S. (2009) Emotional valence and semantic relatedness differentially influence false recognition in mild cognitive impairment, Alzheimer’s disease, and healthy elderly. *Journal of the International Neuropsychological Society*, 15, 268-276. doi:10.1017/S135561770909047X

[40] Kensinger, E.A. (2006) Remembering emotional information: Effects of aging and Alzheimer’s disease. In: Welsh, E.M., Ed., *Frontiers in Alzheimer’s Disease Research*, Nova Science Publishers, Inc., Hauppauge, 213-226.

[41] Bediou, B., Ryff, I., Mercier, B., Milliery, M., Hénaff, M.A., D’Amato, T., Bonnefoy, M., Vighetto, A. and Krolik-Salmon, P. (2009) Impaired social cognition in mild Alzheimer disease. *Journal of Geriatric Psychiatry and Neurology*, 22, 130-140. doi:10.1177/0891988709332939

[42] Drapeau, J., Gosselin, N., Gagnon, L., Perez, I. and Lorrain, D. (2009) Emotional recognition from face, voice, and music in dementia of the Alzheimer type. *Annals of the New York Academy of Science*, 1169, 342-345. doi:10.1111/j.1749-6632.2009.04768.x

[43] Barnes, L.L., Mendes de Leon, C.F., Wilson, R.S., Bienias, J.L. and Evans, D.A. (2004) Social resources and cognitive decline in a population of older African Americans and whites. *Neurology*, 63, 2322-2326. doi:10.1212/01.WNL.0000147473.04043.B3

[44] Quick, J.D., Nelson, D.L., Matuszek, P.A.C., Whittington, J.L. and Quick, J.C. (1996) Social support, secure attachments, and health. In: Cooper, C.L., Ed., *Handbook of Stress, Medicine, and Health*, CRC Press, Boca Raton, 269-287.

[45] Small, G.W. (2008) Beyond standard anti-dementia therapies: Diet, exercise, socialization, and supplements. *CNS Spectrums*, 13, 31-33.

[46] Aartsen, M.J, Van Tilburg, T., Smits, C.H.M. and Knipscheer, K.C.P.M. (2004) A longitudinal study of the impact of physical and cognitive decline on the personal network in old age. *Journal of Social and Personal Relationships*, 21, 249-266. doi:10.1076/josp.21.3.249.2584

[47] Ryan, E.B., Bannister, K.A. and Anas, A.P. (2009) The dementia narrative: Writing to reclaim social identity. *Journal of Aging Studies*, 23, 145-157. doi:10.1016/j.jaging.2007.12.018

[48] Cohen-Mansfield, J., Parpura-Gill, A. and Golander, H. (2006) Salience of self-identity roles in persons with dementia: Differences in perceptions among elderly persons, family members and caregivers. *Social Science & Medicine*, 62, 745-757. doi:10.1016/j.socscimed.2005.06.031

[49] Cotrell, V. and Hooker, K. (2005) Possible selves of individuals with Alzheimer’s disease. *Psychology and Aging*, 20, 285-294. doi:10.1037/0882-7979.20.2.285

[50] de Boer, M.E., Hertogh, C.M.P.M., Droës, R.-M., Ripha gen, I.L., Jonker, C. and Eefsting, J.A. (2007) Suffering from dementiathhe patient’s perspective: A review of the literature. *International Psychogeriatrics*, 19, 1021-1039. doi:10.1017/S1041610207005765

[51] Graham, J. E. and Bassett, R. (2006) Reciprocal relations: The recognition and co-construction of caring with Alzheimer’s disease. *Journal of Aging Studies*, 20, 335-349. doi:10.1016/j.jaging.2005.12.003

[52] Bennett, D.A., Schneider, J.A., Tang, Y., Arnold, S.E. and Wilson, R.S. (2006) The effect of social networks on the relationship between Alzheimer’s disease pathology and level of cognitive function in old people: A longitudinal cohort study. *Lancet Neurology*, 5, 406-412. doi:10.1016/S1474-4422(06)70417-3

[53] Conde-Sala, J.L., Garre-Olmo, J., Turró-Garriga, O., Vilalta-Franch, J. and López-Pousa, S. (2010) Quality of life of patients with Alzheimer’s disease: Differential perceptions between spouse and adult child caregivers. *Dementia and Geriatric Cognitive Disorders*, 29, 97-108. doi:10.1159/000272423
[54] Mega, M.S., Cummings, J.L., Fiorello, T. and Gornbein, J. (1996) The spectrum of behavioural changes in Alzheimer’s disease. *Neurology*, 46, 130-135. doi:10.1212/WNL.46.1.130

[55] Magai, C., Cohen, C.I., Culver, C., Gomberg, D. and Malatesta, C. (1997) Relation between premorbid personality and patterns of emotion expression in mid- to late-stage. *International Journal of Geriatric Psychiatry*, 12, 1092-1099. doi:10.1002/(SICI)1099-1166(199711)12:11<1092::AID-GPS690>3.0.CO;2-X

[56] Droës, R.M. (1991) In motion, on psychosocial care for demented elderly people. Tijdstroom, Utrecht.

[57] Robins Wahlin, T.B. and Byrne, G.J. (2010) Personality changes in Alzheimer’s disease: A systematic review. *International Journal of Geriatric Psychiatry*, 10, 1019-1029.

[58] Rau, M.T. (1993) Coping with communication challenges in Alzheimer’s disease. Singular Publishing Group, Inc., San Diego.

[59] Lezak, M.D., Howieson, D.B., Bigler, E.D. and Tranel, D. (2012) Neuropsychological assessment. 5th Edition, Oxford University Press, New York.

[60] Normann, H.K., Asplund, K., Karlsson, S., Sandman, P.O. and Norberg, A. (2005) People with severe dementia exhibit episodes of lucidity: A population-based study. *Journal of Clinical Nursing*, 15, 1413-1417. doi:10.1111/j.1365-2702.2005.01505.x

[61] Hannesdottir, K. and Morris, R.G. (2007) Primary and secondary anosognosia for memory impairment in patients with Alzheimer’s disease. *Cortex*, 43, 1020-1030. doi:10.1016/S0010-9452(08)70698-1

[62] Gil, R., Arroyo-Anllo, E.M. and Ingrand, P., et al. (2001) Selfconsciousness and Alzheimer’s disease. *Acta Neurologica Scandinavina*, 104, 296-300. doi:10.1034/j.1600-0404.2001.00280.x

[63] Sato, J., Nakaaki, S. and Murata, Y., et al. (2007) Two dimensions of anosognosia in patients with Alzheimer’s disease: Reliability and validity of the Japanese version of the Anosognosia Questionnaire for Dementia (AQ-D). *Psychiatry and Clinical Neurosciences*, 61, 672-677. doi:10.1111/j.1440-1819.2007.01734.x

[64] Edwards, A.J. (2002) A psychology of orientation: Time awareness across life stages and in dementia. Praeger, Westport.

[65] Clare, L. (2003) Managing threats to self: Awareness in early stage Alzheimer’s disease. *Social Science & Medicine*, 57, 1017-1029. doi:10.1016/S0277-9536(02)00476-8

[66] Hulko, W. (2009) From “not a big deal” to “hellish”: Experiences of older people with dementia. *Journal of Aging Studies*, 23, 131-144. doi:10.1016/j.jaging.2007.11.002