The Desocialization Effect – exploring identity and emotional exchange in the regressive stages of Alzheimer's Disease

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ABSTRACT

In applying a conceptual framework derived from social psychology, the article at hand explores the degenerative stages of Alzheimer's disease (AD) as a process of desocialization, in order to shed a new light on an already established neuroscientific body of research. Based on the empirical material of interviews and personal stories with caregivers/relatives to patients diagnosed with AD, the research finds that the process of desocialization unfolds on two interrelating levels. On the first level, the patient's loss of short-term working memory and long-term declarative memory implies a loss of self - both in a situational context and as an understanding of themselves as beings related to a social context of historical continuity. It further finds that the patients in the later stages collapse identities and live through prior roles attached to objects and symbols related to intense emotions. On the second level, it finds that when the patient's diminishing procedural memory deprive them of the behavioral patterns that has shaped their identities. The social surroundings inability to verify their status in a specific role implies a threat to the patient's selves, which eventually results in attempts to avoid the common social rituals that have shaped the relationship between patient's and caregiver/relatives. As this rejection, and degeneration, also entails a threat to the caregiver/relatives concept of self, an attempt to restore this social bond results in the renegotiation of the currencies of emotional exchange in the relationship, in which the caregiver/relatives trade sympathy in exchange for the patient's verification of their own identity.

Keywords:
Symbolic Interactionism, Interaction Ritual Theory, Sympathy, Alzheimer Disease

INTRODUCTION

The study on socialization, from birth to citizenship, represents one of the major bodies of inquiry within the discipline of sociology and social psychology (e.g. Mead 1934; Gilligan 1982; Juul 1995; Hurrelmann 1989/2009). In short, one could say that this is the study of how children, through joint symbolic communication and social pressure, develop the ability of self-reflexivity. This ability in return enables them to align their own action's with the culturally (gendered) norms that defines the socialized citizens behavior (Collins 2004; Goffman 1959, 1955/1967).

Based on established neuroscientific research on the regressive stages of Alzheimer's disease (AD), which is a neurodegenerative, terminal illness that severely affects the patient's memory and cognitive abilities, this article reverse the temporal approach of the previously mentioned theories on socialization (El Haj & Kessels 2013; Romdhane et al 2012; Jahn 2013). Instead, through a conceptual frame rooted in social psychology, this article aims to present a new way of approaching this pathological degeneration as a process of desocialization – from able-bodiedness to disability. Through the analysis of the social interplay between patients diagnosed with AD and their caregivers/relatives, the aim of this article is to explore how close relationships are renegotiated in a transformative process of identity distortion. Or, more specifically, how is identity and emotional exchange handled in an interpersonal relationship when a significant other unwillingly diverge from his/her socialized identity and no longer resembles the person he/she ones were?

In grounding this article in accepted neuroscientific research on the degenerative phases of AD, this question of inquiry is approached in two, overlapping, ways. First, the article sets out to explore how the patient's diverge from their pri-

or able-bodied identities. The purpose of this is to display the structure of social identity and unravel the layers of cultural rituals that define the socialized body. Secondly, it explores how the social relationship between patient and caregiver/relatives, throughout the process of desocialization, is renegotiated. This is done with a specific focus on collective interaction rituals and the redefinition of emotional exchange within a reciprocal system that bridge between sympathy and identity verification.

The empirical material of this exploratory study is based on interviews and personal stories by and with caregivers/relative's to AD-patients, and draws its theoretical outline from the micro-sociological theories of Erving Goffman (1959, 1955/1967), Randall Collins (1993, 2004) and George Herbert Mead (1934). The concept on stratified identities and verification further builds upon the works of Peter Burke & Jan Stets (1999, 2009), Burke & Donald Reitzes (1981, 1991) and Emma Engdahl (2009). While the final bolt in the theoretical framework is based on Candace Clarks (1997) study on the social construction of sympathy.

PREVIOUS RESEARCH

Research on what causes the neuropathological degeneration of the brain in AD, as well as its symptoms, is thoroughly mapped out within the fields of neuroscience. Studies in neurobiology and neurochemistry show how tangles composed of tau protein and plaques composed of beta-amyloid clumps in the brain and blocks the cell-to-cell signaling at the synapses, which leads to a deterioration of the patients cognitive, behavioral and functional domains (Blennow, Leon & Zetterberg 2006; Romdhane et al 2012; El Haj & Kessels 2013; Jahn 2013). Research in neuropsychiatry further shows how most patients develop neuropsychiatric symptoms, such as depression, apathy, delusions, hallucinations and aggressive behavior (Lyketsos et al 2011). An additional number of studies have focused on how genetics, sex, family history and psychosocial stressors may function as triggers which increase the risk for AD later in life (Johansson et al 2013; Bendlin et al 2009; Johansson et al 2014). While other research have shown that higher education may reduce the chances of developing AD and dementia later in life (Wang et al 2012; Ngandu et al 2007). This research on the neurodegenerative phases of AD constitutes the scientifically established base of symptoms upon which the process desocialization in this article is understood.

Previous social research spans from focusing on the history and cultural representation of AD (MacRae 2008; Ballenger 2006; Clarke 2006) to shame, strain and social embarrassment among caregivers (MacRae 1999; Montoro-Rodríguez et al 2009; Wood & Parham 1990) as well as the possible loss of self among AD-patients (MacRae 2010; Sabat & Harré 1992). Research with a particular focus on the interplay between patient and caregiver/relatives spans from developing methods for communication in order to improve the care of the patient; to how social interplay after a diagnosis of AD tend to result in a social depersonalization of the patient (Graham & Bassett 2006; Vittoria 1999; Kitwood 1990, 1993). This interplay is also the focus of Karner and Bobbit-Zeher's article "Losing Selves: Dementia Care as Disruption and Transformation" (2006) in which the authors explores how the regressive process of AD entails a threat to the caregiver/relatives selves and how they, in an attempt to bring order out of chaos, use "constructed

agreed upon patterns of interaction" (2006:551) to reinforce the patient's familiar biography and ease the painful experience of identity distortion

Hence, even though some articles have touched upon elements that are part of what it implies to regress into a desocialized state, to my knowledge, no prior article has approached the neuroscientifically established degenerative stages of AD as a process of desocialization in which the micro-elements of social interplay simultaneously transform and contests identities and emotional exchange.

THEORETICAL FRAMEWORK

Desocialization in this article is understood as a process that unfolds on both a neurological and social level, where the patient's diminishing memory and cognitive abilities entails a transformation of identity that distorts the social interplay with others. To understand this Benjamin Button-esque reality of AD then – from socialized to desocialized body - the focus of the first theoretical section is to come to terms with the essential structure of communication, as prerequisite for socialization. This will further open up for an understanding of how identities form through behavioral patterns and social exchange of "confirmation and validation of self-concepts" (Burke & Reitzes 1981:84). The second theoretical section deals with how identities as performance are culturally interpreted in terms of social norms and what it implies to diverge from the boundaries of face-to-face communication (Goffman 1959, 1955/1967). This section also explore how interaction rituals that generate high emotional energy function as the socialized body's impulse to act and how social identities are shaped through such rituals (Collins 1993, 2004). The third, and final section, examines sympathy-giving as a reciprocal interaction ritual and what it may entail to give sympathy to someone who is incapable of giving it back (Clark 1997).

Role taking and identity verification

According to Herbert Blumer, language is mutually defined symbols used by individuals "to bring order out of the chaos of the world" (Burke & Stets 2009:13). Thus, for communication to function, it demands a mutual focus of attention towards those shared symbols that are ascribed significant value by the individuals involved in a communicational act. Lack of this ability, as for instance seen among children diagnosed with infantile autism, consequentially hinders the capacity of self-reflexivity, which is essential for one to function in society. This capacity, George Herbert Mead refers to as roll taking (1934:100). That is, the ability to place yourself in the position of other's in order to understand why they respond to your actions in a specific manner. This, states Mead (1934), is not only crucial to human consciousness and intelligence, but also a prerequisite for one to develop the capacity to feel empathy.

Self-reflexivity is further dependent on the pendulum between what Mead refers to as 'I' and 'Me' (Mead 1934:175). That is, in order for an individual to understand others attitudes towards him- or herself, 'I', as an acting subject, needs to be able to remember that it was 'Me' that performed the specific action that other's reacted to. It is only through one's ability to remember that he/she can take the role of others and in return develop a concept of 'Self' (Mead 1934:154). Socialization can thus be described as the cognitive process in which children, through social pressure, learn to align their own actions to fit the normative pa-

rameters of social interplay. To inhabit a socialized body is thus to act within this culturally regulated behavioral frame – and remember its boundaries.

A further position of this article is that behavioral patterns do not only define the socialized citizen, but is rather the essence of what characterizes identity in general. An individual's identity is thus understood as a number of roles of varying status that one acts out through socially defined patterns of actions (Burke & Stets 2009; Burke & Reitzes 1981). As the focus of this article is the relationship between patient's and caregiver/relatives, we are first and foremost dealing with individuals who occupy the roles of a spouse, a brother or sister, mother or father etc. These roles further implies a particular status in a group that correlates with a number of actions and skills that determines how others come to understand how well an individual practice that role. One way to understand how the process of desocialization affects identity is therefore to analyze what happens when the patient's, and even caregiver/relatives, diverge from the behavioral patters that are socially ascribed to a role.

Furthermore, identities are understood as "meanings one attributes to oneself in a role" (Burke & Reitzes 1981:84). Thus, as a role is acted out, an individual's understanding of him or herself in that role needs to be verified by those engaged in the interaction, as lack of such consensual validation tends to lead to an insecurity of the self (Burke & Reitzes 1981; Burke & Stets 1999; Engdahl 2009; Tornstam 1978/1992). This also implies that when someone diverge from the behavioral patterns of a role that defines his/her identity, other's inability to verify his/her status in that role will consequentially threaten that individual's concept of self. Since the verification of a particular role is done in dialogue with others though, one's divergence from a behavioral pattern may also imply a threat to someone else concept of self in a role that connects to the former. For instance, the relationship between a husband and wife often implies a pattern of gestures that signals intimacy and solidarity in order to verify their self-concept in that role. Thus, when someone willingly or unwilling diverge from the actions ascribed to a role, the self-concepts of those engaged in that relationship will also be contested. As we will see, this is evident in the empirical material throughout the degenerative phases of AD.

Face-work, Emotional Energy and Interaction Rituals

To illustrate the straining boundaries of interaction rituals (IRs) and how they interrelate with Emotional Energy (EE) as an impulse to act, I intend to begin this theoretical part with a personal example.

> Many years ago in Stockholm I got seated behind a man who looked up at every other passenger who got on the train and said: "Do I know you?" Most people's initial reaction was either to ignore him, laugh or shrug him off with a: "No, I don't think so". The only passengers who actually paid him any affectionate attention were a woman in her mid fifties. And the reason for that was that the man actually conveyed to her why he would ask such a question, when he said: "Do I know you? You see, I've got Alzheimer's, so I don't know."

This example not only shows how the amount of information one communicates comes to dictate how other's will understand him/her in a particular situation, but also how the perception of a spoken line may vary whether it is performed "frontstage" in a public context or "backstage" in a private setting (Goffman

1959:32, 115, 129). The aforementioned domesticating process of socialization thus implies that one is taught how the positive social value, which Goffman calls "face" (1955/1967:5), also is regulated by the specific setting of an IR. Rather than being something inside the body, face is then located in the flow in between people who interact and is only disclosed through other's appraisal of a that performance (Goffman 1955/1967). The evaluation of such a performance though, as pointed out above, is always dependent on whether or not it is understood as congruent with the cultural normative understanding of that face. This implies that failure to display what is understood as proper conduct will be followed by social sanctions. Variations of such social sanctions furthermore become evident throughout the degenerative stages of AD. In particular in the early stages of the illness, before the patient has received his/her diagnosis, these sanctions commonly are expressed in the form of constant corrections. Since the patient's diminishing cognitive abilities deprive them of the capacity to assess the correctness in their actions, these sanctions then entails an enormous threat to the patient's concept of self, which, as I will show in the analysis, leads to a number of social consequences. However, in contrast to previous research (see McRuer 2006; Garland Thomson 1997; Charmaz & Rosenfeld 2006) that shows how a diagnosis that defines social deviance often is conceived as a social stigma (Goffman 1963) the diagnosis of AD tends to entail that the social sanctions towards the patient eventually comes to a halt and allow the caregiver/relatives to engage in care and sympathy-display. How this emotional exchange is executed we will get back to below.

Now, identity is not solemnly the outcome of the diverse ways that an unsocialized individual adapts to social constraints, but also the product of a number of individual choices and experiences (Engdahl 2009). The role's that constitutes a person's identity, and ones status in a specific group or organization, is thus dependent on the experience of specific collective IRs that generates intense EE and symbols of rewarding group solidarity (Collins 2004; Burke & Stets 2009). Since this experience of EE in an IR is individual, the will to recharge certain symbols that signals membership in a group, while reject or avoid others, consequentially shapes one's identity (Collins 1993). IRs that form one's role and status in a group or organization are thus not isolated events, but rather links in "interaction ritual chains" (Collins 2004:17) in which transient emotional energies are carried over between people. A characteristic of EE is that as it develops into a strong steady emotion through IR chains, it also forms the individual's "ability to act with initiative" and enables him/her to "set the direction of social situations rather than to be dominated by others in the micro-details of interaction" (Collins 2004:134). Thus, in Collins theory, in contrast to Meads (1934) where the acting subject 'I' reflects an "unsocialized self" of "pure action" (Collins 2004:204), the socialized individuals impulse to act is EE. And the forcefulness of that impulse is regulated by "past symbolic residues" (Collins 2004:205) attached to a specific IR. None the less, remembrance is a common theoretical thread.

How chains of intense EE generate intimacy and solidarity in a group and simultaneously shape the roles/status of its members becomes apparent in the empirical material through the relationship between patient and caregiver/relatives. Thus, to analyze how these IR chains are contested in numerous ways throughout the degenerative phases of AD is a way to clarify the social consequences of this illness.

The Social Construction of Sympathy as Emotional Exchange
In exploring the social implications of identity transformation and emotional exchange in a process of terminal illness, one further key factor to understand is sympathy-giving as a socially constructed IR chain. In *Misery and Company* (1997) Candace Clark points out three specific components that constitutes sympathy-giving: "empathy (or role taking), sympathy sentiment, and display" (1997:33). Thus, in taking the role of the other and displaying that one recognizes, shares or feels someone else's plight, through symbols such as "condolences or get-well cards" (Clark 1997:57) the societal feeling rule of sympathy-giving comes to function as a form of social glue embedded in IRs, which is then stored in EE and carried over between people (Clark 1997). Display of sympathy is thus also a way to verify the status/role one person holds in relation to another (Burke & Stets 2009). Since the understanding of this solidarity is grounded in a normative expectancy, based on the preconception of how strong an emotional bond *ought* to be in a particular relationship, this also implies the social sanctions carried out towards those who fail to display sympathy vary in forcefulness. As the relationship between patient's and caregivers/relatives often is expected to imply a deep bond of emotional solidarity, caregiver/relatives who fail to display sympathy are therefore often perceived as individuals of low moral worth (Clark 1997). To circumvent such sanctions then, which will be displayed in the analysis, the intimacy in the relationship must somehow diminish.

In order to further understand how the emotional exchange between patient and caregiver/relatives is renegotiated, we must grasp the reciprocal nature of sympathy-exchange. Sympathy is namely always given asymmetrically, where the one who is being sympathized with is one-down on the sympathizer (Clark 1997). That way, sympathy-giving implies a reciprocal obligation to repay the given sympathy. Thus, as the act of repaying sympathy becomes increasingly harder for patients diagnosed with AD, it also tends to upset the social balance of this emotional exchange. Now, on the one hand, to disregard the reciprocal nature of sympathy exchange, through sympathizing with someone who is incapable of giving it back, can be a way to display altruism and higher morale (Clark 1997). This approach to sympathy-giving is also evident among the caregivers/relatives in the empirical material. On the other hand, when someone overinvests in sympathy-giving e.g. repeatedly show sympathy towards someone who is less able or interested in repaying it, sympathy can be exchanged for other currencies, for instance "money, love and support for social identities" (Clark 1997:182). As the patient's ability to partake in this exchange diminishes, this way of compensating for the imbalance of sympathy-giving by renegotiating the currencies in the exchange also becomes evident among the caregiver/relatives in the empirical material.

RESEARCH DESIGN & METHODS
In order to grasp the process of desocialization and the nuances of the interplay between patient's and caregiver/relatives on a micro-level, this article has adopted a qualitative design. Since no prior studies, to my knowledge, have approached the neurodegenerative stages of AD in the same way, an explorative approach to this subject was further in place (Marshall & Rossman 2011).

The personal stories analyzed in the article were accessed through The Alzheimer's Association (alz.org), which is the world's leading voluntary health or-

ganization with focus on AD. A first bundle of forty-nine personal stories were accessed on the 23rd of February 2015 and a second bundle of another twenty-five stories were accessed on the 16th of March 2015. The stories analyzed thus sums up to seventy-four in total. Of these stories seventy-three were relevant to the analysis.

The outline of these stories ranges from dotted lists on how to arrange your life to be able to handle the daily struggle as a caregiver to short story-esque narratives describing the personal experiences of AD. In volume they span from a couple of sentences up to five or six pages. The stories shared were written by ten men and sixty-three women. This gendered asymmetry of care is further also reflected in the stories, where fifty-four of the women and only one man said to be the patient's primary caregiver. In order to increase the credibility and transparency of the research in the article a digital link with open access to these stories has been added to the list of references below.

The second source of empirical material contains of three interviews with caregivers/relatives who volunteered to partake in the study through a representative of the Swedish Alzheimer's Association. These interviews were conducted at the Department for Sociology and Work Science at the University of Gothenburg on the 6th, 9th and 11th of March 2015 and spanned from twenty-seven minutes to fifty minutes. The particular interview material focused on broad questions targeting the situational interplay between patient and caregiver/relatives (Kvale & Brinkmann 2009). The purpose of this was to allow the respondents to emplot those disparate situations and symbols that they found to be significant to the outline of their story about experiencing AD as a social process (Ricoeur 1991a).

In using established neuroscientific research on the degenerative stages of AD in order to explore this process through a conceptual frame of social psychology, an abductive iterative process, between coding of single cases and reflective interpretation, was applied to the empirical material (Alvesson & Sköldberg 2009). Thus, without rejecting previous research and allowing for new cases to transform the over-arching pattern of what desocialization as a social process implies, this allowed for the caregiver/relatives stories to form into an "accrual of narratives" (Bruner 1991:19) reflecting the nuances of this process, which further strengthened the exploratory nature of the research (Alvesson & Sköldberg 2009).

Ethical Considerations

Although the personal stories on alz.org were open to public access, as you did not have to register a membership to read them, and signed with the author's first name. A conscious choice to leave out these names in the article was made. Further, when names appear in the particular stories used as examples in the article, male names were changed to James and female names to Mary, as these are the most common first names in the U.S. The reason for this is that even though these stories were published for open access, it is not possible to assume that the authors intended for their stories to be subject for scientific inquiry.

When conducting the interviews, the guidelines in The Swedish Research Council's publication "Good Research Practice" (3:2011) was applied. Besides revealing the scientific purpose of the research and receiving the respondent's informed consent, a further decision not to disclose the transcribed interview material in the list of references for transparency of the inquiry was done. The reason

for this is that although the material was transcribed in a way that it won't give away the anonymity of the respondents, it is hard to be reassured that they would not regret some things that were told in confidence. And, as pointed out by Marshall and Rossman (2011), to assure the respondents anonymity and getting their informed consent is not good enough for ethical research practice. Rather, good ethical research is first and foremost a conscious decision not to expose the participants in ways that might hurt them (Marshall & Rossman 2011). Therefore the decision not to display the transcribed interviews in their entirety was made.

Finally, the research in this article was conducted with a conscious focus on accountability. Thus, the intention with exploring how different micro-elements interrelate and how they are contested throughout the degenerative stages of AD has been to increase awareness among caregiver/relatives in order to hopefully make AD a less painful journey both to them and the patient's.

ANALYSIS

The first section of the analysis aims to show how identities as "confirmation and validation of self-concepts" (Burke & Reitzes 1981:84) is an interpretative work grounded in the cultural norms that defines the socialized body in face-to-face situations. The purpose of this section is thus to introduce the reader to how identities are defined and contested through normative patterns of actions. The following four sections focus on how the patient's diverge from their socialized self and how this loss of abilities affects the patient's identity and the social interplay with caregiver/relatives. The second section of the analysis therefore explores the caregivers/relatives biographical accounts of the patient's in the personal stories, with a particular focus on how collective rituals that develop into IR chains shape identities and emotional bonds. The following section discuss the early signs of the patient's diminishing cognitive abilities and show how the patient's self-concept's are contested when the caregivers/relatives no longer are able to verify their status/role in face-to-face situations. The fourth section handles how this threat to the patients self affects IR chains and how the caregivers/relatives try to recreate these chains as the patients cognitive abilities regress. The fifth section explores how sympathy-display and emotional exchange is renegotiated, as well as the caregivers/relatives strategies to circumvent the social sanctions imposed on them when they are perceived as failing to display sympathy. The final section of the analysis focus on the last stages of AD and how the patients desocialized state eventually make them collapse their concept of self with prior identities attached to particular symbols and objects that spark emotional residues.

The boundaries of face: identity as interpretation

To explore what it means to diverge from ones socialized body and how identities are dependent on other's interpretation of how well a performance aligns with the cultural norms that defines socialized behavior, the first two examples used to illustrate this describe the symptoms of AD as a form of re-socialization.

In the first example the daughter who has written the story describes her father as a man who was "pleasant but not playful" among his grandchildren. Instead of taking an active part in the social life around him, he rather "chose to watch from his seat on the couch" and wave goodbye as her family left. Even though they only lived a short drive away from each other. Her father would only partake in

gatherings such as birthdays and holidays, and had a tendency to come often off as "grumpy and unapproachable". As the father is diagnosed with AD and the symptoms of the illness gradually changes his behavior, so does her perception of him.

> My children Nora, 10, and Joey, 8, and I visit him weekly, not just on holidays and birthdays anymore. My father's eyes always light up when he sees us coming. I don't know if he remembers our names, but he recognizes us for sure. […] Some days we just sit. He loves looking at the kids. I catch him just staring at them, with a smile on his face. […] When we leave him, the kids will hug and kiss him goodbye and say "love you Papa" and my father will say "I love you too". Before the dementia, he never said those words. The man that I thought would be a dim figure in their minds as adults, will now be part of their fond memories for a lifetime. […] For that, I am forever grateful.

As mentioned earlier, face is not something in or on someone's body, but located in the flow in between people (Goffman 1955/1967). That way, face is rather a form of interpretative work that people engage in through interplay. Hence, although the patient may not comprehend the impact of his new way of acting, the daughter's interpretation of his actions, in the way that they verify her self-concept, is enough for appraisal. The perception of his performance then further develops into an IR chain, as the experience of joyful emotional entrainment increases the frequency by which they come to visit him (Collins 2004). Through this interpretation of the fathers transformation of behavior the daughter is then able to ascribe her father the normative role of *a father* as it verifies her as a daughter.

In a similar case of rectification, the author of the next example tells the story of her father, who prior to his diagnosis has had an affair with another woman for twenty-seven years, while being married to the author's mother. As the father is diagnosed with AD and the symptoms increase, he eventually forgets that he has moved out of their common home and breaks down the door. As he is dismissed from the hospital though, the mother decides to take him back in. This homecoming is described by the author as follows:

> My 87-year-old mother is the saint; she cares for him and loves him. Sad to say, but after all these years, she has him back. True, he isn't the man he was, but in a way that is good. He is sweet to her, holds her hand and tells her he loves her; something that was reserved for the other woman for 27 years. In the end, it is home he came back to. He may not recognize it as such, but in his heart, he has come back to the place he knew, to the woman he never stopped loving and never stopped loving him. For better or worse has taken on a whole new meaning.

In the same way as the previous story, this one reflects how the symptoms of AD conspire to restore a normative social order, as the father's actions towards the mother eventually verifies the author's concept of her. In using culturally sacred objects of EE like "home" and "heart" the author further underlines the natural state of this rectification.

These examples show how the father's deviating behavior, in the sense that it is different from how they acted prior to the diagnosis, also affects the perception of their identities. As the behavior verifies the concept of others their behavior is then perceived as a form of regressive socialization in which the patient's finally display the ability to take on the role of others (Mead 1934).

The final example, which is also the most common in the empirical material, shows how the divergence from the patient's socialized body implies a loss of identity, as the patient's actions no longer aligns with the caregiver/relatives perception of that role.

> **Interviewer:** Looking back to before the diagnosis and up until today, would you say that your relationship to your mother has changed?
>
> **Respondent:** Well… I wouldn't say that I have a mother today. Well, she exists but… I can't talk to her anymore or… She is *there*… but she's no longer a mother. Or how should I put it? She doesn't have that *role* anymore… that, I wouldn't say. [Authors trans.]

The examples above shows how identity not only is something one ascribes oneself in a role, but that this role needs to be verified by others through the patterns of actions that relates to it (Burke & Stets 2009; Engdahl 2009). Thus, when the behavioral pattern that confirms the role no longer is possible for other's to verify, that particular role is contested or erased. How the patient's identity transformation is perceived though, is clearly dependent on how well their behavior aligned with the normative boundaries of interplay prior to the diagnosis.

Biographical Accounts – the socialized self

To further account for the patient's process of desocialization, the approach of this second section in the analysis is to understand how the caregivers/relatives present the patient as socialized selves. These are a few examples that are typical to the empirical material.

> My mother's mind was sharp as a tack, and she could converse about any topic. Better yet, she would put her thoughts into the most beautiful words on paper […] She loved going to the Y and the temple every Friday night.

> My dad grew up working in his dad's garage helping fix and sell cars. He eventually took over the business along with his older brother. […] He worked hard to take care of five kids. We couldn't have asked for a better father. He would play hide-and-seek with us, he took us on vacations to Mackinaw Island and to Florida and more. He also instilled in us the Christian values that he believed so much in.

> She was a great lover of music and children, with a heart full of compassion and loyalty […] Using the gift of music, she taught in a small suburb of Detroit. At the age of 28, she met my father, Morton […] Three years later, they were married and later, had four children, of which I was the youngest. My mother was a great representative of the Jewish faith. She taught the rituals performed during holidays of Hanukkah and Passover to a variety of groups in the community.

Written in pass tense these biographical accounts reflect a nostalgic longing and gratitude towards the patient's portrayed in them. But what the stories in particular describe is the patients and caregiver/relatives common engagement in IR chains of intimacy and solidarity (Collins 2004). In return, since IR chains shape the social identity of those who engage in them, these become nods in the patient's biographies. The mother who loved going to the temple "every Friday night", the father who engaged in play and took the family on vacations and the mother who teaches rituals to the community, are all accounts of such IR chains.

Hence, when mapping the regressive stages of AD it is important not to neglect that these IRs chains also have shaped the identity of those telling the stories. That way, the examples in the article will also reflect how the self-concepts of the respondents and authors are contested by the symptoms of the illness.

Early signs of diminishing cognitive abilities: EE and Self
The first signs of the AD-patients divergence from his/her socialized identity are often described through incidents where a loss of a prior cognitive ability suddenly becomes salient.

> He could not get the car out of park because he had the key out of the ignition.

> She was attempting to write down a recipe for a friend, and she kept asking me how to spell words. I could not understand why my mother could not spell words like: "the", "tablespoon", "batter" and "sugar". I thought she was kidding; those words were easy. I joked with her about it, we both laughed, and that was the end of that.

> And then later we were on holiday by car in England. Ehm…the summer of… 2008… I think it was… 2008 or 2009. And we have been on a great deal of holidays by car, since my mom is afraid of flying. And she has always been the one reading the map, which she was splendid at, while my dad has been the one driving. But I also enjoy reading the map. And then while we were driving around in England she suddenly had no clue of how to read the map. Not *all the time*… but in certain situations she was completely lost. But since I also had a map I was like 'but we have to go that way!' And then she became really irritated… of course. [Authors trans.]

What these examples reflect, but in different ways, is how the patient's increasing inability to perform certain practical skills, which is related to his/her diminishing procedural memory, results in a conflict when the caregiver/relatives temporarily become unable to verify the identity of the patient (Yamadori et al 1996). In the first and second example this incident is shrugged off as a glitch in the machinery. In the third example though, the social context plays an important role for our understanding of how this conflict appears, as it contests the status and role of the patient in that particular situation (Burke & Stets 2009). For, as described in the story above, this is part of an IR chain (repeated family holidays by car) that has positioned the participants in particular roles and statues (Burke & Stets 2009). The EE that is tied to the mother's self-concept of her role as a map-reader then function as an impulse to "act with initiative and resolve" (Collins 2004:134).

What the situation reflects then, as the others are unable to verify her ability to assess which road to take, is how her concept of herself in that role is contested. Now, such conflicts happen every day, but in contrast to the one above they are often resolved when one recognizes that he/she actually is wrong. In the case with patients diagnosed with AD though the diminishing cognitive abilities also take away their ability to *see* that they are wrong. Instead, as the mother in the example, they tend to act on the emotional impulse based on previous experiences of themselves in that role. The conflict that emerges then depends on the fact that others are unable to verify the patient's assessments, at the same time as they appear to be correct to him/her.

This conflict between the patients diminishing cognitive abilities and the emotional impulse to act in accordance with one's self-concept is further evident in the next example. In this story though, in contrast to the one above, the father has received his diagnosis. In return, this also affects the caregiver/relatives reaction to his way of acting, since it verifies the identity traits that they have been forced to accept as part of his identity. Thus, the inability to no longer act the face that he has claimed for himself throughout the years aligns with the deviating traits ascribed to his body through the diagnosis (Goffman 1955/1967).

> My father's responsibility to his wife and children caused him always to keep a close eye on the family finances. (I think he defined himself by the sense of responsibility.) So when, in his "golden years" statements from the financial institution started arriving that didn't make sense to him, he was driven to figure out why. He never could. What he didn't realize was that there was a reason he never could. The Alzheimer's that had taken away his ability to add and subtract had also taken his ability to know that he was unable to add and subtract. So month after month he kept trying. On my visits, he would show me his chipherings, numbers that "proved" to him that money had mysteriously gone missing from his and my mother's accounts.

What both of these latter examples show, is how the cognitive regression of AD in the early to middle stages generates a conflicting paradox that contests the patient's prior identity. That is, on the one hand his/her self-concept does not seem to be affected by the diminishing cognitive abilities, since he/she lacks the ability to *see* that the result of the action is faulty. On the other hand, the caregiver/relatives inability to verify the patient's actions as congruent inevitably also contests the patient's concept of self. Thus, the same social pressure that is directed towards the child throughout the process of socialization is now, again, projected towards the patients socialized self. To the patient though, the image that is mirrored by the social surrounding is believed to be distorted. This in return, as the reflection of that same image constantly is projected back onto him/her, becomes an enormous source of anxiety and conflicts that eventually affects the IR chains in the relation. How these are affected and the measures taken to restore them we will get back to below. That this distress very well could be a contributing factor to why depression, apathy and aggression is a common neuropsychiatric symptom among patients diagnosed with AD, doesn't seem to far-fetched though (Lyketsos et al 2011).

In the later stages of the desocialization process it further becomes evident how EE as an impulse to act in a particular role functions, even when the pendulum between 'I' and 'Me' no longer is intact (Mead 1934).

> One night she woke me from a dead sleep at 2:00 a.m. She shook me as hard as she could, "I smell cigarette smoke. Are you smoking in here!" She screamed at me with such venom in her voice. I tried to tell her that I was not smoking, but she would not listen. She turned and went into the hall then into the bathroom. I proceeded to get up and follow her to make sure that she was not hurting herself. She had started the shower; "I am getting your shower ready, time for school." She had no idea that she had just been yelling at me less than five minutes before.

As seen in the example, the hallucination of the smell of smoke as a symbol of disobedience triggers the patient's emotional impulse to correct her son (Lyketsos et al 2011). In this case then the mother's sense of self in the role as a *mother* still follows a named pattern of behavior which she acts out on emotional impulse (Burke & Stets 2009; Collins 2004). But as the pendulum between 'I' and 'Me' no longer is intact, she cannot recall herself acting (Mead 1934). Although this is not displayed in the story above, eventually this rapid loss of short-term working memory also renders the patient's unable of self-reflexivity, as one cannot take the role of the other if he/she no longer can remember his/her actions (Jahn 2013). None the less understand others reaction to those actions. Thus, this consequentially implies a loss of self.

Contesting and restoring the solidarity ties of IR chains
As the illness progress, the patient's increasing inability to perform certain practical skills related to a role becomes even more evident to the caregiver/relatives.

> She went from a gourmet cook to an arsonist! My mother burnt everything. There are few incidents that stick out in my mind, like trying to make a meatloaf and forgetting to turn the oven on, or making a cake with salt instead of sugar […] My mother had turned on the stove, carefully folding a hand towel; she set it on the burner and placed a pot on top.

Now, as previously mentioned, IR chains of diverse EE shape the identities of those who engage in these rituals. A consequence of the patient's diminishing cognitive abilities - as they prevent him/her from performing in a way that has shaped his/her status and concept of self in a particular role - is that the willingness to engage in particular IR chains related to a specific role also decrease (Collins 1993, 2004). One significant reason for that is that face-to-face encounters extend the possibility that a distorted image that conflicts with the patient's self-concept is mirrored by others. Hence, in order to avoid this threat to his/her self, the patient's reject involvement in social gatherings and many times do so in ways that conflicts with social propriety norms (Goffman 1959). One example, as seen below, is not to attend a birthday party on the premise that you don't want to.

> Well, you know, my mother used to love cooking and was more than glad to cook dinner for the whole family… so we went to their place quite often. But that was also a thing that we noticed… that all of a sudden she didn't

> want to cook for us no more. She was like 'I'm not going to cook any dinner… you can eat at home and then come by later'. So like… those dinners that we had, well… they disappeared. And then… she stopped coming to birthday parties and etcetera… because she didn't want to come. And my dad wasn't allowed to go either… but he went anyway. But she didn't want to meet anyone and found it to be very unpleasant when people came over… And she has always been a very social person with lots of social relations… but the suddenly she did not want that anymore. It almost came to the point where me and my sister where no longer welcome… Eh… but we went anyway, even if she said we couldn't. [Authors trans.]

Since unruly behavior often is followed by social sanctions, people who are peripheral to the emotional centre where the solidarity with the patient is the strongest, may choose to exit the relationship (Collins 2004). Therefore the isolation of the patient's many times goes both ways. But as pointed out by Goffman, when an "individual intentionally or unintentionally breaks a rule of etiquette, others present may mobilize themselves to restore the ceremonial order" (Goffman 1957/1967:114). This engagement in reconstructing the common IR chains that the patient's either have rejected or no longer have the ability to partake in is also evident among the caregiver/relatives in the empirical material. The story below is an example of how this is done when the patient no longer has the ability to understand non-human objects in terms of their function.

> Her answering machine blinks that it has 14 messages, and I begin my weekly ritual of listening to them with her, then clearing them. She cannot remember the steps to listen to them on her own, so this ritual has becomes a part of our Sundays.

The example above shows how rituals function as attempts for the caregiver/relatives to reconnect the patient's to a social context of solidarity and intimacy. When the patient's long-term declarative memory eventually is severely affected by the illness, the meaning of these common objects and symbols used to recharge the emotional residues in a number of social contexts also vanish (Jahn 2013; Collins 1993, 2004). That way the common IR chains that has shaped the identities of both the patient's and the caregiver/relatives no longer can be recharged. The example below shows how such an attempt to relive a specific IR chain through a common symbol fails to evolve into the shared experience of emotional entrainment that the author had hoped for.

> This weekend I took my mother on a long anticipated trip to the Oregon Coast. We used to reside there when I was a child; when we moved away, every summer vacation was planned to return there. My love of the sandy beaches, treasures to find, and the calming effect of the ocean waves came from these very special memories. […] I was sure she would so enjoy getting out of her home and enjoy some fresh and reminiscing. Seeing the ocean beaches would calm her spirit and possibly bring back many great memories. I am sad to admit I think the trip actually gave her feelings of fear and anxiety more than happiness and joy. By the end of the trip, we were all quite exhausted and heavyhearted.

As the patient's no longer are able to recall the value of collective objects and symbols attached to IR chains that has shaped their identities, this loss of memory also entails an alienation from themselves as social beings of historical continuity (Polkinghorne 1995) Consequentially then, as the caregivers/relatives attempts to restore these IR chains become fruitless, they are also alienated from the patient. That way the desocialization of the patient's do not only imply a situational loss of self, as the ability of role taking no longer is possible, but eventually also deprive them of the ability to socially engage with others through common symbols as they lack the ability to place themselves in an historical context.

Sympathy and the renegotiation of emotional exchange
As the loss of these common symbols also implies a threat to the caregiver/relatives selves, sympathy-display, as an act to solidify the solidarity tie to the patient, also comes to unfold in a manner that reflects this condition. Now, as mentioned before, the social nature of sympathy-exchange is reciprocal (Clark 1997). This may also very well be common in the early stages of AD, as the patient might display sympathy towards those grieving his/her illness (Clark 1997). When the AD-patient no longer is capable to engage in this mutual social transaction though, the caregiver/relatives overinvestment in sympathy results in a renegotiation of the currencies in this exchange (Clark 1997). Here is an example of how this unfolds:

> Words of insult, of deep hurt come out of nowhere and in the presence of medical personnel and strangers – all directed at me, about me. I take it all knowing it is the disease and not the James that I used to know. I have learned to never question why he says the things he does to me […] I wait for the real friend to come out, even for a few moments. Then my joy is back as is my willingness to continue the support and care for my dear friend.

As seen above, the caregivers struggle to handle the patient's outbursts of aggression, which is a common neuropsychiatric symptom among AD-patients, has made her renegotiate his currency in exchange for sympathy (Lyketsos et al 2011). In separating the patient from the symptoms of the illness, the caregiver thus awaits for a moment in which the patient is able to verify her identity. This in return enables her to further display sympathy through care. Considering the patient's loss of the ability to focus attention towards mutual symbols and how this implies a threat to the caregiver/relatives selves, evidently this switch of currency may not come as a surprise. How emotionally painful this process is to the caregiver/relatives further becomes evident in the example below, were even the slightest sign of verification result in an emotional outburst.

> But this evening, this one evening, she did more than smile back and give me a kiss. This evening, for the first time in a very long time, she clapped her hands and said, "Mary". And then she smiled and that was it. Not another word. Just Mary. It was the last time I would hear my mother call out my name. How wonderful it sounded to my ears! And as gut-wrenching as it had felt years before when Mom didn't recognize me, it was somehow assuaged by how exhilarating this felt. She called out my name. And that moment lift-

ed me higher than you could imagine. Never would I have thought that there would come a day when something as simple as that would mean so much.

The importance of the patient's currency in this exchange becomes even more salient in the example below, where the patient has stopped to communicate and the caregiver/relative actively engage in creating significant symbols that verifies his/her identity in the relation:

> The secrets are housed deep within where even she cannot always find them. But when I bend low to hug her, our gazes meet, and I see the spark of recognition in her eyes, far back behind the foggy glaze of time. From that distant place, she looks right into me; right into my core, and she knows I am of her own blood.

Identity verification in all stages of AD thus becomes a way for the caregiver/relative to cling on to a form of joint symbol in the communication, even when the patient no longer is capable to communicate such symbols (Mead 1934; Collins 2005). Now, as mentioned earlier, failure to display sympathy tends to be followed by social sanctions. This is especially true of relationships like the one handled in this article, as there is a societal expectation that this kind of social bond is verified through acts and symbols of intimacy and solidarity. How this fear of not displaying enough sympathy affects caregivers/relatives becomes evident in the example below, where the mother no longer is able to partake in this emotional economy.

> She can't put words together anymore and can't talk. She smiles when she sees us, but doesn't even know she has children, except for her stuffed dog. It is depressing to visit her, but it's more depressing if I don't. She is too far away for me to visit often enough, especially with these gas prices. I volunteer at a nursing home near to me; working there makes me miss my mother.

These references to the distance she has to travel, the price for gas and her voluntary work at a nursing home, all exhibits an ambivalent approach to sympathy-display, as well as an anxiety that she doesn't display enough sympathy. Since identities form though mutual exchange of verification. The author further points out the distance between her mother and herself, through remarking on the fact that her mother no longer is capable of identifying her children, but is emotionally attached to a non-human object. Now, as seen in the first section of the analysis, identities are dependent on others interpretations. To circumvent the social sanctions imposed on someone who fails to display sympathy and to renegotiation the intimacy and solidarity in the relationship, the caregiver/relatives interpretative work then sometimes implies that all resemblance with the patient's identity prior to the illness is erased.

> **Interviewer:** Why do you think that is, I mean, that you haven't visited her?
>
> **Respondent:** Because I really don't want that picture in my head. I feel that… Well this is my strongest argument. I don't want that picture of my mom in my head… especially when they are feeding her. I mean, even if it is my mom who is sitting there… I feel like my mom died ten years ago…

> psychologically. Or, my *real* mom did. And it is that image I want to pre-
> serve, if you know what I mean, that image of the happy, positive mom that I
> used to have and not this one… who is really only a shell. Because it is that
> image I will keep for the rest of my life. But if I go there and I see how they
> feed her, I believe that it will be that picture that I get to keep… That *that*
> will be that last image. And that's not a very joyful one. [Authors trans.]

As seen in the example, the respondent no longer identifies the woman living in
the nursing home with his mother. To him, the illness has erased all signs of her
prior identity and to preserve the memory of her he has not visited in over a year.
None the less, it is defined as an "argument", which indicates how deeply rooted
the social sanctions are towards those who fail to display sympathy and the length
one might have to go in his/her interpretative work to avoid those sanctions.

The collapse of identities
In the last regressive stage of AD, although the patient's have already lost their
self-reflexive ability, a few symbols and objects that were charged up with high
EE prior to the illness can come to reflect a sense of self. In this stage though, the
patient's are no longer able to separate their understanding of themselves from the
object, instead they collapse their own identity with the object. Here is an exam-
ple:

> From our conversation, we knew that James still knows that the young man
> and woman in the pictures are he and his beloved. We sat and talked some
> more, and James put on a CD. James loves Sinatra, and so do I, so it was no
> surprise to me that the disc he played was of the young Frank with the
> Tommy Dorsey band. I commented, "Ahh, Sinatra" – at which point James
> went over to the dresser, and, pointing alternately to the CD player and the
> photograph of himself, protested, "That's me." It was obvious he had con-
> flated his own identity with the sound of Sinatra's voice in that period. Then
> a girl singer took over the vocals on the track we were hearing, and I recog-
> nized her as Connie Haines. So I said so, and James again disagreed strong-
> ly, going back to the double-frame and pointing to his young bride, saying,
> "That's her." Somehow, he was able to hold two ideas in his head at the
> same time. He knew that the photograph were of him and his wife. But he
> also "knew", just as certainly, that the photographs were of the singers on
> the CD, the singers making the music that meant so much to him.

In the example James is no longer able to separate himself and his wife at a young
age from the music that was charged up with EE at the time they used listen to it.
To him, the photography and the music, as objects linked together through EE,
become one and the same. Since it's them in the picture then they must be the
ones creating the the music, as these objects are attached to each other.

   When the patients collapse their identities in the last stages of AD they also
tend to move in and out of roles attached to the few symbols or objects that still
spark emotional residues. A grandmother in the empirical material starts to worry
about the chickens that she used to have as a little girl, while another is convinced
that her daughter is her mother and so on. Eventually though, the illness takes
away that ability too, but long before that the patient is found in a desocialized
state.

CONCLUSION & FURTHER RESEARCH

In approaching the degenerative stages of AD as a process of desocialization, this article has presented a new interpretative frame, based on social psychology, to an already established body of research within the fields of neuroscience. In exploring how identity and emotional exchange is contested and transformed throughout this neurodegenerative process, this article has shown how identities, as specific patterns of action, are dependent on the normative order that frames the socialized body. On the first level of this process, the analysis showed how the patient's ability to do role taking cease when the loss of short-term working memory increase and they no longer are able to remember their own actions. As this implies that the patients are deprived of their ability of self-reflexivity, this consequentially results in a loss of self. The analysis further demonstrated how the patient's diminishing long-term declarative memory implies a loss of the ability to place themselves in a social context and understand themselves as beings of historical continuity, as they no longer are able remember the collective symbols that has shaped their identities. Because these symbols and objects are used to recharge the EE of solidarity and intimacy between the patient and caregiver/relatives, it also showed how this entails a threat to caregiver/relatives selves. Finally, on this level of the analysis, it was demonstrated how the patients eventually collapse their identities and tend to act out roles that are attached to the few symbols and objects that still spark emotional residues. On the second level, the analysis showed how the patient's diminishing procedural memory, which affects the patterns of actions related to a role, comes to contest their status and concept of self when the caregiver/relatives no longer are able to verify them in that role. It further showed how this threat to the patient's concept of self in face-to-face encounters eventually lead them to avoid involvement in common IRs, and how this rejection implies a threat to the caregiver/relatives selves. It further displayed how common symbols and objects are used by the caregiver/relatives to repeatedly reestablish the solidarity ties with the patient. And how this threat to the caregiver/relatives own selves, as well as their overinvestment in sympathy-giving, drives them to renegotiate the currencies in this reciprocal exchange through trading sympathy for identity verification. Finally, it showed how caregivers/relatives, in order to avoid social sanctions for neglecting to display sympathy, need to renegotiate their relationship to the patient in a fundamental way.

Thus, based on social psychology and rooted in a thoroughly mapped out body of research within the fields of neuroscience, this article has presented a new way of understanding the degenerative phases of AD as a process of desocialization. A perspective that further enables us to understand what becomes of the socialized body as it regress into a desocialized states. And how this illness impacts the intricate micro-elements of social interplay, as it contests and transform identities and emotional exchange.

This further poses a number of questions for future research. One of these questions that have occupied my mind during the process of research has been whether or not someone who severely diverges from the normative patterns that frames the socialized body can possess any other identity than their deviating traits? In *Stigma* (1963) Goffman explores a number of ways that the deviator might tackle his/her deviation, but most of these are conscious decisions. As seen

in the analysis above though, as the patients cognitive abilities diminish his/her identity tends to solemnly become the interpretative work of others. As this interpretation is further rooted in the limited numbers of faces one can claim for him- or herself, someone who does not have the ability to act according to these given normative patterns also seem unable to possess an identity. This reasoning further seem relevant if one views how characters that do not reflect able-bodiedness tend to be portrayed in popular culture through either otherworldly traits or savant-like abilities. To mention a few portraits that establishes this way of identifying the deviators personality through further deviation there is the Oscar award winning motion pictures *Rain Man* and *Forrest Gump*, as well as the award winning novels *April Witch* (1997) by Majgull Axelsson, *Perfume: the story of a murderer* (1986) by Patrick Suskind and *Horrific sufferings of the mind-reading monster Hercule Barefoot: his wonderful love and his terrible hatred* (2002) by Carl-Johan Vallgren. One relevant subject for future research is thus to explore how the mythological discourse surrounding those who do not reflect an able-bodied behavior is constituted and what becomes of those who diverge from the behavioral patterns of normative identity.

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