

Illumination of Shadowing Behavior in Individuals with Alzheimer's Disease: Proximity-Seeking? As Life Becomes the "Strange Situation"

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Citation

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Abstract

The purpose of this paper is to suggest an intrapersonal help for caregivers through proposing a model for understanding shadowing behavior. This model is based on Bowlby's (1973) discussion of attachment and related concepts such as proximity-seeking, the "strange situation", and the secure base. Building on Bowlby's discussion, Mikulincer and Shaver (2008) developed a visual representation of the dynamics of adult attachment, herein modified and explicated according to its proposed relationship to caregivers and care recipients living with Alzheimer's disease. A potential underlying brain-based rationale, is also presented

INTRODUCTION

Certain behaviors exhibited by an individual with Alzheimer's disease can be particularly difficult for a caregiver to tolerate, including repetitive questioning, hiding objects, and shadowing. Shadowing, a common behavioral symptom in Alzheimer's disease, is associated with increased caregiver stress (Cummings, 2005; Fauth, Zarit, Femia, Hofer, & Stephens, 2006; Gitlin, Winter, Burke, Chernett, Dennis, & Hauck, 2008; Kasl-Godley & Gatz, 2000; Nichols, Martindale-Adams, Greene, Burns, Graney, & Lummus, 2009). Shadowing refers to the close following of another individual (Brodaty, Draper, Low, 2003); and in the dementia caregiving situation, this usually means a spouse, adult child, other close family member or friend.

Specifying the incidence and prevalence of shadowing behavior within the family caregiving setting is problematic, presumably due to grouping and reporting of shadowing information within categories such as the Anxiety Subscale of the Neuropsychiatric Inventory (NPI) (Cummings, Mega, Gray, Rosenberg-Thompson, Carusi, & Gornbein, 1994), or the Revised Memory and Behavior Problems Checklist (Teri, Truax, Logsdon, Uomoto, Zarit, Vitaliano, 1992), or possibly through failure to capture "other" response categories added to existing measures (Gitlin, Winter, Burke, Chernett, Dennis & Hauck, 2008; Gitlin, Winter, Corcoran, Dennis, Schinfeld, & Hauck, 2003). However, significant

dementia stage-related differences in caregivers requests for behavioral management information were identified by Nichols, Martindale-Adams, Greene, Burns, Graney, and Lummus (2009) in their secondary analysis of data from a primary care-based psychoeducational intervention (Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003). The researchers reported that caregivers for individuals with mild dementia were more likely to request a pamphlet about shadowing (16.2%), as compared to caregivers for individuals with moderate or severe dementia (5.9%). During the primary care intervention study, behavior management pamphlets on various topics, including shadowing, were provided to caregivers depending problem behaviors identified by the caregiver. However, no definition or measure of shadowing was found in the primary intervention report or secondary analysis.

A robust proxy measure for shadowing is located on the Anxiety Subscale of The Neuropsychiatric Inventory (NPI) (Cummings, Mega, Gray, Rosenberg-Thompson, Carusi, & Gornbein, 1994), a widely implemented, standardized measure of non-cognitive symptoms in dementia. Specifically, the Anxiety Subscale of the NPI queries as to whether or not the care recipient exhibits fear of being away from the caregiver, or displays nervousness about being separated from the caregiver. Research has demonstrated an inverse relationship between Mini Mental Status Exam

Illumination of Shadowing Behavior in Individuals with Alzheimer's Disease: Proximity-Seeking? As Life Becomes the "Strange Situation"

(MMSE) results (Porter, Buxton, Fairbanks, Strickland, O'Connor, Rosenberg-Thompson, & Cummings (2003) and Clinical Dementia Rating (CDR) (Fuh, Wang, & Cummings (2005), and scores on the Anxiety Subscale of the NPI, indicating an increase in anxiety symptoms, including shadowing with declining cognitive function. Further, Steinberg, Shao, Zandi, Lyketsos, Welsh-Bohmer, Norton, Breitner, Steffens, Tschang, and the Cache County Investigators (2008) reported a point prevalence of NPI-assessed anxiety symptoms, including shadowing behaviors, of 14.1% at baseline with a 5-year cumulative prevalence of 62%. Anxiety symptoms were the third most prevalent in the Steinberg et al., study, following depression and apathy symptoms. Combined, these results provide useful, although imprecise information concerning shadowing behavior in individuals with Alzheimer's disease or a related dementia.

Anecdotal caregiver comments gleaned from research and clinical settings enriches the description of what is known about shadowing behavior. Examples of anecdotal comments include, "if I leave the room, immediately, she calls out", "he sticks to me like glue", and "there's never a moment to myself, not for a bath, not even to go to the bathroom". Comments like, "she stands right there the whole time I'm talking on the phone"; and "Daycare didn't work, he got so upset and tried to open the doors to come after me; it's not worth it", point to difficulties that some caregivers may experience, related to maintaining outside contacts, doing business, or attempting to utilize respite services. Caregivers continue to document the nature and experience of shadowing in vivid detail, communicating with online contacts, both seeking and offering information and support about shadowing behavior (ADEAR, 2009; Alzheimer's Association Online Community, 2011).

While shadowing behavior may be understandable, given the care recipient's increasing levels of dependency, it can be an interruption of other activities, and a hindrance to privacy, as the above examples and online postings illustrate (Alzheimer's Association Online Community, 2011). On a deeper level, shadowing behavior is a persistent reminder of the illness and accompanying losses. The nearly constant shadowing or following by the care recipient, may be episodically difficult for caregivers, and for some a source of sustained emotional distress, which may manifest in many ways including anger. Acceptance and successful management of the behavior may be more or less difficult depending on a number of variables, including the history

and ongoing nature of the caregiver and care recipient relationship, caregiver knowledge of the illness, caregiver depression, fatigue, or illness, and perceived social support (Alzheimer's Association Online Community, 2011; Ingebretsen & Solem, 1998).

The purpose of this paper is to suggest an intrapersonal help for caregivers through proposing a model for understanding shadowing behavior. This model is based on Bowlby's (1973) discussion of attachment and related concepts such as proximity-seeking, the "strange situation", and the secure base. Building on Bowlby's discussion, Mikulincer and Shaver (2008) developed a visual representation of the dynamics of adult attachment, herein modified and explicated according to its proposed relationship to caregivers and care recipients living with Alzheimer's disease. A potential underlying brain-based rationale, is also presented (see Figure 1).

Figure 1

Figure 1: Proximity-seeking model, modified

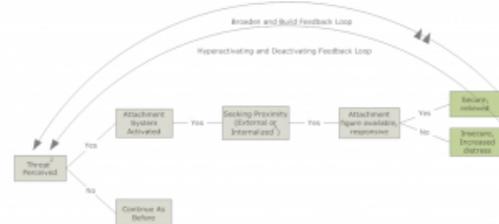


Figure 1 Mikulincer & Shaver Attachment Model, Modified for Individuals with Alzheimer's Disease¹

¹ Mikulincer, H., & Shaver, P. (2007). Adult attachment and affect regulation. In J. Cassidy and P. Shaver (Eds.), *Handbook of Attachment* (2nd ed., pp. 503-531). New York: The Guilford Press.

² Almost continuous in individuals with Alzheimer's disease, particularly by middle stage
Ability of individual with Alzheimer's disease to maintain intermodal attachment figure is uncertain
#Dashed lines denote breaks in care recipient ability to broaden and build

BACKGROUND

Clearly caregiving for a person with Alzheimer's disease is a different experience from parenting a toddler; yet shadowing behavior has noticeable similarities to the proximity-seeking behavior seen in toddlers. Viewed from a caregiver response perspective, the "natural" behavioral pattern is positively biased toward the very young human; it being well-established that certain physical characteristics of the infant, toddler, and even preschooler make their following and calling out behaviors easier to accept and respond to in a caring manner (Kringelbach, Lehtonen, Squire, Harvey, Craske, Holliday, Green, Aziz, Hansen, Cornelissen, & Stein, 2008; Lishner, Ocejka, Stocks, & Zaspel, 2008). In general, adults are not expecting to respond to these types of proximity-seeking behaviors in older adults, and this creates emotional distress for both individuals. At the same time, in our youth-oriented society, it is not uncommon for the mere

appearance and behavior of old age to elicit fear, disgust, or at least ambivalence; all clearly avoidance and non-caring behaviors (McHugh, 2003; Nelson, 2005). However, for the dependent young or old, there is no doubt that the explanations for both caregiver and care recipient behaviors are complex, interacting, and related to survival.

Anger or frustration is a caregiver response behavior that is often elicited in the instance of shadowing by an elderly care recipient with Alzheimer's disease or a related disorder (Ingebretsen & Solem, 1998). One can surmise that this response is due to a cognitive and emotional mindset different from the mindset operating in the typical parent-child attachment scenario; and therein rests an opportunity for both caregiver and care recipient. Mindset, as proposed by Bar (2009), refers to a state of cognitive activation resulting from exposure to an environmental cue that prompts associative activations related to the cue. Mindsets guide behavior through promoting the cognitive, behavioral, and action tendencies that are consistent with contextual requirements. In other words, mindset reduces the effort and attention needed for a particular set of environmental cues by providing a 'top-down' set of predictions based on prior experiences with similar cues, to inform the new experience. When the 'bottom up' information, meaning the information emerging from the new scenario fails to meet expectations, attention must be reallocated to answer the brain's question, "what is this like?" (Bar, 2009). Fortunately, mindset can be altered as events unfold, as information is updated, and even by imagined experience such as simulations. It follows then, that outdated caregiver mindsets related to interactions with the care recipient can be updated and enhanced through various types of learning experiences. If caregivers for individuals with Alzheimer's disease understand the neurological basis for the shadowing behavior, and are motivated to alter their own emotional and behavioral responses, it is possible that caregivers could select a more appropriate and comforting response to the person with dementia. It is likely that the caregivers more appropriate response will be reinforced by the care recipient's positive behavior, and a positive feedback cycle will replace the previous negative cycle. Applying Bar's (2009) notion of mindset to the caregiver for a person with Alzheimer's disease, gives rise to the opportunity for a targeted intervention aimed at altering the caregiver's care recipient related mindsets that are outdated by virtue of the disease progression. Eventual testing of this model will demonstrate whether or not knowledge combined with behavioral

coaching and other intervention strategies can improve outcomes for caregivers and care recipients.

DATA SOURCES

This manuscript was written using articles searched between January 2010 and February 2011 on Ovid Medline, PsychInfo and CINAHL databases. Inclusion criteria were for publications between 1973 to the present, written in the English language, and with a preference for articles with links to full text. Exclusion criteria were papers focused on formal or institutional caregiving, wandering, wayfinding, pacing, elopement, and getting lost. Key words included shadowing, following, Alzheimer's disease, attachment, attachment theory, caregiving, orbitofrontal, orbitofrontal system, proximity-seeking, and mindset. Titles/abstracts were reviewed for relevance, with reading of the full text for those articles deemed relevant to the present discussion. Additional literature was accessed from references provided in articles deemed relevant.

ATTACHMENT THEORY

Bowlby (1973) noted that human beings tend to be fearful in a number of situations including being alone or in the dark, being with strangers or strange animals, experiencing the rapid approach of others, and hearing loud noises. He further articulated that the fear of unwilling separation from one's attachment figure, at any age or stage of life, is an instinctive response based on awareness of increased danger and risk to survival. Along similar lines, Klin, Jones, Schultz, and Volkman (2003) emphasized that the somatosensory apparatus of human beings continuously seeks salient aspects of the environment, particularly those aspects with survival value. It follows that the location and status of kin or caregivers would have a high degree of salience, as compared to competing information about non-kin or inanimate environmental objects.

Healthy attachment dynamics, which do not operate at a conscious level of awareness, reflect an interaction between "psychobiologically attuned organisms" (Schore, 2000, p. 34). In the prototypical infant-mother dyad this attunement allows for the rapid transmission of prosodic-auditory, visual, and gestural information included in the exchange between the two faces and beings, and in this exchange the caregiver serves as a regulator of the infant's arousal level. As a regulator of arousal and soother of stressful negative emotion, the caregiver affects the direction of energy consumption, determining where valuable energy will be

expended in the biosynthetic process. In a similar manner, according to Bowlby (1973), each person across her or his lifespan continues to benefit when life is organized around the secure base of an attachment figure; even though the appearance of the bond, and reciprocity expectations vary significantly from those observed between mother and infant. In fact, from toddlerhood forward, the maturing child and eventual adult, is increasingly encouraged and expected to manage their anxiety and fear with internal representations of mother and home, as well as institutional substitutes like teachers, and later romantic partners and platonic friends for several hours a day, and longer. In all but extreme cases, i.e., war trauma where there is threat to life or bodily integrity, vocal calls for mother or any attachment figure, would be considered highly unusual in mature, healthy adults.

A MODEL OF ATTACHMENT

Mikulincer and Shaver's (2007) model of attachment system activation and functioning in adults assumes cognitively intact individuals, and integrates conceptualizations developed by Bowlby, Ainsworth, Main and others (see Figure 1). These earlier conceptualizations proposed a universally present attachment system, activated automatically in the presence of perceived threat, in order to ensure survival by first eliciting behaviors to attract the caregiver to the infant's side; and once the infant achieved mobility, causing the infant to seek proximity to the caregiver. Mikulincer and Shaver's model is characterized by three components that capture the basic points contained in the earlier conceptualizations. Each component involves monitoring and appraisal by the individual perceiving threat; a process that may occur at an unconscious level. Monitoring and appraisal of threatening events occurs initially, followed by monitoring and appraisal of availability and responsiveness of the attachment figure; and finally, monitoring and appraisal of the utility of proximity-seeking as a coping strategy occurs (see Figure 1). The model allows for seeking proximity to an internalized attachment figure. Further the researchers note that over time an individual's feelings of security can be enhanced or eroded by experience and learning, through engagement with caregivers or attachment figures of varying degrees of responsiveness and availability. Erosion of security by various means can lead to additional behaviors, like hyperactivation or deactivation of proximity-seeking, based on utility beliefs and prior reinforcement.

Due to the effects of neurodegeneration on memory and emotion, Mikulincer and Shaver's model is modified, simplified in the sense of eliminating feedback, and clarified as to the proposed relationship to individuals with Alzheimer's disease (see hatchmarks and notes to Figure 1). For these individuals, threat perception occurs regularly, frequently, and unpredictably even in familiar environments, and in the presence of familiar persons, particularly when the primary caregiver leaves the line of sight (Seignourel, Kunik, Snow, Wilson, Stanley, 2008)(see Table 1).

Table 1: A Caregiver's Story

I did my best to spend every moment with my mom because I knew our moments together would end too soon. As my mother's Alzheimer's progressed, I noticed her need to be with me increased. By the time she entered the middle stage, we saw the need for my family and I to move in with my parents. My dad still went to the office everyday and my sister Linda would come over and spend everyday with mom and I. It may not take a village to care for a loved one battling Alzheimer's, but it does take a small devoted core of people who really care.

We started everyday with our coffee and sourdough bread toast, a daily ritual of Mother's for well over twenty years. She loved to laugh, so we would then watch a comedy on the Lifetime for Women network as background to this morning regimen. Soon after, we would get dressed and I would help her with her jewelry and makeup. I believe that she not only loved the intimacy and attention, but that it was also reassuring for her to feel she was preparing herself for something. After all, as the consummate Southern Lady, Mother never wanted to be seen "undone."

Next we would return to our chairs and another of her favorite TV shows, while she "read the paper." The ability to read had long gone from her life, but holding on to the routines of life reassured her. She dwelled on every page, occasionally sharing a picture that caught her eye.

I would get up and excuse myself to get dressed and she would smile and nod in agreement. So I walked into my closet to choose my attire for the day, I would hear her entering my room, looking for me. She would offer an excuse for following me or ask a question. Of course she didn't need an excuse or question. I could see the look of fear on her face. She wanted to be there with me and I wanted to have her close.

That need for reassurance drove Mother to take every step I did. She followed me everywhere. As hard as it is to watch your loved one decline so rapidly, that was trumped by the need to keep her feeling safe. Now that Mother is no longer with us, I find myself reliving & cherishing many of our moments together. Hearing her footsteps following me or just one more silly question or excuse would be a precious gift.

Now, as I go about my life, I catch my heart shadowing my mother, trying to walk just a few more steps with her, wanting to watch just one more silly sitcom. Since I spend time coaching other newer caregivers, shadowing is something that we talk about often. I try to tell these new caregivers to see the joy in it, to understand that something as simple as allowing a loved one to follow your steps can be more precious than gold or fine jewelry. It's a good thing, a gift that will live in your memory a long long time.

Usually the primary caregiver is a spouse or adult child when a person is affected with Alzheimer's disease or a related disorder. Much like an infant or toddler noting the absence of mother, when the person with Alzheimer's disease or a related disorder misses their caregiver, that stimulus alone is sufficient to activate the attachment system. Typically, verbal queries will begin shortly after the caregiver is noted to be missing, restlessness will ensue, and locomotion will follow as the individual attempts to find their caregiver. However, individuals with Alzheimer's disease and related disorders are unlikely to make use of an internalized attachment figure, as noted in the original model. The question of whether or not an individual with Alzheimer's disease or a related disorder maintains any "dispositional sense of felt security" (Mikulincer & Shaver, p. 505), is not perfectly clear. Also, Alzheimer's afflicted individuals with increased right-sided frontal activation may be more susceptible to fear conditioning. Such a scenario might be likened to a dispositional insecurity. It seems likely that dispositional characteristics, reinforced over thousands of experiences with attachment figures, would be retained to some degree; in the same way that personality traits are observable and identifiable over the course of the illness by spouses, family members, and friends. However, the feedback loop starting at "Security, relieved" and "Insecure, Increased distress", and depicted as feeding back into a "Broaden-and-Build Cycle" or a "Hyperactivating and Deactivating Cycle" (see Figure 1), and then back again into Threat Perceived, indicates that positive attachment

experiences will build a repertoire of positive representations to be accessed during future threat scenarios. In an individual afflicted with Alzheimer's disease, these representations are unlikely to be stored for future access due to the nature of the disorder.

BRAIN-BASED CHANGES IN ALZHEIMER'S DISEASE

Overview. In individuals with Alzheimer's disease, a fairly predictable pattern of neurodegeneration occurs, progressing over a period of years. This degeneration affects "local" activity and overall integration of brain networks (He, Chen, Evans, 2008). Brain changes involve volume loss of gray and white matter, temporoparietal cortical hypometabolism, and the accumulation of amyloid plaques and neurofibrillary tangles (Frisoni, Fox, Jack, Scheltens, & Thomson, 2010; Mosconi, Berti, Glodzik, Pupi, De Santi, & de Leon, 2010). Currently it is not possible to state the exact relationship between anatomic and functional data, however certain details are known. For example, from the earliest evidence of symptoms, gray matter atrophy is present in the precuneus, cingulate, and retrosplenial cortex. Gray matter loss is also present in the posterior parietal and medial temporal areas (Buckner, 2004). Brain regions experiencing the greatest changes are the temporal lobes and limbic area, including the perirhinal and entorhinal cortices and hippocampus. Temporal lobe pathology implicates recent and remote memory impairment, including autobiographical memory. (Damasio, 1999; Van Hoesen, Parvizi, Chu, 2000). Alzheimer's disease related changes in orbitofrontal areas at autopsy, are greater in the posterior and medial dysgranular areas as compared to the anterior and medial granular areas. Neurons in the posterior and medial dysgranular area have important connections to other brain structures like the nucleus accumbens and amygdala (Van Hoesen, Parvizi, & Chu, 2000). These areas are implicated in affective reactivity, emotion regulation, and reward (Davidson, 2004).

Serotonin. Serotonin (5-hydroxytryptamine, 5-HT) is involved in multiple functions within the central nervous system, intestinal processes, and others (Murphy, Fox, Timpano, Moya, Ren-Patterson, Andrews, Holmes, Lesch, & Wendland, 2008). Further, the human serotonin transporter is responsible for removal of serotonin from the extracellular space (Rasmussen and Werge, 2007). Genetic variation has been documented in the serotonin transporter gene (SLC6A4) with specific attention to the promoter region (5-HTTLPR). Multiple alleles have been identified within the

promoter region, consisting of 14 (short, S) and 16 (long, L) basic units, as well as, more rare alleles of differing units (Michaelovsky et al., 1999; Frisch et al., 2000; Nakamura et al., 2000). Additional variation is produced by single nucleotide polymorphisms (SNP's), resulting in S_A, S_G, L_A, and L_G alleles (Nakamura et al., 2000). The S_A allele modulates activity of the promoter, resulting in a change of serotonin reuptake (Hu et al., 2005; Kraft et al., 2005). A significant relationship existed between the 5-HTTLPR short allele and activation of the amygdala in individuals with a personality style characterized by rapid, intense, and automatic emotional processing; as compared to individuals with an alternate personality style characterized by slower, less intense, and more reflective emotional processing (Bertolino et al., 2005). Related studies found significant risk for unresolved attachment in individuals with the less efficient short allele of the transporter. The researchers proposed the serotonin transporter short allele as a possible factor impacting the interconnectivity of the amygdala and prefrontal areas, important in emotional regulation, and by that route affecting attachment (Caspers et al., 2009). It may be that for susceptible individuals, specifically those having greater right-sided frontal activation, fear conditioning could provide a partial explanation for the efforts of care recipients to avoid loss of proximity. Recent investigations of the serotonin transporter lend some support to this hypothesis.

Amygdala. Another possibility is that the caregiver remains an unambiguous, familiar, foreground contextual stimulus for the care recipient until late in the disease process. Therefore, loss of sight of the caregiver elicits a fear reaction because other contextual stimuli no longer afford meaningful information, due to disease process and fading or loss of prior cognitive representations or associations. In this situation, the care recipient is unable to understand or predict what may happen, what he or she is supposed to do, and where he or she is located, based on incoming stimuli. This level of ambiguity is likely to be perceived as "threat", regardless of genotype, via automatic processing through the amygdala, and to trigger a negative autonomic reaction, along with other responses that the care recipient is no longer able to modulate, due to cortical dysfunction (Critchley, Mathias, & Dolan, 2002). As noted by Bowlby the proximity-seeking behaviors are not planned or thoughtful, but are instinctive responses to some sort of environmentally perceived threat, and their underlying purpose is survival (Bowlby, 1984). Schore (2000) proposed the orbitofrontal system as the neural substrate for these

survival responses.

Orbitofrontal. Schore (2000) suggested the right orbitofrontal system as the storage area for one's earliest models of attachment. This area is responsible for monitoring, on a moment-to-moment basis, the emotional significance of external stimuli, adjusting emotional responses, and modulating goal-directed behavior. Schore notes,

the orbitofrontal system is also deeply connected into the autonomic nervous system and the arousal-generating reticular formation, . . . The activity of this frontolimbic system is therefore critical to the modulation of social and emotional behaviors and the homeostatic regulation of body and motivational states, affect-regulating functions that are centrally involved in attachment processes.

In early Alzheimer's disease the orbitofrontal cortex is less affected by pathological changes as compared to the temporal lobe and hippocampus (Frisoni, Fox, Jack, Scheltens, & Thompson, 2010; Shiino, Watanabe, Maeda, Kotani, Akiguchi, & Matsuda, 2006; Zakzanis, Graham, & Campbell, 2003). The orbitofrontal cortex (OFC) is located in the ventral section of the frontal lobe. This area integrates reward and sensory information through connections with the limbic system (hippocampus, amygdala, cingulate) and various sensory elements. Significantly, Lemche et al., (2006) reported bilateral amygdalar activation to a subliminally presented negative attachment stress prime, in their study of 12 healthy young adults. The researchers further stated that significant positive correlations were found between the magnitude of amygdalar activation, and level of attachment insecurity and autonomic activation. Lemche et al., encouraged exploration of the linkage of their findings with animal and human studies on the role of oxytocin in maternal care, and the abundance of oxytocin receptors in amygdalar tissue.

Motor and autonomic function are also influenced through OFC connections with other structures including the nucleus accumbens, hypothalamus, and periaqueductal gray matter (Wallis, 2007). The anterior insular cortex (AIC), a structure bordering the OFC, may have an important role in individual maintenance of both self and other awareness (Craig, 2009), and is therefore of interest to the current discussion. Kringlebach (2005) referred to the OFC as a "gateway to subjective conscious experience" (p. 699), with an important role in assessing the emotional valence of environmental

events.

The information presented in this section allows for the possibility that survival-based attachment behaviors like proximity-seeking, may originate in the orbitofrontal cortex. As Alzheimer's disease progresses, and even when the care recipient no longer recognizes a spouse or adult child as being related, it is possible that pre-conscious information about these primary attachment figures is activated by the still intact instinct for survival. The care recipient's emphatic unwillingness to be separated from their primary caregiver is every bit as convincing as the young child clinging to their mother "as if for dear life".

DISCUSSION AND RECOMMENDATIONS

Interventions for managing shadowing, or proximity-seeking, have met with varying success. Tested approaches include providing information (Nichols et al, 2009), using reassurance or a distraction (Brodaty, Draper, & Low, 2003), and implementing a planned, tailored activity (Gitlin et al., 2008). Gitlin et al., hypothesized that their community-focused, individualized, activity intervention reduced shadowing and other behaviors through building on preserved care recipient abilities, including matching to prior habits, roles, and interests. The researchers also provided teaching instruction and stress reduction techniques to caregivers with emphasis on modifying and simplifying prescribed activities in response to expected future declines. The researchers speculated that care recipients responded positively to the individually tailored intervention because the activities allowed for enhanced role identity, an important aspect of selfhood, and for the productive use of time. Central values demonstrated by the tailored intervention approach were to avoid care recipient overload through task and environmental simplification, and to engage the caregiver through education, training, support, and positive care recipient outcomes.

In a related approach, Buckwalter et al., (1999) and Smith, Gerdner, Hall, and Buckwalter (2004) implemented a psychoeducational intervention for caregivers through presentation of the Progressively Lowered Stress Threshold model, followed by individual assessment of caregiver reported care recipient behavioral symptoms, and development of tailored interventions based on concepts and propositions flowing from the model. In the Buckwalter et al., intervention researchers demonstrated the effectiveness of teaching caregivers about disease-based changes in care recipients' ability to tolerate stress, and the particular nature

of the stressors, including fatigue. Further, the researchers identified care recipient behaviors likely to result from sustained or overwhelming exposure to stress, and proposed theory-based caregiver and environmental alterations needed to accommodate the disease-based changes.

An underlying assumption of interventions with a psychoeducational component, like the Tailored Activity Program TAP and the PLST training, is that caregivers will be motivated, and have the capacity, to learn and apply the concepts and propositions within the model (Smith, Gerdner, Hall, & Buckwalter, 2004). This assumption rests in learning theory and related knowledge from the social sciences. Findings from the TPA and PLST interventions confirm the correctness of this underlying assumption, and also provide support for the development of additional interventions using theory and models to illustrate and discuss underlying processes about a given phenomenon. The principles are as follows: to the degree possible, researchers and clinicians should provide a research-based account of the phenomenon of interest, like shadowing, and link the account to "usual experience" to strengthen learning through association. Then, a detailed description of caregiver, care recipient and environmental conditions most likely to result in minimizing deviations from "usual" must be carefully scaffolded to the care recipient's particular history and behavior symptoms. Finally, periodic reinforcement of model application through follow-up visits, telephone calls, groups meetings or televisits is needed to counteract a natural tendency to return to "standard operating procedures" (SOPs) for interacting with another human being. Importantly, these SOPs may vary from couple to couple, family to family, and culture to culture, but application of the principle is consistent.

Based on currently available information, the concepts and propositions of human attachment theory, combined with knowledge about the structure and function of the normal and degenerating brain, hold promise for the design of psychoeducational interventions aimed at equipping caregivers to interact effectively with care recipients who shadow. Specifically, such interventions would include a) basic information about the automatic nature of the threat response and survival behavior, b) general information about neurodegeneration, and the progressive loss of important brain-based associations, c) specific information about how loss of brain-based associations increases the difficulty of the care recipient in interpreting environmental stimuli, d) theory based information, through application of the

proximity-seeking concept to shadowing behavior, and e) intersubjective information specifying how, for the care recipient, all places may seem like Ainsworth and Bell's "strange situation" (Ainsworth & Bell, 1971). An additional experiential component of such an intervention could illustrate the pervasiveness and inflexibility of human expectations for social behavior, as well as the difficulty in "over-riding" those expectations when interacting with an individual who has adult physical characteristics, even if they are functioning at a much lower level. Finally, caregivers with varying perspectives could serve as peer interveners, sharing stories and experiences, providing assistance in reframing the meaning of shadowing behavior, and exploring alternative emotional and behavioral responses to shadowing (see Table 1). Research is needed to examine the effects of peer interveners engaged in story sharing and problem solving with other caregivers, whether by face to face communication, books and other written materials, media like video and CDs, or social networking via blogs, online forums, and other online offerings.

Post intervention journaling is another activity with the potential to facilitate caregiver reflection and changes in mind-set. Through journaling about the details of the day-to-day passing of time in the company of an individual suffering from Alzheimer's disease, the caregiver may arrive at important personal and interpersonal realizations. A Caregiver's Story (see Table 1) also suggests that journaling could be a means of preserving personal, poignant, and humorous memories of times spent with a loved one, to be treasured, shared, consulted, and revisited over time.

IMPLICATIONS FOR NURSING AND OTHER DISCIPLINES

This paper contributes to the field of neurology by setting forth a plausible, theory-based rationale for shadowing behavior, by providing research-based examples of interventions for caregiver education, and by suggesting avenues for future research. Further research is needed to understand the overall complexity of the brain, as well as pathways and mechanisms underlying a specific behavior, such as shadowing. A combination of genetic, imaging, and observational data, best gathered in the context of an interdisciplinary research team, is likely to yield the richest results. Further depth would be achieved by capturing caregiver and care recipient context via unobtrusive video and GPS technology. Implementation and assessment of interventions would also benefit from technological infusion.

At this moment, we are far from understanding simple behavioral symptoms and their impact on caregiver and care recipient well-being. However, employing the full complement of current resources, along with interdisciplinary synergy, could inform many of Bowlby's unanswered questions and musings.

References

- r-0. Alzheimer's Disease Education and Referral Center (ADEAR). (2009). Challenging behaviors: Special issues for family care. Accessed on 2/8/10 @ <http://www.nia.nih.gov/nia.nih.gov/Templates/ADEARCommon/ADEARCCCommonPage.asp>
- r-1. Ainsworth, M., & Bell, S., (1971). Attachment, exploration, and separation: Illustrated by the behavior of one-year-olds in a strange situation. *Child Development*, 41(1), 49-67. Accessed 2/8/10 @ <http://222.jstor.org/stable/1127388>
- r-2. Alzheimer's Association Online Community. (2011). What are your experiences with shadowing? Message Boards Forum Index. <http://alzheimers.infopop.cc/eve/forums/a/tpc/f/214102241/m/2721062012>
- r-3. Bar, M. (2009). The proactive brain: memory for predictions. *Philosophical Transactions of the Royal Society B*, 364, 1235-1243.
- r-4. Bertolino, A., Arciero, G., Rubino, V., Latorre, V., DeCandia, M., Mazzola, V., Blasi, G., Caforio, G., Hariri, A., Kolachana, B., Nardini, M., Weinberger, D., & Scarabino, T. (2005). Variation of human amygdala response during threatening stimuli as a function of 5-HTTLPR genotype and personality style. *Biological Psychiatry*, 57, 1517-1525.
- r-6. Bowlby, J. (1984). Psychoanalysis as a natural science. *Psychoanalytic Psychology*, 1(1), 7-21.
- r-7. Bowlby, J. (1973). *Separation: Anxiety and anger*. [Vol II of Bowlby's Attachment and Loss Trilogy] New York: Basic Books.
- r-8. Brodaty, H., Draper, B., & Low, L. (2003). Behavioral and psychological symptoms of dementia: A seven-tiered model of service delivery. *MJA*, 178, 231-234.
- r-9. Buckner, R. (2004). Memory and executive function in aging and AD: Multiple factors that caused decline and reserve factors that compensate. *Neuron*, 44, 195-208.
- r-10. Buckwalter, K., Gerdner, L., Kohout, F., Hall, G., Kelly, A., Richards, B., Sime, M. (1999). A nursing intervention to decrease depression in family caregivers of persons with dementia. *Archives of Psychiatric Nursing*, 13(2), 80-88.
- r-11. Caspers, K., Paradiso, S., Yucuis, R., Troutman, B., Arndt, S., Philibert, R. (2009). Association between the serotonin transporter promoter polymorphism (5-HTTLPR) and adult unresolved attachment. *Developmental Psychology*, 45(1), 64-76.
- r-12. Craig, A. (2009). How do you feel—now? The anterior insula and human awareness. *Nature Reviews Neuroscience*, 10, 59-70.
- r-13. Cummings, J. (2005). Behavioral and neuropsychiatric outcomes in Alzheimer's disease. *CNS Spectrums*, 10(11Suppl 18): 22-25.
- r-14. Cummings, J., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D., & Gornbein, J. (1994). *Neurology*, 44(12): 2308-2315.
- r-15. Damasio, A. (1999). The feeling of what happens. *New*

York, New York: Harcourt Brace.

- r-16. Davidson, R. (2004). Well-being and affective style: neural substrates and biobehavioral correlates. *Philosophical Transactions of the Royal Society B*, 359, 1395-1411.
- r-17. Fan, Y., Batmanghelich, N., Clark, C., Davatzikos, C., & Alzheimer's Disease Neuroimaging Initiative. (2008). Spatial patterns of brain atrophy in MCI patients, identified via high-dimensional pattern classification, predict subsequent cognitive decline. *NeuroImage*, 39(4): 1731-1743.
- r-18. Fauth, E., Zarit, S., Femia, E., Hofer, S., & Stephens, M. (2006). Behavioral and psychological symptoms of dementia and caregivers' stress appraisals: Intra-individual stability and change over short-term observations. *Aging & Mental Health*, 10(6), 563-573.
- r-19. Frisconi, G., Fox, N., Jack, C., Scheltens, P., & Thompson, P. (2010). The clinical use of structural MRI in Alzheimer's disease. *Nature Review of Neurology*, 6(2): 67-77.
- r-20. Frisch A, Finkel B, Michaelovsky E, Sigal M, Laor N, Weizman R (2000). A rare short allele of the serotonin transporter promoter polymorphism with alcohol dependence. *Am J Med Genet B Neuropsychiatr Genet* 133:79-84.
- r-21. Gitlin, L., Winter, L., Burke, J., Chernett, N., Dennis, M., & Hauck, W. (2008). Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: A randomized pilot study. *American Journal of Geriatric Psychiatry*, 16(3), 229-239.
- r-22. Gitlin, L., Winter, L., Corcoran, M., Dennis, M., Schinfeld, S., & Hauck, W. (2003). Effects of the home environmental skill-building program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH initiative. *The Gerontologist*, 43(4): 532-546.
- r-23. Gershon MD (1999). Review article: roles played by 5-hydroxytryptamine in the physiology of the bowel. *Aliment Pharmacol Ther* 13 (Suppl 2):15-30.
- r-24. Hu X, Oroszi G, Chun J, Smith TL, Goldman D, Schuckit MA (2005). An expanded valuation of the relationship of four alleles to the level of response to alcohol and the alcoholism risk. *Alcohol Clin Exp Res* 29:8-16.
- r-25. Ingebretsen, R., & Solem, P. (1998). Spouses of persons with dementia: Attachment, loss and coping. *Norwegian Journal of Epidemiology*, 8(2): 149-156.
- r-26. Kendler KS, Kuhn JW, Vittum J, Prescott CA, Riley B (2005). The interaction of stressful life events and a serotonin transporter polymorphism in the prediction of episodes of major depression: a replication. *Arch Gen Psychiatry* 62:529-535.
- r-27. Kraft JB, Slager SL, McGrath PJ, Hamilton SP (2005). Sequence analysis of the serotonin transporter and associations with antidepressant response. *Biol Psychiatry* 58:374-381.
- r-28. Klin, A., Jones, W., Schultz, R., Volkman, F. (2003). The enactive mind, or from actions to cognition: lessons from autism. *Philosophical Transactions of the Royal Society B*, 358, 345-360.
- r-29. Kringelbach, M. (2005). The human orbitofrontal cortex: Linking reward to hedonic experience. *Nature Reviews Neuroscience*, 6, 691-702.
- r-30. Kringelbach, M., Lehtonen, A., Squire, S., Harvey, A., Craske, M., Holliday, I., Green, A., Aziz, T., Hansen, P., Carnelissen, P. & Stein, A. (2008). A specific and rapid neural signature for parental instinct. *PLoS ONE* 3(2): e1664. doi: 10.1371/journal.pone.0001664
- r-31. Lemche, E., Giampietro, V., Surguladze, S., Amaro, E., Andrew, C., Williams, S., Brammer, M., Lawrence, N., Maier, M., Russell, T., Simmons, A., Ecker, C., Joraschky, P., Phillips, M. (2006). Human attachment security is mediated by the amygdale: Evidence from combined fMRI and psychological/physiological measures. *Human Brain Mapping*, 27, 623-635.
- r-32. Lishner, D., Ocejka, L., Stocks, E., Zaspel, K. (2008). The effect of infant-like characteristics on empathic concern for adults in need. *Motivation and Emotion*, 32, 270-277.
- r-33. Lotrich FE, Pollock BG (2004). Meta-analysis of serotonin transporter polymorphism and suicide: results of a meta-analysis. *Biol Psychiatry* 55:1023-1030.
- r-34. McHugh, K. (2003). Three faces of ageism: Society, image and place. *Aging & Society*, 23, 165-185. doi: 10.1017/S0144686X0200113
- r-35. Michaelovsky E, Frisch A, Rockah R, Peleg L, Magal N, Shohat M, Weizman R (1999). A novel allele in the promoter region of the human serotonin transporter gene. *Mol Psychiatry* 4:97-99.
- r-36. Mikulincer, M. & Shaver, P. (2007). Adult attachment and affect regulation. In J. Cassidy and P. Shaver (Eds.) *Handbook of attachment* (2nd ed. pp. 503-531). New York: The Guilford Press.
- r-37. Mosconi, L., Berti, V., Glodzik, L., Pupi, A., De Santi, S., & de Leon, M. (2010). Pre-clinical detection of Alzheimer's disease using FDG-PET, with or without Amyloid imaging. *Journal of Alzheimer's Disease*, 20(3): 843-854.
- r-38. Nakamura M, Ueno S, Sano A, Tanabe H (2000). The human serotonin transporter gene linked polymorphism (5-HTTLPR) shows ten novel allelic variants. *Mol Psychiatry* 5:32-38.
- r-39. Nelson, T. (2005). Ageism: Prejudice against our feared future self. *Journal of Social Issues*, 61(2): 207-221.
- r-40. Nichols, L., Martindale-Adams, J., Greene, W., Burns, R., Graney, M., & Lummus, A. (2009). Dementia caregivers' most pressing concerns. *Clinical Gerontologist*, 32: 1-14. doi: 10.1080/07317110802468546
- r-41. Porter, V., Buxton, W., Fairbanks, L., Strickland, T., O'Connor, S., Rosenberg-Thompson, S., & Cummings, J. (2003). Frequency and characteristics of anxiety among patients with Alzheimer's disease and related dementias. *Journal of Neuropsychiatry and Clinical Neuroscience*, 15(2): 180-186.
- r-42. Rasmussen HB, Werge TM (2007). Novel procedure for genotyping of the human serotonin transporter gene-linked polymorphic region (5-HTTLPR)- a region with a high level of allele diversity. *Psychiatric Gen* 17:287-291
- r-43. Schore, A. (2000). Attachment and the regulation of the right brain. *Attachment & Human Development*, 2(1), 21-47.
- r-44. Seignourel, P., Kunik, M., Snow, L., Wilson, N., & Stanley, M. (2008). Anxiety in dementia: A critical review. *Clinical Psychology Review*, 28(7): 1071-1082. doi: 10.1016/j.cpr.2008.02.008
- r-45. Shiino, A., Watanabe, T., Maeda, K., Kotani, E., Akiguchi, I., & Matsuda, M. (2006). Four subgroups of Alzheimer's disease based on patterns of atrophy using VBM and a unique pattern for early onset disease. *NeuroImage*, 33, 17-26. doi:10.1016/j.neuroimage.2006.06.010

- r-46. Smith, M., Gerdner, L., Hall, G., & Buckwalter, K. (2004). History, development, and future of the Progressively Lowered Stress Threshold: A conceptual model for dementia care. *Journal of the American Geriatrics Society*, 53, 1755-1760.
- r-47. Steinberg, M., Shao, H., Zandi, P., Lyketsos, C., Welsh-Bohmer, K., Norton, M., Breitner, J., Steffens, D., Tschanz, J., & Cache County Investigators. (2008). Point and 5-year period prevalence of neuropsychiatric symptoms in dementia: The Cache County Study. *International Journal of Geriatric Psychiatry*, 23(2): 170-177. doi: 10.1002/gps.1858
- r-48. Van Hoesen, G., Parvizi, J., & Chu, Ching-Chiang. (2000). Orbitofrontal cortex pathology in Alzheimer's disease. *Cerebral Cortex*, 10, 243-251.
- r-49. Wallis, J. (2007). Orbitofrontal cortex and its contribution to decision-making. *Annual Review of Neuroscience*, 30, 31-56.
- r-50. Wendlend JR, Martin BJ, Kruse MR, Lesch KP, Murphy DL (2006). Simultaneous genotyping of four functional loci of human SLC6A4, with a reappraisal of 5-HTTLPR and rs25531. *Mol Psychiatry* 11:224-226.
- r-51. Zakzanis, K., Graham, S., & Campbell, Z. (2003). A meta-analysis of structural and functional brain imaging in dementia of the Alzheimer's type: a neuroimaging profile. *Neuropsychol. Rev.*, 13, 1- 18.

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