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FINAL TECHNICAL REPORT

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TITLE OF PROJECT: People with Dementia as Witnesses to Emotional Events

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Abstract

Purpose:

Demented elders are often the only witnesses to crimes against them, such as physical or financial elder abuse, yet they are disparaged and discounted as unreliable. Clinical experience with this population indicates that significant emotional experiences may be salient to people with dementia, and that certain behaviors and characteristics enhance their credibility as historians. For example, someone in an early stage of the disease may be able to reliably report on an event with strong emotional content. This is the first systematic research to identify people with dementia with reliable emotional memory and their characteristics.

Design & Methods:

A cross-sectional study of 95 people with dementia (aged 55 and older) and a control group of 50 older adults was conducted. Memories of recent autobiographical events that have both positive and negative emotional content were elicited during a structured interview. Accurate recollection of these events was independently verified by a non-demented informant, usually a family member. In addition, both members of the dyad were interviewed independently to assess other characteristics of the older adult participant: demographics, depressive symptoms, functional and cognitive abilities, medications, health conditions, confabulation behaviors and characteristics of the dyadic relationship. Researchers also assessed people with dementia for disease stage, awareness of their cognitive impairment, and neuropsychiatric symptoms. A validated test of emotional memory was administered to qualified participants to verify the novel structured interviewing assessment developed for this study. The study assessments were conducted during a home visit by two researchers.

Results:

A significant subset of older adults with dementing illnesses can reliably report emotional events in their lives. Compared to people with dementia with less reliable emotional memory, these individuals are able to report details of the event accurately and to recall the same event again after a short time delay.

They are also likely to be an earlier stage of the disease, more aware of their own cognitive impairment, more likely to report negative events in their lives and to be able to recall an event without cues.

Implications:

Older adults with dementia who are victims of crime should be evaluated for their ability to remember emotional events in their lives, and based on the results, allowed to provide testimony about the criminal events.

Introduction

Five million Americans have Alzheimer's disease, a number that is expected to triple by the middle of this century (Hebert, Scherr, Bienias, Bennett, & Evans, 2003). It is estimated that as many as fifty percent of these people are also mistreated or neglected (Cooney & Mortimer, 1995). While the victimization rate of this vulnerable population is staggering, these crimes go undetected frequently and are prosecuted infrequently. Demented elders are often the only witnesses to their own abuse, yet they are disparaged and discounted as unreliable. Lacking other persuasive evidence, frustrated law enforcement personnel are stymied in their investigations and often feel compelled to close these cases, believing that a time-consuming investigation will not lead to a successful prosecution.

What is not widely known is that people with dementia frequently retain very specific cognitive function (cognitive reserve), while sustaining other very specific cognitive deficits. The evidence is growing that memory for an emotional event is one of the reserved cognitive abilities often retained through the early stages of Alzheimer's disease and related dementias (ADRD). Elder mistreatment clearly is an adverse emotional experience for those who endure it. Those who serve elders with dementia attest to their ability to retain emotional material (an outing, financial difficulties), while information that is more mundane (a meal, a phone conversation) is more readily forgotten. This project systematically explored that observation, and it adds to the body of knowledge that guides those who discover, mediate, investigate, and prosecute crimes against older adults.

Prevalence estimates for Alzheimer's disease and related dementias (ADRD) indicate there are 5.3 million Americans with the disease today and half a million new cases will develop annually (Alzheimer's Association, 2009). This is in part due to the rapid increase in the population aged 75 and up (Hebert et al., 2003). Prevalence of ADRD is directly associated with age and among the oldest Americans as many as half of the population are afflicted with a dementing illness. In addition, a high proportion of people in residential care facilities are diagnosed with ADRD. The population of older Americans with dementia has been of interest to elder abuse researchers because their cognitive impairments and dependency on others for their care and safety leave them vulnerable to mistreatment. Studies have found high prevalence of abuse and neglect of people with dementia that approaches 50% (VandeWeerd & Paveza, 2005; A. Wiglesworth et al., (In press)). Researched estimates for prevalence of physical aggression alone toward people with dementia range from 5.4% -19.7% in community settings (Compton, Flanagan, & Gregg, 1997; Coyne, Reichman, & Berbig, 1993; Hamel et al., 1990; Paveza et al., 1992; A. Wiglesworth et al., (In press)). Published data on reports of elder mistreatment substantiated by Adult Protective Services do not break down the proportion of victims who are demented since these data are seldom collected in social services databases (Teaster et al., 2006), but pilot data indicate a rate of about 10%, with the caveat that underreporting of these crimes is likely much higher than underreporting of crimes against non-demented victims (Rater, 2005). Regardless, with the projected growth in the population segment vulnerable to dementing illnesses, a parallel increase in elder mistreatment of these vulnerable people can be expected.

Dementia (or ADRD) is defined as a decline in intellectual ability involving significant impairment of memory and at least one other cognitive function, resulting in an inability to carry out everyday activities. A victim's ability to remember the events of a crime is frequently crucial to prosecuting the crime, and this is certainly the case in elder mistreatment since victims and perpetrators are often the only eyewitnesses. Even with financial abuse, although a paper trail may provide some evidence, the alleged perpetrator can counter an accusation with a statement that property was not stolen, but freely given, when the alleged victim cannot reliably state that no such permission was granted. Eyewitness

testimony in elder mistreatment cases often comes down to the victim, and if the victim has been diagnosed with dementia those in the criminal justice system may assume that the case cannot be pursued, either because they think they cannot rely on the victim's testimony or because they think that a jury will not do so. In fact, the kind of memory function that is tested to diagnose dementia (usually verbal memory for mundane information) differs from the kinds of memories generated by someone experiencing elder mistreatment. There is growing evidence that emotional memory is spared in many people with dementia.

Emotional memory

When emotion combines with memory, memories are more salient. This has been shown in studies of normal adults (Cahill & McGaugh, 1995; Dolan, 2002; S. B. Hamann, Cahill, & Squire, 1997; S. B. Hamann, Cahill, McGaugh, & Squire, 1997; E. A. Kensinger, Brierley, Medford, Growdon, & Corkin, 2002; E. Kensinger & Schacter, 2008; E. Kensinger, 2009), people with amnesia (S. B. Hamann, Cahill, & Squire, 1997; S. B. Hamann, Cahill, McGaugh et al., 1997) and people with dementing illnesses (H. Kazui et al., 2000; Moayeri, Cahill, Jin, & Potkin, 2000; Satler et al., 2007), though results are mixed with the latter (S. B. Hamann, Monarch, & Goldstein, 2000; E. A. Kensinger et al., 2002). One protocol involves recall of the details of short stories shown as slide shows, with some of the slides accompanying emotionally arousing plot details, while others contain neutral material. Emotional arousal promotes both short- and long-term memory of the story details (Cahill & McGaugh, 1995). Others have studied so-called flashbulb memories for major events (the Kennedy assassination, 9-11) and found these memories may be preserved better in older than in younger adults (Thomas-Antérion, Collomb, Borg, Nevers, & Laurent, 2006), and can be at least partially spared in AD as well (Budson et al., 2004; Ikeda et al., 1998). Most appropriate to the proposed project are studies of emotion related to autobiographical memory (Christianson & Safer, 1996; Davis & Follette, 2001; Rubin & Berntsen, 2009; Rubin & Berntsen, 2009; Schlagman, Kliegel, Schulz, & Kvavilashvili, 2009), and these are perhaps the most salient memories of all, since they engage all sensory channels and their potential to trigger an emotional response in the research participant is not due to fabricated research procedures, but to lived events. Directly experienced traumatic events are more resistant to forgetting over time than other types of memories (Pezdek & Taylor, 2002).

Seeking to further analyze the emotional memory phenomenon, others have found that emotion enhances attention (Davis & Follette, 2001). Attention is a distinct cognitive construct necessary for the formation of memories. It is often spared with Alzheimer's disease (Dolan, 2002). One example of the role of attention in memory has been called "tunnel memory," which describes the propensity of those viewing an emotionally arousing traumatic event to automatically narrow attention to those critical details that were the source of the emotional arousal (Safer, Christianson, Autry, & Österlund, 1998).

Emotions have positive or negative valence and the same is true of emotional memories. A 'negativity' bias for attention to stimuli exists in younger adults (Carretié, Mercado, Tapia, & Hinojosa, 2001), and this biases their memory toward negative rather than positive stimuli. Some evidence indicates that older adults have a 'positivity' bias (Charles, Mather, & Carstensen, 2003). A study of young adults showed that memory for emotional and especially negative arousing items is less prone to distortion than is memory for neutral items, and that negative arousal enhances the vividness of memories (E. A. Kensinger, Garoff-Eaton, & Schacter, 2006).

Studies of the brain's mechanisms of emotional memory begin to explain its relative sparing with age and dementia. The memory loss of Alzheimer's disease is associated with damage to the hippocampus that impairs encoding or storage of new memories. Emotional arousal and encoding of emotional

memories activates the amygdala, which may modulate memory storage elsewhere in the brain (Canli, Zhao, Brewer, Gabrieli, & Cahill, 2000; S. B. Hamann, Ely, Grafton, & Kilts, 1999; McGaugh, Cahill, & Roozendaal, 1996). In addition to imaging studies, research with amnesiacs (S. B. Hamann, Cahill, & Squire, 1997; S. B. Hamann, Cahill, McGaugh et al., 1997) and people with amygdalar damage (Mori et al., 1999; Phelps, LaBar, & Spencer, 1997) indicate the importance of the amygdala to emotional memory.

Emotional memory and dementia

A variety of study protocols have shown that emotional memory may be spared in ADRD, despite the loss of verbal or declarative memory that is the hallmark of the disease. A successful protocol for enhancing memory in dementia patients introduced an environmental manipulation by associating memories with experiences that aroused positive emotions (e.g., a pleasant outing) instead of using classic memorization techniques, such as repetition (Moore, Sandman, McGrady, & Kesslak, 2001; Sandman, 1993). To augment the finding of partial sparing of flashbulb memories in AD patients (Budson et al., 2004; Ikeda et al., 1998; Thomas-Antérion et al., 2006), one group was able to relate amygdalar sparing in AD patients directly to emotional memory performance (Mori et al., 1999). Researchers also found improved memory for emotional items by AD patients when using neutral and arousing stories and slides (H. Kazui et al., 2000; Moayeri et al., 2000). One study found that the flashbulb memory enhancement was associated with visual rather than verbal memory (H. Kazui, Mori, Hashimoto, & Hirono, 2003). However, it is not clear that emotion improves AD patients verbal recall of emotional words (E. A. Kensinger et al., 2002; E. A. Kensinger, Anderson, Growdon, & Corkin, 2004), or emotional narratives (E. A. Kensinger et al., 2004). Synthesizing these findings, it appears that sparing of emotional memory in ADRD may rely on visual and/or autobiographical memory, rather than verbal memory, which is always impaired.

Some studies differentiate memory function in different types of dementia. Subjects with a fronto-temporal lobe Semantic Dementia had recognition memory, especially for pictorial items, that was associated with performance on frontal lobe tests and not with hippocampal atrophy (J. S. Simons, Graham, & Hodges, 2001; J. S. Simons et al., 2002) indicating the importance to memory of receiving information through non-verbal channels. (“Recognition” is cued memory as opposed to “recall”, which is uncued.) Recognition is better preserved in older adults than recall, for example they may not be able to recall a word from a list, but given the word, they can say that it was on the list.) Other studies found that people diagnosed with Semantic Dementia had better autobiographical memory for recent events than people with AD, but poorer remote memories (Hou, Miller, & Kramer, 2005; Ivanoiu, Cooper, Shanks, & Venneri, 2006). Frontal lobe function has also been associated with preserved ‘source’ memory – or memory for contextual information (time, place, peripheral details surrounding an event) (J. S. Simons, Dodson, Bell, & Schacter, 2004). To sum up, dementias are characterized by differentially preserved cognitive function and by differential sparing of brain structures that underlie cognitive function associated with emotional and autobiographical memory.

Other characteristics of ADRD may have an impact on reliable emotional memory. Neuropsychiatric symptoms can be quite common, for example, delusions occurred throughout the disease course (34-49% prevalence) in probable AD patients, peaking in the second year, before declining. Hallucinations (8-17% prevalence) were somewhat stable across the follow-up period and fairly persistent (Holtzer et al., 2003). Disinhibition, a relatively common characteristic of advancing dementia, can interfere with attention and therefore with memory storage (Davis & Loftus, 2003). Confabulation (the tendency to ‘make-up’ information rather than give accurate information or report that you do not remember or do not have reliable information) in AD has been associated with poor performance on episodic memory

measures but not on other measures of cognitive functioning (Cooper, Shanks, & Venneri, 2006). Also, some ADRD patients are unaware of their symptoms and illness, and level of awareness decreases with dementia progression, psychosis and apathy, but increases with depression and anxiety in AD (F. R. J. Verhey, Rozendaal, Ponds, R. W. H. M., & Jolles, 1993).

Some factors that occur with ADRD apply to aging adults in general and can interfere with emotional memory. For example hearing and vision loss, prevalent with aging, can block the registration of memories, even though the brain's cortical and subcortical structures for forming, storing, and retrieving memories are intact. Depression is common in early AD and can negatively impact memory (Jorm, 2000).

The current study hypothesized that some people with dementia have reliable emotional memory for events in their own lives and that they differ from people with dementia whose emotional memory is less reliable or unreliable in that they are at an earlier stage of the disease, they engage less in confabulation and neuropsychiatric behaviors that might interfere with memory formation such as delusions, hallucinations, illusions, disinhibition, anxiety, apathy and agitation and they are more aware of their cognitive impairment. In addition, those with reliable memory will be able to provide more details related to the memory, and to discuss the memory again with the same accuracy after a time delay.

Older adults as witnesses

Criminal justice investigators and jurors tend to stereotype older witnesses, assuming that their memories may be inaccurate. It is true that, compared to younger adults, older adults provide less accurate and less complete eyewitness reports, and make more errors (Davis & Follette, 2001). Not only with AD, but with all older witnesses, it is important to interview them as soon as possible after an event. Research on effects of age on serving as a witness as well as the practical difficulties of elders operating in the legal system raise a number of concerns about elders functioning as witnesses to crimes (Davis & Follette, 2001; Davis & Loftus, 2003; Nunez, McCoy, Clark, & Shaw, 1999; Wright & Holliday, 2005). Many of these difficulties - such as being overwhelmed by events, having mixed feelings about the perpetrator and letting the stress of or delays in testifying interfere with giving accurate testimony - parallel those of child witnesses and need to be addressed similarly (Task Force on Child Witnesses of the American Bar Association Criminal Justice Section, 2002).

Strategies for overcoming problems with witnesses relate to how questions are asked (Hyman & Loftus, 2002). Experts recommend using a structured interview protocol to improve the quality of information retrieved in investigative interviews. This helps ensure that suggestibility does not enter in, and interviewers do not influence outcomes. The protocol attempts to exhaust open-ended questioning strategies (Sternberg, Lamb, & Esplin, 2002).

In the current study, the researchers evaluated demented persons' memories of recent emotional experiences using structured interview techniques that began with open needed questioning and progressed to questioning using first category cues and then, if needed, cues of specific events as related by an informant to the person with dementia. A standard instrument for assessing adverse life events tailored for older adults provided a list of categories of events that happen to older adults and these were used to cue or trigger adverse memories. The list was supplemented with positive memory categories such as a family gathering and the birth of a grandchild. Similarly, the demented person's informant, usually a spouse or other family member, participated in a parallel, but independent, interview to verify whether the person with dementia was accurate in reporting emotional memories. This information was analyzed by raters, to allow ranking of the participants based on the reliability of

their memory for emotional events, and therefore their potential to serve as reliable witnesses to their own mistreatment. A control group of non-demented older adults and their informants provided a baseline of normative data for the study.

The underlying characteristics or variables for comparison between groups were based on the investigators clinical experience in leading an elder abuse forensic center.(A. Wigglesworth, Mosqueda, Burnight, Younglove, & Jeske, 2006) The characteristics of particular interest included: the stage of the dementia (early vs. moderate or severe); the presence or absence of neuropsychiatric symptoms (e.g., hallucinations, delusions, agitation); the individuals' awareness of their own memory deficits or dementia; confabulation behaviors (e.g., providing fictitious responses when confronted with questions about things they do not know); as well as the ability to provide details about the emotional memory and to recall the memory again after a delay. The researchers conducted a formal and rigorous study of these criteria as hypothetical predictor variables for identifying those people with dementia who are reliable witnesses to their own abuse. The findings have the potential to change the way elder mistreatment cases are handled by the criminal justice system.

Methods

The study design is a cross-sectional, one-time assessment of a convenience sample of Older Adults diagnosed with mild or moderate stage dementia and their Informants, as well as non-demented normal control Older Adult participants and their Informants. (The paired individuals are referred to as a dyad.) Data was collected in the home by a two-person research team. The study was fully enrolled with 103 dementia dyads and 50 normal controls.

Recruitment and consenting

Inclusion criteria for dementia participants were age 55 or greater, a diagnosis of mild to moderate dementia, established through review of medical records, and availability of an informant who is familiar with the patient's recent history. Normal control participants and their informants were matched for age and gender. Venues for recruitment included, participants in other research studies at the University of California, Irvine; families who contacted the local Alzheimer's Association chapter and clients of a senior health clinic, an adult day care facility and a participating senior center. Other resources included an online article in a local newspaper, an article in a newsletter for a senior education program and a broadcast email to UC Irvine employees. Details are available in Appendix 1.

ADRD patients and normal controls who were interested in participating in the study were asked to provide a release of recent medical records in order to confirm the presence or absence of a dementing illness. All informants and control participants were screened by telephone, using a modified version of the Short Portable Mental Status Questionnaire (SPMSQ; Erkinjuntti, Sulkava, Wilkström, & Autio, 1987) to assess for the absence of cognitive impairment. If all criteria were met, the study assessment itself was scheduled and conducted in participants' homes at a later date. At that time, dementia patients were assessed for their capacity to consent to research and a self-certified surrogate was sought when decision-making capacity was not present, as required by the state of California. Decision-making capacity was assessed using a tool modeled after the MacArthur Competence Assessment Tool for Clinical Research.(Applebaum & Grisso, 2001) Each dyad consented in writing prior to the initiation of data collection.

Data collection methods

