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Ashley Keefe Diaz  
Awareness of Trigger Events  
Among Clinicians Working  
With Elders With Dementia

## ABSTRACT

This qualitative study was undertaken in order to determine what clinicians perceive to be trigger events that influence dementia onset and if these events are used in the therapeutic process. This study asked the following research questions: What is your experience as a clinician working with elders who have dementia? As a clinician, what is your understanding of trigger events? How do you incorporate the knowledge of triggers into your therapeutic process? Tell me about the types of events that you have found that trigger elderly onset of dementia: medical? Trauma? Etc? What specific techniques have you found helpful in working with elders with sudden onset of dementia? Participants were recruited by the snowball data collection technique by contacting a professional network of clinicians in person and by e-mail and telephone. Thirteen participants completed a face-to-face or telephone interview. The findings of the research showed that clinicians shared a basic knowledge of trigger events to dementia including emotional trigger events. However, clinicians reported a different understanding of the way in which these events trigger dementia than this researcher originally hypothesized. Clinicians do report using the knowledge of trigger events in therapy as a way to discern coping skills and identify areas to address.

AWARENESS OF TRIGGER EVENTS AMONG CLINICIANS WORKING WITH  
ELDERS WITH DEMENTIA

A project based upon an independent investigation,  
submitted in partial fulfillment of the requirements  
for the degree of Master of Social Work.

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2010

## ACKNOWLEDGEMENTS

This thesis could not have been completed without the help of many people whose contributions are greatly appreciated. I would like to thank all of the clinicians who gave up their valuable time to be interviewed for this project, and Elaine Kersten, EdD, for her time, patience and support. Last of all I would like to thank Joe, Mom, Dad, and the rest of my family for supporting me through this long process.

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## CHAPTER I

### INTRODUCTION

As the human body ages, changes in mental and physical health are inevitable. In the elderly, these changes are significant and can alter the person's entire lifestyle without warning. One of the most difficult changes is the loss of brain function, often termed elder onset dementia. This condition affects a person by impaired memory, language, and judgment. Onset of dementia can be slow and progressive or sudden and unpredictable. It can affect people who have heretofore been in relatively good health and who are stable and living independently. Because of the devastating effects of this condition to both family members and the individual, and because issues frequently come up in therapeutic situations, understanding how and what triggers onset of elder dementia is important for clinical social workers and other mental health professionals.

An eighty-year-old woman living in LA was recently robbed at gunpoint in the middle of the night. Prior to this traumatic event, the woman was in good physical health and possessed great mental capacity. Immediately after the robbery occurred, she began exhibiting symptoms of Post Traumatic Stress Disorder (PTSD) and began seeing a therapist to address this. She also began exhibiting symptoms of dementia, was no longer able to remember daily tasks, conversations, or familiar faces. Although this woman was of old age, her dementia, and its etiology, is of interest.

Many studies have identified that a traumatic event can enhance the risk of dementia (Charles, Bouby-Sereiys, & Clement, 2006; De Lepeleire, Heyman, & Buntinx, 1998). Stressful situations including traumatic life events are associated with a presence

of glucocorticoids in the hippocampus, the part of the brain that affects memory, learning and emotions. Prolonged exposure to glucocorticoids can have negative affects on the hippocampus, directly influencing the functions affected by dementia (Charles et al., 2006).

Although it is generally accepted that there are genetic pre-dispositions for dementia, information about the types of trigger events and the influences that contribute to the onset of dementia is less known. Clinicians treating the elderly population may be able to provide a unique perspective about what they perceive to be the triggering events and how these events manifest.

Clinicians serving the elderly population will benefit from the material explored in this study. Specifically, this study examines and identifies the trigger events and influences that result in dementia. Knowing about possible trigger events may allow the clinicians to explore these issues in treatment. This study will provide the opportunity to capture the existing and unknown information about trigger events.

## CHAPTER II

### LITERATURE REVIEW

This study is designed to explore what clinicians treating clients with dementia perceive to be the trigger events for dementia and how this information is used in therapy. This chapter will include a review of what other researchers have identified as the types and leading risk factors for dementia and will focus only on late onset dementia. Late onset dementia is generally defined as affecting persons over the age of 65. Although there is still mystery surrounding the exact causes of dementia, I will focus on the most prevalent and widely accepted causes in the literature. Alzheimer's disease (AD) and vascular dementia are the most prevalent causes of dementia in older adults respectively (van der Flier & Scheltens, 2005). Genetics, vasculature, and environment are all known to be common triggers to late onset dementia and will be explored further in this literature review. Depression and Mild Cognitive Impairment will also be discussed relative to dementia.

#### *Alzheimer's Disease*

Alzheimer's Disease is a progressive and fatal brain disease that is the most common form of dementia. Plaques and tangles in the brain are believed to cause cell death leading to memory loss and cognitive decline (Alzheimer's Association, 2010). It is known that Alzheimer's Disease (AD) has a genetic component. One gene has been identified as a risk factor for AD, but the presence of this gene does not guarantee AD. Its presence does however increase the probability of the disease (Patterson et al., 2008). The association between the specific allele and Alzheimer's Disease is stronger among



women than among men (Patterson et al., 2008). Women have been found to be at greater risk for developing AD even when life expectancy is a control (McCullagh, Craig, McIlroy, & Passmore, 2001). Hormone replacement therapy was previously suggested as a protective factor for women for whom it was thought to prevent or delay AD onset (McCullagh et al., 2001). There are several ways both genetic and vascular that estrogen was believed to influence onset including improving cerebral blood flow, reduction in  $\beta$ -amyloid deposition, and neuroprotection or suppression of ApoE (McCullagh et al., 2001).

Increased oxidative stress levels are a characteristic of Alzheimer's Disease and vascular dementia (Bennett, 2009). "An increased level of reactive oxygen species in the vasculature, reduced nitric oxide bioavailability, and endothelial dysfunction leading to vascular disease is associated with vascular dementia. In Alzheimer's disease, an increased amount of amyloid- $\beta$  peptide induces elevated reactive oxygen species production thereby causing neuronal cell death and damage" (Bennett, 2009, p. 245). It is unclear whether these changes in oxidative stress levels are reactionary or causal (McCullagh et al., 2001).

The brain of a person with Alzheimer's Disease is typically inflamed, but again this may be a response to the disease or the cause. For this purpose, anti-inflammatory medications were studied and determined to have a negative association with the risk of developing AD possibly delaying nerve cell damage (McCullagh et al., 2001).

Another example of disease influencing a risk factor is found in the category of head trauma. The course of dementia found in boxers looked similar to that of Alzheimer's Disease, resulting in further study of head injury as a risk factor (McCullagh

et al., 2001). Dementia has been found to be a risk factor for falls and fall injuries in nursing home patients (van Doorn et al., 2003). The increased risk of falling is attributed to impaired judgment, gait, visual-spatial perception, and the ability to identify and avoid potential dangers (van Doorn et al., 2003). A long term study of WWII servicemen admitted to the hospital during military service with a moderate or severe head injury experienced an increased risk of AD (Patterson et al., 2008). Until this study, head injury as a risk factor for dementia was debatable due to compromised recall ability (McCullagh et al., 2001).

Lower education levels have been cited as a risk factor for Alzheimer's Disease in some studies, but others have not been able to yield the same findings (McCullagh et al., 2001, Sando et al., 2008). Education as a protective factor against Alzheimer's Disease increased with the level of education present in a study of older aged persons in Norway (Sando et al., 2008). Higher education levels may allow greater insight to a person's cognitive decline or to greater access to diagnosis and treatment. Still unknown is whether education throughout the lifespan is responsible, or whether it is only education acquired during childhood that contributes as a protective factor (McCullagh et al., 2001).

Other possible contributors to dementia are solvents and heavy metals like iron and aluminum (McCullagh et al., 2001). High levels of iron may contribute to the formation of free radicals and oxidant stress. Aluminum has been a controversial risk factor in the past several years in response to the discovery of aluminum in the neurofibrillary plaques and tangles (McCullagh et al., 2001). Since this connection studies have shown that although there is no causal link between aluminum and dementia, the presence of aluminum may affect the development or progression of AD

(Shcherbatykh & Carpenter, 2007). Scientists hypothesize that cumulative oxidative damage over time can explain late life onset and slowly progressing disorders like dementia (Shcherbatykh & Carpenter, 2007).

Toxins such as pesticides, fertilizers, fumigants and defoliants were found to be associated with an increased risk of Alzheimer's Disease at occupational exposure levels (Patterson et al., 2008). The interaction between genes and toxins such as these may be responsible, as is hypothesized for the interaction between toxins and Parkinson's Disease with Dementia (Hubble et al., 1998).

Behavioral changes like sleep disturbances, restlessness, pacing, delusions, and hallucinations often occur in persons with AD (Alzheimer's Association, 2010). In addition to these behavioral changes, Knopman, Boeve and Petersen (2003) warn of the personality changes that co-occur stating,

Personality changes may antedate the more obvious memory changes but may be evident only in retrospect. Apathy, loss of interest in previous pastimes and activities, and loss of initiative are all part of the insidious changes in a person who is developing AD. Insight is usually lost early in the process. However, insight is not invariably absent, and preserved insight should not be considered a strike against a diagnosis of AD. Some patients with AD can have prominent depression either spontaneously or as a result of their sense of declining function (p. 1294).

It is clear how difficult the task of diagnosing a patient with cognitive decline. Clinicians must consider several factors when trying to distinguish AD from other types of

dementia. Physical exams and neurological tests are useful in establishing a diagnosis and brain imaging is available to detect structural brain changes.

While there is no cure for AD, treatments like medications and therapeutic interventions can influence the behavioral and personality changes that occur. Although effective treatments such as cholinesterase inhibitors and vitamin E are available, researchers express that treatments are needed which substantially slow the progression of AD (Knopman et al., 2003).

### *Vascular Dementia*

Vascular dementia is a term describing cognitive impairment due to changes in the brain vasculature. The changes in blood vessels are due to causes such as blockages and narrowing and result in varying manifestations depending on which area of the brain is affected. Symptoms of vascular dementia include confusion, agitation, memory loss, gait problems, depression, decline in ability to organize thoughts and actions, and poor memory and concentration (Mayo Clinic, 2010). Often in the event of strokes the symptoms appear suddenly and have a predictable progression. Other times the symptoms appear more slowly and gradually. Vascular dementia and Alzheimer's Disease can co-occur making it more difficult to diagnose (Mayo Clinic, 2010).

The prevalence rate is between 1 and 4% for adults over the age of 65 (Mayo Clinic, 2010). Age is the most well known risk factor for dementia and is the only universally accepted non-genetic risk factor for dementia (van der Flier & Scheltens, 2005). Due to consistent results in multiple studies, estimates provided for incidence and prevalence of dementia double with every 5 years of age (van der Flier & Scheltens, 2005, McCullagh et al., 2001). The hypothesis for this is that older adults have been

exposed longer to the adverse genetic and environmental factors for significantly longer periods of time (McCullagh et al., 2001).

Heart disease, hypertension, diabetes mellitus, and smoking are vascular risk factors that have been shown to be associated with Alzheimer's disease as well as with other diseases like stroke (American Stroke Association, 2004). van der Flier & Scheltens (2005) states, "Explanations for these associations include: (1) the coincidence of common disorders in the elderly; (2) vascular and cerebrovascular disease precipitating AD; (3) an additive or synergistic (AD + vascular) pathogenesis of dementia; and (4) misclassification of vascular dementia as AD" (p. 5). The presence of the above mentioned vascular risk factors in midlife are associated with dementia in later life, but it is unknown at what point the risk factors begin to cause dementia (Knopman et al., 2003).

Estrogen as a hormone replacement was not found to be efficacious as a treatment for subjects with AD (McCullagh et al., 2001). Further investigation into estrogen therapy showed that estrogen increased risk for stroke and myocardial infarction (Patterson et al., 2008). It was discovered that the risk of dementia increased with the use of estrogen alone or in conjunction with progesterone in The Women's Health Initiative Memory Study, a randomized controlled trial of over 7000 women over age 65 (Patterson et al., 2008).

Genetics have been identified as a cause of a familial form of dementia, but less than 5% of all cases of dementia can be accounted for by genetics specifically. The large remainder of dementia cases is believed to be caused by the interaction between DNA and other variables such as environment (van der Flier & Scheltens, 2005). Referred to as the "common variant" hypothesis, this supports the ideas that genetic variables interact in

various unpredictable ways with non-genetic variables to cause diseases and in this case, dementia (van der Flier & Scheltens, 2005).

The combination and interaction of environmental factors including diet, exercise, substance use, gender, head trauma, stress, education, exposure to chemicals, and psychological trauma are limitless. Many of these risk factors change with aging or across socioeconomic status. As van der Flier & Scheltens illustrates, an important relationship is that between the disease and the risk factor (2005). Once the disease is introduced, it can profoundly influence the risk factor. For example, dementia can affect a person's ability to perform activities of daily living such as remembering to eat or prepare a healthy meal (van der Flier & Scheltens, 2005). Future research regarding the progression of this type of dysfunction would be helpful to determine what pharmacological or non-pharmacological interventions would be appropriate and if those interventions could stave off this type of decline (Paul, Maloney, & Boyle, 2010). Knowledge about the nature of decline affecting ability to accomplish tasks of daily living would be useful for treatment providers of patients with dementia in helping with rehabilitation and maintaining function (Paul et al., 2010).

Although we know what risk factors are associated with vascular dementia, it is possible for these factors to change over time as the make up of the brain is physically altered. Exploring the impact of specific predictors of impairment among persons who already have vascular dementia would provide further clarity and fill the void where this research is absent, ultimately improving treatment options (Paul et al., 2010). Another related area for future study is determining what amount of vascular change is necessary to begin affecting daily functioning (Paul et al., 2010). In summary, a better

understanding of the progression of vascular dementia would allow clinicians to better identify persons at risk before the level of daily functioning has declined.

### *Depression*

Dementia and depression often coexist in the elderly population (Ganguli, Du, Dodge, Ratcliff & Chang, 2006). Various studies have postulated theories explaining the relationship. Depression may be a response to a related medical condition that is a risk factor for dementia, such as a head injury or a vascular condition (Korczyn & Halperin, 2009). An alternative theory is that depression is a sign of dementia, not a predictor (Korczyn & Halperin, 2009).

Many people have a lack of insight into depressive symptoms and/or cognitive decline and may not recognize a relationship. If a person is aware of his/her cognitive decline, he/she may become depressed as a reaction and unable to accurately report the order of onset. Simple memory testing is not the only way by which to diagnose dementia. In some cases, extensive follow-up is necessary to determine whether or not depression could be responsible for the cognitive decline. Neuropsychological testing and treatment for depression including medications are appropriate options. (Bryden, 2002).

The hippocampus is a core region of the limbic system that plays a vital part in learning, memory, motivation and emotion. A reduction in hippocampal volumes can lead to changes in affect and cognitive dysfunction, and as seen in dementia, complex memory (Frodl et al., 2006). Studies of major depression have shown consistent reduction in hippocampal volumes, but this change has also been found in studies of schizophrenia, post-traumatic stress disorder, dementia and diabetes mellitus (Frodl et al.,

2006; Sheline, Gado, & Kraemer, 2003). It is believed that increased levels of stress hormones and a lack of neurotrophic factors contribute to changes in the hippocampus (McCullagh et al., 2001). Sheline et al. (2003) states, "depression-related volume loss does appear to be cumulative, suggesting that immediate recognition and treatment of depressive episodes is important in order to prevent damage" (p.1517). Once recognition is established, anti-depressants may be useful because they are capable of reducing the stress hormone levels and increasing neurogenesis in the hippocampus (Frodl et al., 2006). Researchers hope that future studies should determine whether therapeutic interventions could produce similar effects.

Although cognitive decline is found with depression and dementia, it is usually present even after the depression passes. Cognitive decline is usually not attributable to depression alone and is regularly indicative of incipient dementia (Ganguli et al., 2006). It is possible that depression is a prodromal symptom of Alzheimer's Disease, which would constitute depression as "a harbinger rather than a risk factor for the disease" (Ownby, Crocco, Acevedo, John, & Loewenstein, 2006, p. 531). Depression and Alzheimer's Disease may share risk factors for vascular disease and both have been found to have underlying inflammation possibly due to cytokines that affect cognition (Ganguli et al., 2006). Researchers have also noticed a possible genetic link between Alzheimer's Disease and depression which will require further study to firmly establish the relationship between the two.

### *Incipient Dementia*

With aging a degree of cognitive decline is inevitable (Petersen, 2004). Mild Cognitive Impairment (MCI) is defined as "cognitive decline greater than that expected



for an individual's age and education level but that does not interfere notably with activities of daily life” (Gauthier et al., 2006, p. 1262). In 2006 it was estimated that between 3% and 19% of individuals over age 65 experience MCI (Gauthier et al., 2006). It is considered a risk factor for dementia because although many people with MCI return to their pre-morbid state or improve, the majority (more than 50%) advance to demented stages within 5 years of onset (Gauthier et al., 2006). In the case of the 44% of people with mild cognitive impairment that improved there were many factors were thought to be involved including: education, vascular risk factors, psychiatric status, genetics, hormonal changes, and use of anticholinergic drugs (Gauthier et al., 2006). Patients with MCI are 5 to 10 times more at risk of developing dementia than their cognitively healthy counterparts (Knopman et al., 2003). Those with more severe MCI have a greater risk for developing dementia (Knopman et al., 2003).

There are various subtypes of MCI such as the amnesic subtype (aMCI), which is most frequently encountered. This phase is considered the prodromal phase of Alzheimer's Disease (Whitwell et al., 2009). At this early phase the person exhibits "abnormal" memory impairment, but is still able to maintain activities of daily living (Petersen, 2004, p. 183). The person does not yet have enough cognitive impairment to warrant a diagnosis of dementia, but a slight degree of functional impairment is present which can be difficult to distinguish from other age-associated problems (Petersen, 2004). Because stages of MCI can be difficult to differentiate from dementia or Alzheimer's disease, the clinician is often responsible for exercising clinical judgment to determine the diagnosis.

The Global Deterioration Scale (GDS) was developed as a severity rating scale to assess dementia. Of the seven stages identified, stage 3 is mild cognitive impairment where the person may display impairment affecting social and occupational activities. Stage 4 is considered early dementia where the impairment begins to affect activities of daily living. Loss of self-esteem generally accompanies the memory loss (Knopman et al., 2003). Some people with incipient dementia are cognizant of the functional changes taking place while others are unable to recognize the decline. For those who are unable to notice the changes, it becomes the responsibility of those around him/her to observe the warning signs of repetitive stories, missed events, and unpaid bills. Diagnosing Mild Cognitive Impairment requires considerable attention from the clinician and often corroboration of the client's family or friends. The presentation of cognitive decline can vary from person to person and may be caused by MCI as well as many other factors.

#### *In treatment*

In many cases it appears that dementia becomes exacerbated after significant life changes like traumatic events, loss of a spouse, relocation, etc. Brain function is reduced by way of the various diseases that cause dementia (Bryden, 2002). When this occurs, the threshold of the brain is lowered and thereby less able to cope with outside stimuli. (Bryden, 2002). In the early stages, the person is able to utilize coping skills that he/she developed throughout his/her lifetime, but as the dementia and cognitive decline progress, the person's ability to cope declines. This reduced ability to cope alters the ease with which a person completes even day-to-day tasks. As a result the person with dementia may begin to withdraw or socially isolate. Given that reactions to minor stimuli can be this drastic, one can imagine that reactions to larger stressors can be catastrophic

and experienced as “challenging” when the person no longer has the internal resources to manage (Bryden, 2002, p. 145).

The presentation of dementia is important to understand because it varies widely depending on the stage of progression as well as other factors that are discussed above. Generally speaking, dementia presents as “disordered behavior: confusion, cognitive difficulty, memory loss” (Bryden, 2002, p.142). Bryden (2002) describes other influences:

The manifestation of dementia varies according to the PWiD’s (person with dementia) pre-morbid psychological status, which is dependent on biography and personality. It is also affected by the PWiD’s social context, particularly as cognitive decline lowers the PWiD’s stress threshold and the ability to deal with relational difficulties (p. 145).

Another important factor that influences the dementia presentation is the person’s coping mechanisms that may be lifelong behaviors or only recently acquired. Gaining insight into the person’s past coping skills can be valuable for a clinician to understand why the person may be using these skills and whether the skills are adaptive or maladaptive. Clinicians believe that reactions like depression, anxiety, denial and even psychosis are responses to the cognitive difficulties and neurological changes that take place (Bryden, 2002).

Kitwood (1995) proposed a formula to demonstrate the interaction of various factors and the resulting dementia manifestation:  $D = P + B + H + NI + SP$ . Personality (P) is the person’s resources and avoidances. Biography (B) is the person’s life history,

supports and losses. Physical Health (H) is the biological factors like vasculature. Neurological Impairment (NI) is the actual neurological damage sustained by the brain. Social Psychology (SP) is the environment of the person and should note what impact it has on the person's well being. The outcome of the relationship between each of these factors can vary significantly, thereby greatly influencing the symptomatology from one client to the next.

When beginning with a client, clinicians typically gather a history and timeline of important life events. Bryden (2002) suggests creating a genogram to develop a social lifeline in order to provide an inventory of personal resources and responses. Similar to treatment with any type of client, treatment with a person with a dementia is intended to promote emotional stability, self-esteem and self-identity. It should also address the internal influences that affect the person's way of adapting to dementia:

The aim of treatment is to increase emotional security, and to create and maintain self-worth and a sense of identity, through addressing the internal factors that affect the person's way of adapting to dementia (Hausman, 1992). This requires the therapist to 'hold' the person, to contain their emotional trauma, and to allow space for personal renewal through talk, by: Establishing a relationship in which the patient feels cared about; providing an emotional outlet; enhancing self-esteem; minimizing psychological and behavioral difficulties; increasing coping skills; enhancing role function; giving sense of control; allowing grieving for losses, capacities and relationships; developing and maintaining the most mature and productive defenses possible while shedding inappropriate ones; developing insight; and finding a sense of meaning (p. 150).

In order to accomplish any of these tasks, the clinician must utilize his/her knowledge of the patient's history and pre-morbid condition.

### *Summary*

It appears that we know the various forms of dementia and the risk factors for each type, but authors have emphasized the difficulty of diagnosing and treating these types of dementia because they often occur together and present similarly. This chapter reviews the definition of late onset dementia as it will be understood for the purposes of this study. An overview of dementia is given including Alzheimer's Disease, vascular dementia and incipient dementia. The presentation of each of these types of dementia is outlined, as are the risk factors and treatment interventions. Areas needing further study include exploring the impact of predictors of impairment and determining what amount of vascular change is necessary to limit a person's ability to function independently. In general a better understanding of the progression of vascular dementia is needed to better identify at-risk persons. Finally, the progression of incipient dementia and the ways in which it becomes evident requires further study to promote awareness and bring patients in for treatment prior to any precipitating event.

This literature review provided a knowledgebase of what clinicians perceive to be the triggering events to dementia. Knowing what the precipitating events are may inform the clinician's understanding of the onset of dementia and other psychosocial factors. The study conducted helped further the understanding of the influences about the clinician's therapeutic role. The purpose of this study was to contribute to the knowledge base for clinicians who are working with a dementia population.

## CHAPTER III

### METHODOLOGY

This project is a qualitative study designed to elicit clinicians' perspective on perceived triggers to adult onset dementia. The goal of the study is to identify what factors clinicians understand to be triggering or precipitating events in an effort to find out whether this is used in therapy. The specific research question guiding this study is: "What events do clinicians perceive to precipitate dementia?"

#### *Sample Selection*

I recruited 13 clinicians in greater Western Massachusetts area from multiple areas of clinical work (program directors, treatment coordinators, social workers, psychologists and Master's level mental health clinicians). Participant eligibility was determined by the following characteristics: 1) clinicians had an active caseload of elders with dementia; 2) clinicians held an advanced clinical degree in mental health such as a master's degree in social work (MSW), or were a psychiatrist or clinical psychologist or other Master's level mental health clinician; 3) clinicians have had continuing education/training in working with elders; 4) all participants were able to conduct an interview in English. Years of experience in the field ranged from 3 to 20+ years. All were currently employed in private practice, inpatient or community settings.

Thirteen clinicians participated in this study; 10 women and 3 men. Two of the men interviewed for this study were licensed clinical social workers with MSW degrees, one of which works in private practice and the other in an outpatient clinic. The third

male holds a PsyD and works in an outpatient setting. Of the 10 female participants, 8 hold MSW's and 2 hold PsyD's. While 7 of the female participants work on inpatient or rehabilitation units primarily, 2 work in outpatient settings and one works primarily in private practice. All participants have a current caseload of clients with dementia comprising 2-80% of their entire caseloads. All participants self-identified as white. Efforts were made to recruit clinicians diverse in race, gender and professional experiences with a population of persons who have dementia.

### *Recruitment Process*

Various social service agencies and private practices in the Western Massachusetts area were identified by internet search. Other participants were identified through professional contacts at my field placement. I asked for referrals through these contacts and received the names of people working with the population of interest. I contact these people by telephone and email with the same recruitment letter. When I received responses, I reviewed the required characteristics to ensure that all participants met the criteria. Participants were emailed or faxed an informed consent letter for them to review, sign and return prior to scheduling an interview. The letter of informed consent that was emailed and faxed to participants included an explanation of the purpose of the study and efforts to ensure confidentiality. Some interviews were face to face while others were conducted by telephone. All participants agreed to have the interview audio recorded. At the beginning of the interview I reviewed the signed informed consent and asked each participant to answer demographic questions including: sex/gender, race, number of years in the mental health field, specific educational/training experiences in

elderly mental health care; and the amount of elder clients with dementia on their current caseload.

### *Informed Consent Procedures*

A copy of the informed consent letter was sent by mail, e-mail and fax to the participant prior to the interview. For face-to-face interviews, informed consent signatures were obtained through personal contact immediately prior to the interview. I brought two copies to the interview, one for the participant to keep and one for myself. For interviews completed by telephone, the informed consent was sent to the participant to be signed and returned before the telephone interview. At the beginning of the interview the informed consent was reviewed with each participant. I provided a brief explanation of the project purpose and design and describe the nature, benefits and risks of participation. Each person was asked to answer voluntary demographic questions to identify the diversity of the participants.

### *The Nature of Participation*

I conducted individual face-to-face interviews at mutually agreed upon times in semi-private setting such as offices where confidentiality and safety could be maintained. Interviews were also be completed by telephone. Participants were informed that the interviews will be audio recorded and transcribed by this researcher following the interview. Each interview lasted between 15-45 minutes. Participants were informed that their participation is completely voluntary and that all identifying information would be removed to ensure confidentiality. Participants were reminded that they were able to refuse to answer any question and that they could withdraw from the study at any time before March 30, 2010.



### *Precautions Taken to Safeguard Confidentiality and Identifiable Information*

Each interview was audio taped. All names of participants were removed from initial surveys and codes and numbers used in their place. Informed consents and any additional paperwork with identifying information on it were kept in a secure and locked location in addition to being separate from transcribed interviews so as to protect the identity of the participants. Interview audio files were secured and password protected during the course of this research endeavor to ensure confidentiality and standard to Federal regulations will be kept for three years following completion of this research project and subsequently destroyed.

I personally completed the transcribing of all interviews and did not share any identifying information with outside sources with the exception of my research advisor. Electronically stored information was password protected and was not able to be accessed by individuals other than myself. After writing the findings, I assigned the audio file and transcript an ID and changed all identifying information. Although interview quotes were used, all identifying information and names were removed during the transcription process. Transcripts were not shared with anyone and all information was presented in aggregate without identifying information. Due to the qualitative nature of this study, anonymity was not possible. Again, any and all identifying information was removed in order to ensure confidentiality for each participant.

### *Data Collection Process*

Data was collected using a semi-structured individual interview. Interviews were held in locations that were most convenient to the participant or over the telephone. Federal regulations and confidentiality regarding the audio recording was included in the

review of the informed consent form with each participant prior to the interview.

Participants were notified that their statements may be used for publication at some point in the future and that this Master's thesis was part of graduation requirements for the Smith College School for Social Work. Although a copy of the informed consent letter was sent during the recruitment process, I brought another copy to the face-to-face interviews. The demographic questions were also reviewed prior to the interview questions. All interviews were recorded using a digital voice recorder. I also took handwritten notes and on occasion asked participants to further explain statements.

Immediately following the interviews, each survey, demographic questionnaire and audio file was coded with a number and transcribed word for word. Interview questions focused on what clinicians perceive to be triggering events, their experiences with dementia, useful techniques and impact on therapy.

#### *Data Analysis Process*

Data collected from interviews was analyzed by this writer. Demographic questions and interview responses were analyzed separately with interview responses being transcribed and coded for common themes. Data was reviewed and common themes were highlighted as they emerged throughout participant response.

## CHAPTER IV

### FINDINGS

This study asked the following research questions: What is your experience as a clinician working with elders who have dementia? As a clinician, what is your understanding of trigger events? How do you incorporate the knowledge of triggers into your therapeutic process? Tell me about the types of events that you have found that trigger elderly onset of dementia: medical? Trauma? Etc? What specific techniques have you found helpful in working with elders with sudden onset of dementia? The major findings of this study indicate that most respondents are familiar with the term “trigger events” and possessed a thorough understanding of the possible events that can contribute to dementia onset in any way. This chapter will include an in depth description of the qualitative findings.

#### *Similar Experiences Working with Dementia*

Most clinicians interviewed have experience working in inpatient or nursing home settings, community practice settings and clinics, and private practice. Services provided most commonly in this field include psychotherapy or supportive counseling, family work, screening or assessments, and case management. Other less frequent experiences include neuropsychological testing, advocacy, support groups, home visits, outreach work, and program development.

*Nature of trigger events: from medical procedures to toxin exposure*

The most commonly understood trigger event reported was loss of a significant person, either a spouse or significant other, child, social network, or caretaker. The majority of clinicians responded that they understood there to be some type of incipient dementia present that a trigger event exacerbated. For example, many clinicians believe that often there is an incipient dementia present, but is unnoticed because a spouse or caregiver may be over-accommodating for the person with dementia. When the spouse or caregiver dies, the incipient dementia becomes more evident to others. One clinician in private practice described her understanding:

My personal opinion is that the illness is already there and somebody is traumatized enough by the death of a spouse, retirement, or loss of any major kind of anchoring supports all of a sudden we see these symptoms. My sense is that illness is already there, it's just that the person is so grounded that we don't really see it until we remove those major thwarts and all of a sudden the person seems to be ill. They are just not able to adapt and adjust the way somebody without any of that vulnerability could. But then on the other hand it could be that it actually rattles their system enough that it actually triggers the onset of that illness.

The symptoms of dementia are often more obvious following traumatic events, perhaps due to the brain's inability to accommodate change. The brain may be less able to adapt during a stressful time, or the event could be so profound as to cause changes in the brain.

Some clinicians also acknowledged the influence of medical events including traumatic brain injury, stroke, other vascular events, hypoxia, metabolic disorders, and

anesthesia. Genetics and substance abuse were commonly noted trigger events to dementia. These events are more easily identified through use of medical tests. One participant explained,

Sometimes CT scans and MRIs can show events in the brain that would explain vascular dementia and that would involve some kind of anatomical change.”

Other medical tests could unveil uncontrolled hypertension. Urinary tract infections can cause disorientation or delirium. The same participant recalled, “There’s that old saying in clinical gerontology that if you have an older woman who presents in the emergency room with psychiatric decompensation, the first thing to do is a urine test because especially older women are much more prone to urinary tract infections than anyone else. Urinary tract infections really, really make older people very different. Delirium will look like dementia in somebody who does not otherwise have dementia. It will also exacerbate dementia that is already there.

It is useful for clinicians to ensure medical tests in order to rule out conditions that resemble dementia. Once this happens, the clinician has a clearer picture about what type of dementia they are working with.

Several psychosocial stressors were typically identified such as changes in lifestyle, social isolation, family changes, retirement, sensory deficits, change in environment, and relocation. One participant explained the influence of lifestyle factors,

Some of the research coming out of the Alzheimer’s Association is about the lifestyle choice that people make are as important in delaying the onset of

Alzheimer's as the things that you're born with and they are as effective as some of the neuroprotective medications that are on the market, so it's really an interplay of what you're born with and the choices you make in your life.

A key finding was that some clinicians perceived "trigger events" as events that made existing conditions more noticeable. Specifically, some clinicians perceived that 'trigger events' were events that actually made an existing dementia worse or more noticeable. These clinicians emphasized that there was a form of dementia present prior to the event, though perhaps before these events, dementia was not really evident. The 'trigger events' seemed to heighten the dementia, rather than lead to it:

I don't think that trigger events are what create dementia, but I think that trigger events are what make dementia worse... The way I see trigger events working is if someone has dementia (and sometimes that's fairly well masked), an event such as a loss or particularly, a medical event really traumatizes or re-traumatizes the person and that is where I see triggers making a huge difference in terms of cognitive loss.

Another participant similarly explained, "I think of dementia as an organic brain disorder independent of circumstances. But I can think of situations in my experience in which situations of stressful circumstances brought it to life."

Depression was another trigger event identified, often along with anxiety. One participant explained,

I don't know that anxiety and depression are trigger events, but they certainly go along with the onset of dementia. I do think that treating particularly anxiety can

sometimes improve cognitive function so I think that there are a lot of people that become pretty panicky when they start to feel disoriented and start to have difficulty organizing things to the extent that they used to. And I think that it just triggers this kind of anxious mood that makes focus and concentration more difficult, so I've had some luck with having clients get supportive therapy and typically an SSRI.

Anxiety and depression may be considered 'trigger events', but may also be symptoms of an existing dementia. Depression and anxiety can produce similar cognitive effects and appear similar to dementia. For some of these clients, medication and therapy to treat the depression and anxiety are effective options.

Only one clinician identified age as a trigger event for dementia, describing it as "the window for the onset of dementia gets open wider the longer you live." The probability of developing dementia as a person ages is increased.

#### *How trigger events are used in the therapeutic process*

The clinicians interviewed incorporated the knowledge of trigger events into the therapeutic process in various ways. The most commonly reported answers were through family work, through psychoeducation and diagnostically. One participant summarized this, "I do a lot of education and I try to do a lot of normalizing with not just the client. When you're working with a geriatric population, families come with the clients quite often."

Some of those interviewed believe that understanding the trigger events can inform them of the loss of skills and abilities or general cognitive decline, present stability and helps them create plans for the client:

You would want to know about any current trauma and you'd also ask about any past trauma for kind of different reasons. The current trauma you would want to get an idea if there are any current events that are exacerbating symptoms. With past trauma you want to get an idea of how they would be coping with current trauma based on their history.

Others are able to use the information about the triggering event to determine whether or not medication may be necessary or beneficial.

The knowledge of trigger events informs the use of basic clinical skills such as tailoring communication and learning the client's cues for a few participants. One social worker on a psychiatric inpatient unit describes the following:

The therapeutic role most of the time with being present with someone who has dementia is just actually being present with them and learning their cues and just getting in tune with them. As a social worker on an inpatient setting, I think that very often my knowledge about triggers impacts how I approach working with the patient and the family, which is a big part of my role. A lot of times folks who come in from home or from a nursing home or other setting like that, we really have to look at some of the behavioral causes that led to them being inpatient. We have to work with the family or providers on things that led to them needing this



level of care. So I think that my knowledge of triggers is really important and crucial in my role.

Understanding the behavioral causes and events contributing to inpatient admission is necessary for discharge from an inpatient unit. Another clinician echoed the importance of using the trigger events stating:

Those stressful events are going to be a lot less stressful if they can be talked through. People can be helped even to just recognize that these are very understandable feelings help to reduce the confusion that people have and I find it to be really helpful.

Information about a trigger event may allow a clinician to normalize, validate and provide an outlook for a client who is experiencing a trigger event. Resolving stress about the trigger event may have an impact on the presenting dementia.

Not all clinicians felt that knowledge of triggers was important for their therapeutic role with the client. A small few specifically stated that knowledge of trigger events was not used in psychotherapy. Of the two participants that reflected this finding, one explained:

At some point the reason I come on board has little to do with the individual psychotherapy with the person because they are not interested in what got them confused as much as they are say if they are manifesting behavioral changes or they are at risk because they are not managing well at home or if the family is concerned and doesn't know what the next step is when a dementia diagnosis hits. I certainly do talk with the individual, the dementia patient, about what has just

happened. How really able they are to work through it at that point is unclear to me.

Although this participant does not strictly rule out use of trigger events in psychotherapy, a client centered approach is emphasized.

### *Types of trigger events*

Participants were asked to describe the types of events that that trigger elderly onset of dementia. The participants obtain this information through a variety of ways, self report by the client, family report and medical history. The trigger event is not always clear and often the clinicians use their own judgment to form an understanding of what events precipitated onset of dementia. It is common for clinicians to begin working with a person with dementia following a trigger event:

I do think a traumatic shock to the system. I was talking about physical, but emotional would definitely do it too. I usually hear about it more when I'm doing a history. I'll find out what was going on with this person and I think maybe what the case is that people are going along with their lives and there's this underlying process and you don't see it, but then there's this shock to the system whether it's a hospitalization or the trauma and then suddenly things are all shaken up and they don't get back to their baseline.

When asked to describe the types of events that trigger elderly onset of dementia clinicians typically classified types of events as medical or emotional trauma.

Hospitalizations, anesthesia, vascular events, toxin exposure and surgical interventions are the medical trauma events that are commonly understood by participants to influence

dementia onset. Emotional trauma or psychosocial events such as PTSD, retirement, moving, social isolation, depression, and substance abuse were identified. Moving or relocating to another home as many elderly people do is thought to have an impact on dementia because of the change in environment, routine and pattern. A participant stated, “That can kind of disrupt things for patients especially if it’s to a more stimulating environment, like a nursing home after they’ve been in their own homes by themselves.” For some people even moving to another side of the room is a triggering event.

The most commonly identified emotional trigger event was the loss of a spouse, child, or caregiver and was noted by nearly every participant. One participant clarified the way that she views the loss of a spouse as a triggering event:

The way we see loss of a spouse is not a triggering event, is that often spouses cover for each other without even realizing that that’s what they’re doing. It’s this very subtle dance where a wife may start to rely more and more on a husband to make decisions. And the husband without even realizing it may be cuing the wife more and more to keep her on track. And then if the husband is either suddenly hospitalized or dies the wife is going to be not just grieving the loss of the spouse, but also not having that support system. That’s often when kids say, “We didn’t realize how bad mom was. Mom has gotten much worse since dad died.” But it’s not necessarily that mom’s gotten that much worse, it may be that it’s that much more evident because they really were relying on the spouse for keeping them on track and keeping their anxiety under control because they felt very safe with them. And for any of us, if we feel more anxious our brains aren’t going to function well. In doing the dementia evaluations, we not only look for dementia,

we look for anxiety and depression. Not as causal, but as masking. They used to talk about pseudo depression and I think that's not so in vogue in the literature anymore to call it a pseudo depression as much as it is to say if you're depressed you're not functioning cognitively as well as when you're not depressed. If you're anxious, you're not coding information as well because you're not paying attention to it, not because you have a primary problem with encoding, but because you're not concentrating on it. Not because you have dementia, but because you're distracted.

When a person begins to show signs of dementia that were not seemingly present before his/her spouse's death, it is often assumed that the deceased spouse was providing a lot of structure for the person with dementia. The family begins to notice the signs of dementia after one parent has died because the family assumes a more involved role in the remaining parent's daily life. Simply stated by another participant, "Any unexpected and significant life change definitely would cause not only anxiety and strong emotion but would also require the person to really function a lot more cognitively than they've had to." Some people are unable to accommodate this type of cognitive change required to adjust to a different daily life.

In addition to death of a significant person, various types of loss associated with old age were noted including loss of purpose or responsibility, loss of housing, loss of independence and loss of skills and abilities. One participant working on an inpatient unit described the significant toll that compounded loss can have for an elderly person stating, "Multiple significant losses can really be a major trauma. There's certainly a lot of

stressors that go with aging, but I see it more with the bigger traumatic ones.” A single traumatic event is often seen to have a profound impact on a person’s cognitive abilities. When multiple traumatic events are experienced in sequence to each other, it seems that the triggering effect can be even greater.

### *Family involvement*

The family becomes aware of the dementia patient’s declining cognitive abilities through various ways. Often times a family notices a change in the surviving parent after the death of a spouse. Participating clinicians most often understood this to mean that one spouse was providing a lot of structure and routine for the patient with dementia. However, this dementia may have gone unnoticed to all parties and the over-accommodating may have happened subconsciously. After the spouse’s death, the family becomes more aware of the remaining parent’s inability to carry out tasks of daily living like tooth brushing. The person with dementia may make medication errors or driving mistakes. Some families become aware of changes in the patient’s personality like increased usage of “four letter words” and false accusations. Repetitive story telling is often a signal that family members are in tune to. A participant stated, “Within the dementia process they can’t necessarily make those filters.” This inability to filter information in the same way as before is attributed to structural changes in the frontal lobe of the brain. Most clinicians also noted that families notice the mental health issues or mood changes that accompany dementia like depression and anxiety. However, clinicians state that even when these mood changes are present, the person with dementia may not even be aware. The family member is typically more distressed than the person with dementia and is mostly responsible for bringing the person in for treatment.

### *Useful techniques*

The specific techniques that clinicians found useful when working with this population varied from practical to therapeutic interventions. Clinicians recommended ordering baseline medical assessments, neuropsychological evaluations in order to properly assess what type and stage of dementia the client is at. The stage of dementia largely determines what kind of treatment the clinicians provide:

In thinking about psychotherapy I really try to figure out where the person is in the process of dementia. Because early stage, you are usually very able to talk about their feelings and their losses and their understanding about what is happening to them. It varies mid stage to dementia and end stage, they don't even have language. So whether you're doing psychotherapy with someone really depends on where in the dementia process they are and how much I'm doing supportive work versus more in depth work.

The participants commonly reported this type of supportive work as a useful technique. Although supportive therapy is typical in most therapeutic roles, when working with clients with dementia the supportive role is focused on the following: "Support around lifestyle change, around cognitive change, around ability change. Trying to help people restructure their environment around lifestyles so they can support a higher level of functioning." As reported above, changes in environment can be especially disorienting for the dementia patient. Discovering new ways to accommodate change in the environment is a useful tool.

Practical techniques reported include providing structure for the client, introducing self-soothing, introducing lifestyle changes, referring to support groups, providing sensory stimulation, distraction, visualization and memory strategies. A clinician working on an inpatient unit suggested, “Any self soothing that they might be able to engage in. If they like music, sensory stimulation, some foods, some tastes, some smells, some music, but anything that is familiar to them that they can still engage in.” The familiarity produced with sensory stimulation is thought to comfort the person with dementia and help reduce anxiety. As previous statements have described, clinicians see increased cognitive functioning when anxiety levels are reduced. With the same reasoning, many participants also find utility in treating any associated depression or anxiety.

Family work is an important component of working with an elderly dementia population. Nearly all participants stated that family work comprised a large portion of their work:

I have actually found it more helpful to work with families because they are usually the ones who are more concerned or distressed about the dementia. Sometimes the people with the dementia are not aware of it, or of depression as well, but it is almost more important or just as important to work with the families.

At times the person with dementia is brought in by the family and is much less involved in the treatment in some ways. Indirectly working with the client who has dementia

through the family can have a significant impact for the identified client. Participants are able to ensure a stable support network for the client through family work.

Really what people need is family support and structure. The adult children need to feel like they are capable of managing whatever is going to come up. If there is an associating depression or anxiety I treat that behaviorally in the older person. Make sure the support system is in place, so I would say much more family intervention than anything.

Most of the clinicians interviewed stated that they viewed their primary roles as providing education to the person with dementia and the family. Establishing a secure support network was mentioned consistently, coinciding with the frequently reported practice of involving the family as described above.

Participants found certain clinical skills to be helpful when working with elders with dementia. They identified the use of nurturing, normalizing, validating, following cues, being present, using attachment, Cognitive Behavioral Therapy, and reminiscence therapy. Some attest that anxiety can be relieved with the use of normalizing and validating the experience of dementia for both the client and the family. Some participants believed that case management skills are utilized more with this population than therapeutic skills. A program director described this as:

Case management in terms of connecting them to services, getting them started with whatever treatment is out there, the medications, memory medications. I used to refer people with mild cognitive impairment to the group at the hospital, but that is not there anymore. I do a little bit of teaching memory strategies and



usually that is more with the families so it is a range of environmental changes in the house if that person is at home. Labeling things, making lists, making signs. I do a little bit with the elders with the dementia themselves like keeping a notebook, writing things down, referring to the list.

Both families and the person with dementia can benefit from being taught memory strategies and being encouraged to make environmental adjustments. Each of these techniques is intended to improve the cognitive functioning of the person with dementia as much as he/she is able. The use of trigger events in therapy was primarily reported to be through family work, psychoeducation and diagnostically.

### *Summary*

The key findings of this study are that clinicians working with elders with dementia shared similar professional experiences ranging from inpatient rehabilitation programs to private practice. The nature of trigger events was found to vary between medical, environmental and psychosocial. Types of trigger events were most commonly categorized as medical or emotional trauma. The family member is typically found to be more distressed than the person with dementia and is mostly responsible for bringing the person in for treatment. When asked about useful techniques for work with this population, participants responded that medical assessments are important for a differential diagnosis. Participants also reported family work as the most useful tool.

The following chapter will explore the meaning of these findings. It will conclude with the study's research limitations, and implications for future social work practice and research.

## CHAPTER V

### DISCUSSION

The objective of this qualitative study was to explore what clinicians treating elderly clients with dementia perceive to be triggering or precipitating events to dementia. The known, unknown and hypothesized influences of dementia were explored through the narratives of clinicians treating dementia in various settings. This chapter offers a discussion of the key findings. Further, this chapter offers implications for future research and for clinical social work, limitations of the current study, and final comments. The findings will be presented according to the key themes that emerged, including: accommodating change, incipient dementia, family work, depression and anxiety, use of trigger events in therapy, and medical events.

#### *Accommodating Change*

A review of the literature reveals that current writings on trauma and dementia focus on the brain's inability to accommodate change following a traumatic or stressful event. The findings from this study support Bryden's (2002) statements that brain function is reduced by way of the various diseases that cause dementia.

The neuropathology of the various diseases that cause dementia results in a reduction in brain function. This impacts on a person who has a unique life story and psychological status, and important current and past human and spiritual relationships, set in a social environment (p. 142).

As cognitive decline progresses, the person's ability to cope changes and day-to-day activities are impacted. Participants described the ways in which the person's threshold for stress is lowered by whatever mechanism. One participant stated:

If you have a fragile brain, if you are starting to have issues of dementia with cognitive changes and then there is an event, a life changing event, whether it is the loss of a spouse, whether it is relocation to a new community, I think people are less able to cope with that. Their frontal lobes may not be as resilient. They may not be able to use some of the skills that they have used previously to cope with anxiety. The people that they have relied on may not be available for them to rely on which may make them more depressed and anxious and if they are more depressed and anxious, the underlying brain functioning is going to be more stressed.

As changes in daily routine, changes in environment and new tasks are introduced the person is no longer able to tolerate these changes as well as they were able to before.

Current literature establishes that a person's coping mechanisms influence the presentation of dementia. Participants in this study provided statements that support this and emphasized the importance for gathering a history. A participant explained that past coping skills might inform the clinician about what the person may be currently using:

You would want to know about any current trauma and you would also ask about any past trauma for different reasons. The current trauma you would want to get an idea if there are any current events that are exacerbating symptoms. Past trauma you want to get an idea of how they would be coping with current trauma

based on their history. And then if you find for example that they retired two years ago, their wife died one year ago, they have not been doing well since then, they have not been eating as well, that have not been sleeping as well, you start getting information about what could be contributing to their cognitive decline.

This participant points out the importance of gathering a comprehensive history including past trauma as that may impact their current functioning.

### *Incipient Dementia*

The participant's responses to the understanding of trigger events specifically loss of a partner, child, or other significant person, corresponded with Mild Cognitive Impairment literature. Findings showed that clinicians viewed events of loss not as triggering, but as uncovering a pre-existing dementia. Participants described unidentified stages of dementia consistent with the definition of Mild Cognitive Impairment: "cognitive impairment greater than that expected for an individual's age and education level, but that does not interfere notably with activities of daily life" (Gauthier et al., 2006, p. 1262).

Most clinicians noted that they did not typically see these clients until after there was more significant dementia present, after an event like the death of a spouse. One participant stated:

The way I see loss of a spouse is not a triggering event, but often as spouses cover for each other without even realizing that that is what they are doing. It is this very subtle dance where a wife may start to rely more and more on a husband to make decisions. And the husband, without even realizing it may be cuing the wife

more and more to keep her on track. And then if the husband is either suddenly hospitalized or dies, then the wife is going to be not just grieving the loss of the spouse, but also not having that support system and that is often when kids say, “We didn’t realize how bad mom was. Mom has gotten much worse since dad died.” But it is not necessarily that mom has gotten much worse, it may be that it is that much more evident because they really were relying on the spouse for keeping them on track and keeping their anxiety under control because they felt very safe with them.

The presentation of clients to treatment after a stressful or traumatic event is re-enforced by most of the participants. Another reason may be due to the varying professional experiences of the participants and the avenues by which clients present to them. This finding was a surprise to this researcher due to the fact that it was not present in the literature reviewed for this study.

Participants observed a loss of self-esteem accompanying memory loss at stages of dementia where activities of daily living were affected. This finding is consistent with the literature of Knopman et al. (2003) in which it is noted that self-esteem loss appears to accompany memory loss. In the current study, participants suggested strength based approaches, nurturing and supportive therapy in order to build or maintain self-esteem.

#### *Family Work*

According to the current literature of Mild Cognitive Impairment, diagnosing MCI often requires corroboration from family and friends because the dementia is still in a stage where the client may be unaware of his/her diminishing capacity (Knopman et al., 2003). In this study, participants acknowledged the important role of working with the

client's family or support network. Some participants stated that they work primarily with the family and most often found that someone else like a family member brought the client in for treatment. As one participant described:

The kind of re-orientation required for that kind of move from their own home to assisted living or living with family members ends up being more challenging. Because of that challenge people around them realize that they are not really processing very well.

Another participant described other ways that the family becomes involved stating:

The family becomes aware of diminishing abilities to do daily living activities, errors in daily living, examples: people leaving the stove on or driving accidents that they never used to have, suddenly not being able to manage their funds anymore. On occasion there are behavioral changes that the family noticed. Suddenly more disinhibited, they might be more inappropriate in social settings, things like that. If they start swearing when they did not use to swear. And a lot of the time there is a response to medical procedures and respond with any kind of delirious reaction can bring them into treatment for evaluation of dementia.

Through working with the family, clinicians are able to establish a consistent support network and resolve other psychosocial stressors. The benefits of family work are described by one participant, "It just seems to me that extended family members need a lot of support and sometimes just seeing another person interacting with the person who has dementia is helpful in that way. I think that if the person with dementia has a basic sense that their family members are not burdened and feel okay, that they feel better."

Most of all the participants reiterate the idea that family work is an essential component of work with the dementia population and that most times the family is responsible for bringing the client in for treatment.

### *Depression and Anxiety*

When discussing depression and anxiety, the most common theme that emerged was the need to treat depression and anxiety behaviorally and/or through the use of medications. Clinicians reported that anxiety, depression, denial and psychosis are reactions to the cognitive decline, as is also stated in the literature of Bryden (2002). Most clinicians viewed depression as reactions to declining abilities, not predictor of dementia. Most also described a level of confidence in the ability to treat depression and anxiety behaviorally and with medication. Although participants explained the importance of referring clients to receive MRI's and other diagnostic tests, they did not explicitly discuss the relationship to hippocampal volumes to depression that is prevalent in the literature of Frodl et al., (2006); McCullagh et al., (2001); and Sheline et al., (2003).

### *Use of Trigger Events in Therapy*

Bryden (2002) suggested the following techniques to promote emotional stability, self-esteem, and self-identity:

Establishing a relationship in which the patient feels cared about; providing an emotional outlet; enhancing self-esteem; minimizing psychological and behavioral difficulties; increasing coping skills; enhancing role function; giving sense of control; allowing grieving for losses, capacities and relationships; developing and maintaining the most mature and productive defenses possible

while shedding inappropriate ones; developing insight; and finding a sense of meaning (p. 150).

Findings from this study were consistent with these suggested tools, as many clinicians reported using those mentioned in conjunction with CBT, supportive therapy, nurturing, etc. for the chief goal of helping the person increase cognitive function and reduce anxiety.

### *Medical Events*

Participants addressed many of the events responsible for causing vascular dementia such as strokes, hypoxia, vascular changes in the brain, hypertension, diabetes, and head injury. These types of events are well established in the scientific literature of vascular dementia. As previously mentioned, participants validated the need to order a baseline medical evaluation and neuropsychological evaluation in order to determine the nature of the dementia.

Although much of the literature described in this review discusses the difficulty of diagnosing dementia, participants did not express difficulty with this task. This may be in part due to the differing roles of the participants surveyed and due to the varying stages of dementia at which clients are seen. Many clients already have an established diagnosis of dementia by the time they present for treatment with the participants surveyed.

Although age is the most well known risk factor for dementia (van der Flier & Scheltens, 2005), only one clinician described age as a trigger event. Age as a risk factor is prominent within literature hypothesizing that it is because the clients are exposed to



environmental or genetic factors increasingly over time (McCullagh et al., 2001). One participant stated:

Some of the research coming out of the Alzheimer's Association is about the lifestyle choices that people make are as important in delaying the onset of Alzheimer's as the things that you are born with and they are as effective as some of the neuroprotective medications that are on the market. So it is really interplay of what you are born with and the choices you make in your life.

The literature also supports this by stating,

After 65 years of age, the incidence and prevalence of Alzheimer's disease doubles every 5 years. It is reasoned that older individuals have longer exposure to putative environmental and genetic influences. However, Alzheimer's disease in advanced age is not inevitable; differences in distribution and density of senile plaques and neurofibrillary tangles exist between patients and age-matched controls (McCullagh et al., 2001, p. 24).

Genetic factors and environmental factors are both believed to be responsible for contributing to dementia, but research is unable to express the exact relationship between these types of factors or quantify what amount of exposure is necessary for dementia to be present.

#### *Implications for clinical social work practice*

These findings have implications for future clinical practice. First, clinicians working with people with dementia should perform full assessments of the clients that they encounter in order to consider what events or factors might have impacted the onset

of dementia in any way. Second, clinicians should become familiar with the techniques and treatments that are effective with this population. Due to the closing of several programs for elders with dementia, clinicians in the Western Massachusetts area are increasingly required to perform a variety of roles in their work with this population. They may be required to take a more active role in diagnosing dementia, as some of the facilities where people were diagnosed are no longer in operation.

### *Study limitations*

There are several limitations of this research. Sample size was relatively small with only 13 participants. Future study may be conducted as a survey type study, with a greater sample size, perhaps using web-based system such as Survey Monkey. Another limit was that this study was racially homogenous, and consisted solely of participants who worked in midsize towns in Western Massachusetts, which limits the generalizability of the study. While the researcher would have liked to have a larger and more diverse sample size had timing allowed for a more thorough selection process and further interviewing, the research provides a strong beginning for further research in the dementia field and an initial sense of where further exploration is needed.

### *Conclusion*

On the topic of emotional or psychosocial trigger events to dementia there continues to be a lack of literature that this study aims to fill. The main point from this study is that clinicians shared a basic knowledge of trigger events to dementia including emotional trigger events. However, clinicians reported a different understanding of the way in which these events trigger dementia than this researcher originally hypothesized. Clinicians do report using the knowledge of trigger events in therapy as a way to discern

coping skills and identify areas to address. Recommendations for further research include exploration around the relationship between emotional trauma and dementia, and research about incipient dementia. Research is also needed regarding treatments that can slow cognitive decline.

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## APPENDIX A: HSRB APPROVAL LETTER

January 12, 2010

Ashley Diaz

Dear Ashley,

Your second set of revisions has been reviewed and all is now complete. We are happy to give final approval to your project.

*Please note the following requirements:*

Consent Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your interesting study.

Sincerely,

Ann Hartman, D.S.W.  
Chair, Human Subjects Review Committee

CC: Elaine Kersten, Research Advisor

## APPENDIX B: INFORMED CONSENT FORM

Date:

Dear Participant:

My name is Ashley Diaz and I am a second year graduate student at Smith College School for Social Work. While working on my Masters in Social Work, I am required to complete a master's thesis. This master's thesis will be used to fulfill graduation requirements (presenting the results to the Smith community) and has the possibility of being submitted for publication. The purpose of my research is to gather the unique perspectives that clinicians treating elderly persons with dementia may have about what they perceive to be the triggering events to dementia and how these events manifest. I am interested in the use of these traumatic trigger events in therapy.

I am asking that you be a participant for my study based on the fact that you meet the following criteria; Have an active caseload of elders with dementia; Have an advanced clinical degree such as a clinical social worker, with a master's degree in social work (MSW), a psychiatrist or clinical psychologist or other Master's level mental health clinician; have had continuing education/training in working with elders; are able to conduct a face-to-face or telephone interview in English. Interviews will last approximately 30-45 minutes. Interviews will be recorded and transcribed by this researcher following the interview. Participants will be screened during initial phone or e-mail contact and given a brief demographic questionnaire during the interview. Participants who will be interviewed by telephone will be sent a copy of the informed consent to sign and return prior to the interview.

Minimal risk from participation is anticipated for this study. You may feel uncomfortable at times because you are sharing and exposing personal opinions that might be judged and/or compared to those of other clinicians. Expectations for confidentiality will be discussed at the beginning of every interview. Although information will be held in confidence, it is not possible to guarantee anonymity in this study.

You will receive no financial compensation. A benefit of participation in this study would be that as a clinician, you would be given the opportunity to further examine your own knowledge and understanding of trigger events to dementia and will be able to evaluate your use of those events in therapy. At your request, I will send a summary of the results of this study. These findings may give useful information in terms of how other clinicians in the mental health field recognize and address the trigger events of dementia. It is possible that the results of this study will generate further investigation into dementia and increased awareness of clinicians to utilize these events in therapy.

The interview will be audio taped. I will transcribe and analyze all the data. I will keep all materials in a locked file cabinet for three years according to Federal regulations. After the three year period, the data and audio recordings will be destroyed, provided that I no longer need access to them. No identifying information will be included to ensure confidentiality. My research advisor will have access to the confidential research data

after all identifying information is removed. Any quotes or vignettes will be disguised to eliminate identifying information in order to ensure participant confidentiality.

Participation in this study is completely voluntary. You may withdraw before, during, or after the interview until March 31, 2010. You may also refuse to answer any question. If you withdraw from the study, all materials relating to you will be immediately destroyed. All materials will be destroyed when I

If you have any questions about this study, you may e-mail me at the address provided. You may call the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413)-585-7974.

Thank you for your time and willingness to participate in this study.

**YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.**

Participant Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Research Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Researcher's contact:**

Ashley Diaz

Please keep a copy of this consent for your records.



## APPENDIX C: INTERVIEW GUIDE

- What is your experience as a clinician working with elders who have dementia?
- As a clinician, what is your understanding of trigger events?
- How do you incorporate the knowledge of triggers into your therapeutic process?
- Tell me about the types of events that you have found that trigger elderly onset of dementia? Medical? Trauma? Etc.?
- What specific techniques have you found helpful in working with elders with sudden onset of dementia?