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The effect of the reciprocal nature of friendship on the experience of Malignant Social Psychology in community dwelling persons with mild to moderate dementia

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A Thesis

entitled

The Effect of the Reciprocal Nature of Friendship on the Experience of Malignant Social

Psychology in Community Dwelling Persons with Mild to Moderate Dementia

by

Jennifer J. Perion

Submitted to the Graduate Faculty as partial fulfillment of the requirements for the

Master of Liberal Studies in

Adult Liberal Studies

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The University of Toledo
May 2016

An Abstract of

The Effect of the Reciprocal Nature of Friendship on the Experience of Malignant Social

Psychology in Community Dwelling Persons with Mild to Moderate Dementia

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Social scientists have identified negative social exchanges, known as Malignant

Social Psychology, that can erode perceptions of self-worth and negatively influence

one's social identity. When a person with dementia encounters social exchanges such as

shunning, infantilization or stigmatization, it creates a negative experience that can be

especially difficult to overcome. Friendship, which is a mutually voluntary relationship

often outside of the caregiver/care recipient dynamic, may offer benefits for persons with

dementia if it has a reciprocal nature that provides opportunities for a more balanced

exchange. This study examines friendship for persons with dementia, and whether

opportunities exist in such relationships for reciprocal behavior that might influence the

experience of Malignant Social Psychology for these individuals.

Six men and four women who identified as experiencing memory problems were recruited from education and support programs sponsored by a chapter of The Alzheimer's Association. The majority of the participants were White and had at least some college education. They had an average age of 76 years and all reported their health as good or very good. During a one-time face-to-face interview, participants were asked questions about existing friendships, including opportunities for mutual support and help. The data were analyzed using a qualitative phenomenological method that revealed themes of friendship that are valued by persons with dementia. Five themes emerged: 1) recognizing the importance of longevity in friendship, 2) helping one another is a normal part of friendship, 3) feeling "alive" through the give and take in friendship, 4) knowing somebody is there for them, and 5) seeking security through friendship.

Opportunities for further research into the importance of friendship as it pertains to feelings of positive identity and usefulness exist. Understanding the benefits that friendship provides, and ways to encourage the continuation of existing friendships, will allow professionals and caregivers insight into ways to provide enriching, fulfilling experiences for persons with dementia.

This thesis is dedicated to Barbara and Georgia. Your challenges, past and present, are the inspiration for this study.

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Chapter 1

Introduction

Advances in research methodologies in the early 20th century led to a greater understanding of the physiological changes in the brains of those who experience cognitive loss (Kitwood, Balwdin, & Capstick, 2007). What was once considered a normal part of aging, senility became a disease, and as a result became the responsibility of medical science (Kitwood, 1997). The strong focus on biological and physical science meant that the personal and social aspects of dementia were relegated to the background– a shift that has been referred to as the "'Alzheimeritization' of senility" (Ragnhild Hedman, Hansebo, Ternestedt, Hellstrom, & Norberg, 2013; Kitwood et al., 2007). When the social side of dementia was examined, it was mainly from the perspective of professionals and caregivers who tended to stress family and societal burdens over the individual experience (Beard & Fox, 2008; MacRae, 2010) and focused on the very worst scenarios for the individual with dementia (Hulko, 2009). Moved to the periphery of the discussion, persons with dementia became representations of the disease rather than individuals, limiting their societal roles and perceptions of self-worth (Beard & Fox,

2008; Heggestad, Nortvedt, & Slettebo, 2013; Hulko, 2009; Piiparinen & Whitlatch, 2011).

The introduction of the personhood movement in the 1990s began a shift in focus as social scientists began to look at the experience of dementia through the eyes of the individual, changing the way that living with the condition is understood (Ragnhild Hedman et al., 2013; Kitwood et al., 2007). Using a person-centered approach, researchers have developed theories such as Malignant Social Psychology, Social Constructionist Theory and Social Positioning Theory to understand how dementia threatens personal identity and recognize the tasks necessary to maintain relationships and a healthy self-image for persons with dementia (Ragnhild Hedman et al., 2013; MacRae, 2010).

Reciprocity is one of the key components to healthy relationships, but as a person with dementia begins to lose autonomy, opportunities to maintain bonds through give and take decrease (Graham & Bassett, 2006; Quinn, Clare, & Woods, 2015). Family relationships, while important to a person who is cognitively impaired, are threatened as the balance of power between caregiver and care recipient begins to falter (Forbes et al., 2011). Relatives and professionals often fall prey to stigma and pre-conceived notions about the limitations that exist for a person with dementia, overcompensating and removing opportunities for individuality and balance in relationships (Bourkel, Ferring, & Weber, 2012; Graham & Bassett, 2006). Often the care recipient reacts to

overcompensation with anger or frustration, which is misread as symptoms of dementia and creates even more imbalance (MacRae, 2010).

Friendship, which by nature is voluntary and mutually supportive, may help protect self-esteem for persons with dementia. Opportunities for healthy reciprocal relationships among friends and peers may help persons with dementia maintain a positive self-image and overcome negative experiences of social behaviors such as stigma and infantilization (i.e. Malignant Social Psychology) by providing relationships based on equality, shared interests, and camaraderie (Chen & Feeley, 2013; Clare, Rowlands, & Quin, 2008). This study reflects the possibility that the reciprocal nature of friendship influences the way that persons with dementia experience Malignant Social Psychology and enhances feelings of self worth.

Theories

Several theories have been developed to help researchers understand the social changes that occur as a result of cognitive decline. This section describes some of these theories, and how they relate to a discussion about the value of friendship.

The Personhood Movement and Malignant Social Psychology

Beginning in the 1990s, advocates began to focus on the personal experience of dementia. A forerunner in this movement was Tom Kitwood, a British psychologist who

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began to notice the way that the social and psychological elements of dementia care were almost completely subverted to the medical and scientific discussion – a trend that he referred to as the "standard paradigm" (Kitwood, 1997; Kitwood et al., 2007). Kitwood felt that too much emphasis was placed on the nuts and bolts of dementia, overshadowing the human element that had the potential to provide true comfort and happiness to persons with dementia (Sabat, 1994). His research focused on the way that societal reactions to people with dementia affects their quality of life (MacRae, 2010). "Our frame of reference," he asserted, "should no longer be person-with-DEMENTIA, but PERSON-with-dementia" (Kitwood, 1997, p. 7).

Kitwood's attention to the individual over the disease began a movement toward a person-centered approach of caring for people diagnosed with dementia. The personhood movement calls for people with dementia to be treated as if they retain all of the abilities necessary for active participation in personal and social activities (Hughes, 2014; Saunders, de Medeiros, Doyle, & Mosby, 2011). This person-centered approach, coupled with attention to early detection of cognitive deficits, encourages professionals to think about developing management strategies to improve the quality of life for persons with dementia rather than merely medicating and controlling behavior (Clare et al., 2008; Kitwood et al., 2007). As the person-centered approach spread, researchers noticed that the way an individual with dementia is treated often begins with assumptions about his or her abilities that are based on stigma. The diagnosis of dementia becomes a "master status" overriding all other personal attributes (Heggestad et al., 2013; MacRae, 2011). The term "excess disability" has been used to describe situations where disadvantaged

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persons are treated as incapacitated to a greater extent than the actual condition warrants

(Sabat, 1994). No longer viewed as competent, abilities and skills are questioned and

normally held roles of status or authority are diminished, creating a tainted identity

(Beard & Fox, 2008; Sabat, Johnson, Swarbrick, & Keady, 2011).

Kitwood identified seventeen ways that a person can be subjected to negative

social behavior, which he termed "Malignant Social Psychology" (Kitwood, 1997).

Table 1 The 17 types of Malignant Social Psychology

Accusation	casting blame on a person for behaviors or deficiencies that are due to illness or decline
Banishment	disregarding a person, acting as if he or she is not present
Disempowerment	Denying a person the right to use retained abilities or to engage in self-initiated activities
Disparagement	saying things to a person that causes him or her to feel less important or deficient
Disruption	intruding on a person physically or verbally, disturbing or preventing the person's personal wishes
Ignoring	speaking or acting in a way that excludes a person as if he or she were absent
Imposition	directing a situation or action, even when it is clear that the action is undesirable to the individual
Infantilization	speaking or acting toward a person as if he or she is a child
Intimidation	engaging in threatening communication (physical or verbal) that controls a person through fear or coercion
Invalidation	refusing to recognize and validate the emotions and experiences of another
Labeling	using a person's illness or disability as the primary identity, and basing all interaction on that definition
Mockery	behaving in a way that causes a person to feel humiliated or made fun of
Objectification	treating a person as if he or she is an object rather than an individual with awareness
Outpacing	intentionally communicating in a way that causes confusion or prevents understanding
Stigmatization	ostracizing a person and treating him or her as if they are unclean
Treachery	Using dishonesty or trickery to control or maneuver another person
Withholding	failing to provide for a person's physical or emotional needs

When the identified behaviors are present, they cause damage to a person's sense of individuality and self-image (Kitwood, 1997; Kitwood et al., 2007). Family members and professionals do not set out to treat another person in a way that creates embarrassment or diminishes self-esteem, rather they frequently jump to the conclusion that they must take disproportionate control because of assumed deficiencies that may not be present (Sabat, 2002; Sabat et al., 2011). In addition to the 17 behaviors that comprise Malignant Social Psychology, Kitwood identified 10 behaviors that promote positive interactions: recognition, negotiation, collaboration, play, sensory stimulation, celebration, relaxation, validation, emotional support, and facilitation. These positive behaviors, argued Kitwood, help people with dementia retain a positive self-image, remain socially involved, and experience a higher quality of life (Kelly, 2009; Kitwood, 1997).

It is important to note that Kitwood and the social scientists that followed were not denying the presence of a medical element in dementia (Ragnhild Hedman et al., 2013). Dementia is an incurable, degenerative disease. Damage to nerve cells located in the brain leads to the loss of cognitive skills including language, memory and the ability to solve problems. Alzheimer's disease, the most common form of dementia, affects 1 in 9 older Americans, and is the sixth leading cause of death in the United States (*2015 Alzheimer's Disease Facts and Figures*, 2015). In the early stage of Alzheimer's disease, problems with memory are limited to word and name recall and social difficulties that require planning and organization. A person in the early stage of dementia may lose or misplace objects and have trouble remembering recent events or new information. The

problems experienced at this stage are generally not serious enough to prevent the person

with dementia from living in the community or engaging in a social life. The middle

stage of dementia, which is generally the longest, involves even greater deficits in the

ability to recall information, including personal details. Confusion is more pronounced,

and mood swings occur more frequently. At this stage a person with dementia may need

more help with activities of daily living such as dressing and bathing. Cognitive decline

creates a greater increase in wandering and other dangerous behaviors. The late stage of

the disease often necessitates continuous caregiving as the person with dementia becomes

incapable of effectively communicating, voluntary movement skills decline and

susceptibility to complications such as pneumonia increases ("Stages of Alzheimer's,"

2015). The degeneration of abilities is accepted by social scientists; however it is asserted

that the experience of dementia cannot be limited to medical science to the exclusion of

social and personal considerations (Sabat, 1994). Kitwood wanted caregivers to think

about how people with dementia are treated socially and how that impacts their quality of

life (Hughes, 2014). Over time social scientists have added to the discussion of Malignant

Social Psychology through the application of Social Constructionist Theory and Social

Positioning Theory.

Perceptions of "Self" Using the Social Constructionist Theory

When a person is diagnosed with dementia, they are forced to integrate the

condition into their personal identity, including the burden of stigma and negative social

reactions (Beard & Fox, 2008). While recognition of a person as an individual is

important to the maintenance of dignity, it is often missing for persons with dementia with the focus instead on decline and loss (Heggestad et al., 2013; MacRae, 2011). To discuss this deficit, it is necessary to understand what is meant by identity. The Social Constructionist Theory, developed by Rom Harre´, has been used in research to explain the concept of identity and the ways that society contributes to personal identity. Social Constructionist Theory describes identity, called "selfhood" as having three parts: Self 1, Self 2, and Self 3 (Kelly, 2009; Sabat et al., 2011).

Self 1 is the internal sense of self that each person perceives as unique and special. Self 1 is described using words such as "I" and "me" (Kelly, 2009). This is an internal, intimate identity and is largely unaltered even in advanced stages of dementia. Even when personal history is lost, the ability to identify oneself remains (Raginhild Hedman, Hellstrom, Ternestedt, Hansebo, & Norberg, 2014; Sabat, 2002).

Self 2 is comprised of the beliefs that a person has about oneself such as skills, personality traits, special abilities and deficiencies. For persons with dementia, Self 2 is at risk because this identity is based on an accumulation of images and can be diminished when defined by negative attributes such as memory loss or cognitive limitations (Kelly, 2009; MacRae, 2010; Sabat et al., 2011).

Self 3 is the identity that others show to the world, and by which others perceive a person. Unlike Self 1 and Self 2, which are created by the individual, Self 3 requires that at least one other person cooperate in the creation and maintenance of the identity

(Raginhild Hedman et al., 2014; Sabat, Fath, Moghaddam, & Harre, 1999). How others behave toward and respond to a person with dementia largely influences his or her social position in the community. Positive social reactions put the person with dementia in a place of control and healthy self-image, while negative reactions create isolation and stigma that threatens the maintenance of a positive identity (Clare, 2003; Sabat, Napolitano, & Fath, 2004). Community influence on identity, especially Self 3, is known as social positioning, and a companion theory was developed to explain the hazards to identity which a person with dementia experiences, and the reactionary behaviors that are used to counter these threats.

Social Positioning Theory

Social Positioning Theory is used to describe the ways that people interact with each other, and how these interactions either support or break down the public identity of individuals (Sabat et al., 2004). Social positioning occurs when people in a social setting behave in a manner that determines the way an individual is perceived. A person's social identity (Self 3) is completely dependent upon the way that others allow him or her to be positioned, so the manner in which others respond to an individual can either support a positive position or create a negative position (Harre', Moghaddam, Cairnie, Rothbart, & Sabat, 2009). Positive social positioning encourages acceptance and a healthy self-image (Sabat et al., 2004). Negative positioning develops as a result of Malignant Social Psychology. An individual may react to negative positioning in an attempt to create a

more advantageous position, which is known as reflexive positioning (Sabat et al., 2004).When a person with dementia experiences instances of Malignant Social Psychology such as disempowerment or stigmatization, it can lead to the loss of self-worth and contribute to feelings of depression, frustration and anger (Scholl & Sabat, 2007). Often caregivers and professionals fail to recognize reflexive positioning, instead attributing reactions such as anger and frustration as further proof of diminished capacity (Forbes et al., 2011; MacRae, 2010; Sabat et al., 2011; Saunders et al., 2011).

The three theories described in this chapter are frameworks that can be used to understand how a person who has been diagnosed with dementia experiences the social environment and understands his or her place in it. In the next section, the theories are applied to the experience of reciprocity in relationships to explain how opportunities for give and take can influence identity.

Reciprocity

Social psychologists consider reciprocity to be a key element in all social bonds, and imbalance presents a threat to relationships (Broese van Groenou, Hoogendijk, & van Tilburg, 2013; Fyrand, 2010). When one member has unequal power in in a relationship, feelings of indebtedness may create resentment and frustration. This is true with people in poor or frail health, as the ability to give decreases and the need for assistance increases. The care recipient loses power to negotiate in such relationships, and the caregiver may

feel resentment because the relationship is one-directional. When this happens, healthy

relationships begin to break down as both sides struggle to find reciprocal balance, often

causing tension and conflict (Fyrand, 2010; Graham & Bassett, 2006; Quinn et al., 2015).

Older adults are often perceived as being in need of support, with little attention paid to

their need to offer something in return. Having a diagnosis of dementia does not take

away the ability for a person to create and maintain social relationships, which includes

satisfying the reciprocal elements necessary to keep a relationship healthy (Offord,

Hardy, Lamers, & Bergin, 2006). Studies have shown that even older adults with

diminished capacities, such as those with Alzheimer's disease or mental disorders, are

capable of providing comfort and support to others (Doyle, de Medeiros, & Saunders,

2011).

Family and Reciprocity

        In a family where one member has dementia, the task of maintaining healthy

relationships can be difficult as family caregivers struggle to accept the changes in their

loved one and accept new responsibilities (Piiparinen & Whitlatch, 2011). When

caregivers position a person with dementia as incompetent, they tend to make decisions

for rather than *with* the person, especially in situations where safety is the primary

concern (Bourkel et al., 2012). The more time and energy that caregivers allocate to

controlling behavior, the less time they have to attend to the emotional and personal

needs of the care recipient (Forbes et al., 2011; Piiparinen & Whitlatch, 2011). This may

actually aggravate the situation, causing the person with dementia to react negatively

through defiance or outbursts of anger in an attempt to reposition him or herself on more

equal footing. In turn, this causes further reactions from family members in an attempt to

control unwanted behaviors (Piiparinen & Whitlatch, 2011; Sabat et al., 2004). When a

person with limitations – social, physical, mental, or financial – receives help, but is

limited in their ability to reciprocate, feelings of frustration, shame, burden, and

resentment can result from the imbalance. Limiting the amount of accepted assistance

and withdrawal may be the only way to control the reciprocal balance when one feels a

sense of indebtedness (Fyrand, 2010). Resentment and conflict can arise as both sides of

the caregiver/care recipient dyad struggles to find reciprocal balance (Graham & Bassett,

2006; Quinn et al., 2015).

Friendship and Reciprocity

The well being of a person with dementia is closely tied to the level of positive

social inclusion that they experience, providing emotional, psychological and health

benefits (Doyle et al., 2011; Forbes et al., 2011; MacRae, 2011). Friendships may provide

valuable opportunities for personal connections, especially for older adults who

experience a decline in social opportunities that were once supplied through work and

parenting duties (Stevens & Van Tilburg, 2010). Friendships are often free from the

disagreements and frictions that exist in family relationships, with all parties retaining the

option of terminating the relationship if it becomes unsatisfactory (Chen & Feeley, 2013).

Often based on mutual interests, experiences, and pastimes, friendships can be very personal and individualized, bringing meaning and connection to people in older age (Stevens & Van Tilburg, 2010).

Having friends can be important to the reciprocity balance. Family members tend to provide practical support necessary for safety and well being, while friends share a more evenly distributed relationship based on voluntary actions. Research shows that material help is most appreciated by older adults when provided by family, while the most emotional and psychological benefit is derived from reciprocal relationships that exist outside of the family dynamic (Huxhold, Miche, & Schuz, 2014; Li, Fok, & Fung, 2011).

Long-term friendships are especially beneficial, as parties are able to share a continuity of identity over time rather than relying solely on current capabilities, but there are opportunities for a variety of friendships to exist. Peer support among members with like-experiences, such as dementia support groups, offer many of the benefits that individual friendships provide. Some of the crucial elements that are provided in peer support relationships include shared experiences, and positive, reciprocal support. Relationships that grow from a common experience or interest can mitigate negative positioning, since the factors that cause imbalances in the caregiver/recipient dyad are not present (Keyes et al., 2014). One research study by L. Clare et al. (2008) looked at members of a dementia advocacy and support group for positive signs of social support among its members with early stage dementia. The researchers found that the support group created an environment rich in reciprocal friendships and a sense of inclusion that

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diminished feelings of exclusion and loneliness. Members of the group were encouraged to offer support and advice, which established a balanced exchange between members. Feeling needed and competent in their roles, members expressed an increase in self-esteem and a greater interest in life (Clare et al., 2008). Participating in peer support encourages people with dementia to feel engaged and useful. This represents a healthy reciprocal exchange, as members both give and receive support (Keyes et al., 2014).

This chapter provided a description of the development of person-centered study among social scientists and theories that are used to describe the social experiences for persons who experience cognitive decline. The next chapter will present examples of existing literature that investigate friendship for persons with dementia. An interpretation of the findings as they relate to the theories presented in this chapter will be provided as well as an explanation of limitations and opportunities for further research.

Chapter 2

Review of Selected Literature

Focus on the personal experience of dementia has led to numerous studies investigating how friendships form and how persons with dementia interact with others. Researchers have attempted to show that persons with dementia possess the skills necessary to create and maintain friendships. A search for peer-reviewed research literature addressing the role of friendship in persons with dementia resulted in six articles. The articles, all published after 2010, were selected as recent examples of research regarding dementia and friendship, and included discussions of social exchange and reciprocity.

Design and Limitations of the Selected Literature

This section provides a brief description of each of the studies used in the literature review. The methods used to perform the research as well as limitations are provided for each study. Appendix A provides a table with additional details about the selected studies.

A study conducted by de Medeiros and colleagues (de Medeiros, Saunders, Doyle, Mosby, & Van Haitsma, 2011) focused on the residents and staff of an assisted living residential care unit. Thirty-one residents in the moderate to late stages of dementia and fourteen staff members were asked a series of questions about social dynamics within the unit, such as identifying friend pairings and sources of conflict. Following the semi-structured interviews, ethnographic observations of the residents and staff were conducted over a six-month period to test the validity of the information provided during the interviews. Two researchers coded field notes and transcripts and then the entire study team reviewed the data to determine the types and quality of interactions, and assigned themes to the types of interactions. The study attempted to understand differences and similarities in how staff and residents define friendship, and investigated the ways that staff members can misinterpret or impede friendship through Malignant Social Psychology. The research looked at friendships among the residents of a long-term care facility, not at outside friendships. While key elements of friendship including reciprocity were identified, they were not investigated as they pertain to the experience of Malignant Social Psychology.

In the first of two studies by Harris, the author never actually met the participants, but gathered information based on references to friendship in a general discussion of life experiences by people with dementia (Harris, 2011). The original study was comprised of eight participants who were members of one unidentified chapter of The Alzheimer's Association. Most of the study participants were in the early stages of dementia and all were community-dwelling White females. Harris used a qualitative grounded theory

approach to identify themes regarding friendship, arguing that the fact that the topic of friendship arose organically during the interviews underscored the importance of this relationship in the lives of persons with dementia. The study addressed the importance of friendship and reciprocity and touched on Malignant Social Psychology. Since this is a secondary analysis of data, however, it is limited in scope and makes assumptions about the importance of the casual mention of friends that may in fact not be accurate.

In the second study by Harris, the researcher looked at the quality of friendship from the perspective of both parties in the dyad (Harris, 2013). Recruiting for the study began with two visits to individuals with dementia who were members of of an Alzheimer's Association early stage advisory board. In the presence of care partners, ten people in the early stages of dementia were interviewed in a group setting. Harris used these initial interviews to find two women with a friend of 20 years or more living nearby. She then used a snowball sampling technique to find one set of friends in the moderate stage of dementia, and one set in the late stage. Recruitment produced four sets consisting of women between the ages of 57 and 85 years. Seventy percent of the participants were White; the remaining thirty percent were African American. All of the friendships ranged from 20-47 years in duration. Each of the parties were interviewed to determine the dynamics, importance, and reciprocal elements of the friendship. While the findings relate to the importance of friendship and reciprocity, the study looked at a very specific type of relationship involving women with very long term friendships, disregarding other types of friendships for persons with dementia and whether they provide similar experiences.

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Social skills were the focus of the study conducted by Kontos (2011). Using observational methods, the researcher made multiple visits over an eight month period to a long-term care facility serving Orthodox Jewish residents of Eastern-European descent with moderate to severe dementia. The study looked at the retention of social abilities that are important to create and maintain friendships. The research focused heavily on ethnic habits that were learned early in life, maintained socially throughout the course of life and retained even after cognitive decline. The goal of the study was to show that social skills are maintained even into the later stages of dementia, and that they are used to communicate and connect. The research was not specifically about friendship or Malignant Social Psychology and relied on observation alone, with no opportunity for the participants to express their own thoughts on the experiences of social interactions.

Malignant Social Psychology and Social Positioning are common topics in Steven Sabat's research. In the Sabat and Lee (2011) study, the possibility of friendship between persons with dementia was explored. Using an observational approach, Sabat and his colleagues spent four months at a day center where elderly people with a variety of neurological disorders, including dementia, attended. At the end of the observation period, verbal and non-verbal exchanges were analyzed by the researchers for themes, and used to discuss the possibility of meaningful relationships among persons with dementia and ways that Malignant Social Psychology can impede such relationships. This study was about friendship in general, and did not specifically address reciprocity.

The final study included in the review looked at changes in social relationships following the diagnosis of dementia, and emphasized the importance of looking outside of the immediate family to meet the social needs of persons with dementia (Ward, Howorth, Wilkinson, Campbell, & Keady, 2011). The article consisted of two parts, the first of which was an essay written by a person with dementia about the changes in his social sphere following the diagnosis of dementia. The second part of the article was a study that looked at social dynamics within a peer-led support group. The research was conducted during a single visit to the group and consisted of observations during a group session and interviews with the staff who acted as facilitators. The author of the essay and the participants in the peer group were all community dwelling adults in the early stages of dementia. The article is unique in that it provides a first-person account of social dynamics for persons with dementia. The presence of Malignant Social Psychology and the importance of friendship were addressed in the article, but it did not specifically address what about friendship is important.

Related Threads of the Selected Literature

An analysis of the reviewed literature revealed four primary threads related to healthy friendships for persons with dementia:

Persons with dementia are capable of creating and maintaining friendships

All of the studies supported the fact that persons with dementia retain social skills necessary for the creation and maintenance of friendships. The diagnosis of dementia does not signal an end to the social needs of an individual, nor does it render them incapable of interacting socially (Harris, 2013). The literature shows that recognition of the various forms of exchange is important when considering friendship possibilities among persons with dementia. Verbal skills are not always necessary to convey thoughts or feelings, and friendships should not be based on conceptions of friendship among the general public (de Medeiros et al., 2011; Kontos, 2011; Sabat & Lee, 2011).

In the study by Sabat and Lee (2011), participants in an adult day care center were able to recognize social cues and to respond with empathy and humor to situations that occurred. The ability to engage in behavior that is dictated through an understanding of the context of a situation is a key example of retained social skills (Sabat & Lee, 2011). The study by Kontos (2011) involved the observation of residents in a nursing facility revealed that an understanding of even complex social concepts like etiquette and modesty were present. Residents recognized inappropriate behavior in others and even in advanced stages of dementia, they practiced what they considered to be proper behavior. Belching or other anti-social behaviors were acknowledged with censoring looks and facial cues. Similarly, residents expressed praise, affection, and gratitude for positive interactions (Kontos, 2011).

The study by Ward et al. (2011) looked at a self-regulated dementia support group, where members planned and led meetings with assistance from supportive staff. The researchers found that members were able to maintain structure in their meetings and to find purpose in the discussions that they led with minimal supervision. Members appreciated the ability to share feelings with others who understood the challenges of dementia and the shared experience bonded the group together (Ward et al., 2011). The 2011 study from Harris found that friendships where both parties recognized the existence of dementia and adjusted expectations accordingly, were more able to overcome deficiencies and thrive.

Friendships are important to persons with dementia

Observations and interviews conducted by researchers revealed evidence of the perceived value of friendships among persons with dementia. One of the reports by Harris (2011) used data from an unrelated research project to identify the importance of friendship for persons with dementia. The original study looked at the overall experience of dementia in persons in the early stages of the disease. While the interviews used were not focused on friendship, the researcher found that the concept of friendship was a recurring theme in the data. The researcher inferred that the unprompted discussion of friendship pointed to the importance placed on this type of relationship among persons with dementia. The other study by Harris (2013) looked at the quality of friendships when one member has been diagnosed with dementia. She found persons with dementia enjoyed a variety of relationship types, ranging from close family-like relationships to

casual friends who shared similar pastimes. Harris also found that friendships can change over time, with some becoming more distant, but others strengthening following a diagnosis. Friendships made after the diagnosis of dementia still had meaning and brought mutual satisfaction.

A key factor in the value placed on a friendship was the element of choice that allowed individuals to develop friendships to fit their unique needs. Sabat and Lee (2011) found that members of a day program gravitated toward others who shared similar traits, and were observed making decisions based on companionship preferences. When examining "facilitated friendships", Ward et al. (2011) found that peer groups could serve the needs of many people who are living with dementia. Involvement in a peer group may create opportunities that otherwise would be missing in a person's life, and provide a supportive community free from stigma (Ward et al., 2011). Finally, enjoyment that is derived from friendships in persons with dementia may be exhibited in simple gestures and signs of recognition. Looking at residents in a long-term care facility, Kontos (2011) found signs of pleasure in simple eye contact and recognition of discomfort.

Opportunities for friendships provide persons with dementia the chance to experience the positive social interactions that were identified by Kitwood as promoting a healthy self-image. The study by de Medeiros et al. (2011) included examples of interactions that allowed residents in a long-term care facility opportunities to provide support to each other. A study participant explained her role in helping fellow residents with greater disability, and how this helping role gave her a feeling of being needed.

Helping others made her feel validated and recognized as useful. Other residents were observed offering emotional support and recognition of personal experiences and preferences. Harris (2011) found that study participants valued friendships that offered opportunities to engage in peaceful pastimes such as sharing meals and simply relaxing. Sabat and Lee (2011) found that members of a daycare program enjoyed a sense of humor in social interactions, and that these exchanges gave participants a chance to engage in validation and play.

Reciprocity is a key factor in healthy friendships, and is valued by persons with dementia

Participants in both studies by Harris (2011, 2013) emphasized the importance of reciprocity, even if their abilities were diminished. Simply the ability to perform an act that put the relationship on more equal footing brought a sense of well-being to the persons with dementia (Harris, 2011, 2013). Sabat & Lee (2011) made note of numerous attempts among members of a day program to provide support and assistance to one another. Many of the interactions were as simple as helping to overcome verbal deficiencies or providing empathy. Kontos (2011) witnessed similar acts among residents in a long-term care facility.

Observations of residents in residential care showed examples of individuals engaging in acts of reciprocal friendship that ranged from helping when communication was difficult (de Medeiros et al., 2011) to seeking assistance when needed (Kontos, 2011). The study by de Medeiros et al (2011) looked at the way that residents in an

assisted living residential care unit understood friendship through combined interviews with residents and staff members to determine whether the way the two groups defined friendships differed. The researchers found that both groups defined friendship as comprised of four key elements: common interests, intimacy, reciprocity and reliability/assistance. Residents cited simple exchanges such as being nice to each other as acceptable acts of reciprocity (de Medeiros et al., 2011). When asked to identify key elements necessary for healthy friendships, respondents in the study by Harris (2011) indicated that healthy friendships must benefit both parties in the relationship.

In her 2013 study, Harris found that the most esteemed factors of friendship were loyalty, constancy, trustworthiness, reciprocity, and acceptance. Respondents identified commitment of choice in friendship as different than commitment due to obligation, such as with family members. Harris included an example of these traits exhibited by an individual who continued to visit her friend with dementia regularly, even though there was little recognition or engagement. Visits were satisfying for both of the friends because they both found enjoyment from their time together. The friend with dementia, while failing to recognize her visitor, still enjoyed the interaction. The friend without dementia derived a sense of satisfaction in following through with her duty and showing her loyalty after many years of a more evenly reciprocal friendship. Even in the last stages of the disease, these friends were still engaging in the give and take of a mutually beneficial friendship (Harris, 2013).

Malignant Social Psychology creates barriers to healthy relationships

Research shows that non-demented individuals may fail to understand the ways that friendships are experienced by persons with dementia, and unwittingly apply stigma that prevents meaningful interactions (de Medeiros et al., 2011; Harris, 2011). The presence of Malignant Social Psychology represents a threat to the physical and emotional well-being of persons with dementia, creating feelings of "isolation, incompetence, loneliness, frustration, depression, and unworthiness" (Sabat & Lee, 2011, p. 323).

According to Ward et al. (2011), participants of a member-facilitated support group shared experiences of disempowerment, treachery, mockery, disparagement, and banishment (Ward et al., 2011). This study included an essay written by a person who had been diagnosed with dementia and shared his personal experiences of Malignant Social Psychology in his life. The author's encounters with Malignant Social Psychology led him to conclude that society is ignorant about the way that dementia is experienced (Ward et al., 2011). In the study by Harris (2013), labeling and stigmatization were the most commonly occurring behaviors identified as Malignant Social Psychology by individuals with dementia. Stigma and labeling can cause friendships to deteriorate, impacting friendships for the person with dementia as well as their spouse or other family members (Harris, 2013).

In the study by de Medeiros (2011) caregivers were identified as risk factors in the creation and maintenance of friendships. Stereotypes that cause physical and social positioning based on assumptions of ability, convenience, or commonality (such as gender), impeded the possibilities for meaningful relationships (de Medeiros et al., 2011). Caregivers applied definitions to friendships that failed to consider alternate forms of communication and connection. As a result, when asked to identify existing friendship pairs, the staff members named people who shared common traits such as gender, and ignored true interactions such as conversation, empathy, and reciprocal behavior. Interviews and observation revealed that most of the friendship pairings identified by staff members were erroneous. In one instance, staff members identified a group of men who occupied the same table at mealtime as close friends, when in fact the men themselves revealed that no friendships existed, and they shared a table only because staff placed them together. The researchers concluded that persons with dementia are capable of forming and maintaining friendships, but that Malignant Social Psychology – specifically stigmatization, disempowerment, labeling and invalidation – were practiced by staff members, and represented a barrier to the natural formation and maintenance of friendships (de Medeiros et al., 2011). Sabat and Lee (2011) determined that persons with dementia may benefit most from natural interactions that are under their control, rather than those managed by caregivers based on their interpretation of connection or shared interests.

Discussion and Application to Research

This review presents research literature that investigated the role of friendship for persons with dementia. While each of the studies focused on the social aspects of friendship differently, they all support the idea that friendships are important to persons with dementia, and that the presence of dementia does not eradicate the social skills necessary for the creation and maintenance of friendships. The prior research also establishes that reciprocity is an important part of healthy friendships. Reciprocal behavior for persons with dementia may entail simple acts, but these behaviors satisfy the social requirement and bring a sense of balance in relationships. The studies reviewed acknowledge that Malignant Social Psychology creates serious obstacles in the lives of persons with dementia, and that positioning by caregivers impedes the creation and maintenance of organic friendships that may help overcome the experience of Malignant Social Psychology.

Limitations of this review include the relatively few studies that are available. While studies of the personal experience of dementia are growing in number, research into specific elements of friendship for persons with dementia are limited. Another limitation of the review is that the definition of friendship is fluid. Communication problems inherent with dementia make it difficult to confidently examine concepts such as quality of friendship and personal satisfaction derived from social interaction. Finally, due to the nature of the studies, which follow phenomenological or ethnographic methods that by necessity are small in scope they may fail to properly represent a diverse community of people with dementia and their experiences.

There remain opportunities for further research into the role reciprocity plays in friendships for persons with dementia and investigation into the ways that it may affect the experience of Malignant Social Psychology. The study described in the next chapters will investigate reciprocity in friendships where at least one person in the dyad has memory deficiencies in order to better understand the effect on the phenomena of Malignant Social Psychology. The application of reciprocity to Kitwood's concept of Malignant Social Psychology may reveal previously unappreciated opportunities for increased quality of life for persons with dementia.

Chapter 3

Methodology

This chapter describes the design of the research project, including recruitment, ethical considerations, instruments and procedures, and the process of analysis.

Design of Study

This study applied a qualitative phenomenological approach to interviews conducted with community dwelling persons who were experiencing memory loss. Rather than relying on interpretations from outside parties such as clinicians or caregivers, phenomenological research focuses on the personal experience of social phenomena. This form of study looks at how individuals interpret an experience, and how that construction is used to form an understanding of the world (Patton, 2015). An important concern in a phenomenological study is maintaining focus on the individual's experience, so that the resulting analysis is based exclusively on his or her understanding of the phenomena (Merriam & Tisdell, 2015). The goal of this study was to understand

how persons with memory loss interpret reciprocity as it occurs in friendship, and whether it has an effect on the experience of Malignant Social Psychology.

Participants

Selection of participants was limited to community dwelling people over the age of 60 with memory loss. Staff at the Alzheimer's Association were present during recruiting efforts and assisted in the review of potential candidates. Because the staff were familiar with members, and had already determined the presence of memory problems in the individuals, the decision to accept membership in programs as valid proof of memory problems was made and no further testing was conducted. Individuals were excluded if they were unable to identify between one and four current friends, did not speak fluent English to facilitate interviewing, or did not have a caregiver or family member to sign the informed consent form.

Recruitment was based on a purposeful sampling approach. Purposeful sampling is helpful when the goal is to develop greater understanding of a specific theme or group of themes rather than gain generalized knowledge about a large demographic (Cresswell, 2013; Frazer, Oyebode, & Cleary, 2011). Participants were selected because they are experts in the experience being studied, with recruitment focused on finding individuals who were able to provide personal insight, rather than concentrating on randomness or the number of subjects (Maxwell, 2013). The number of people studied is much less important than the quality of the experiences that the participants can relay, and how

common those experiences are so that themes can be developed. Sample sizes for the typical phenomenological study are usually between one and ten participants (Frazer et al., 2011). Most researchers begin with a maximum number of people to be sampled, but adjust as they analyze the interviews and determine the point where the research has reached "saturation". The saturation point in data collection occurs when no new information is being provided by participation and the answers become redundant (Merriam & Tisdell, 2015). In the case of this study, the design allowed for the inclusion of up to 20 individuals.

Procedures

Participants were recruited from support and education groups sponsored by the Northwest Ohio Chapter of The Alzheimer's Association. The researcher attended regularly scheduled meetings and offered a brief explanation of the project, inviting interested parties to leave a phone number for a follow-up call, as well as allowing them to take an informed consent form for their review. Individuals who expressed interest were called within three days of the initial contact, at which time a brief screening was conducted to determine eligibility for inclusion in the study and the study was described in greater detail. When possible, a family member or caregiver was given information about the study during the phone call as well. For those individuals who were still interested in participating, a face-to-face interview was scheduled.

The interviews lasted approximately one hour and took place in an office of The Alzheimer's Association. Informed consent was read to the potential participant and a caregiver (e.g. family member) simultaneously, and consent was obtained from both the participant and the caregiver prior to the interview.

Confidentiality

Both the University of Toledo Social, Behavioral and Educational Review Board (SBE-IRB) and The Alzheimer's Association Research Committee reviewed and approved the study design. The researcher followed recruitment methods, interview questions and storage processes of sensitive material as it was presented to the review committees. Interested parties were given a copy of the informed consent form at the time of initial contact so that potential participants and family members could review it. At the time of the interview, the informed consent form was explained to both the participant and a caregiver or family member. Both parties were advised of the minimal risks, including confidentiality concerns. The interview was not conducted until after both parties had signed the informed consent form.

Identifying information was present only on the consent form, which was stored in a locked cabinet located at the University of Toledo. A unique identification number was assigned to each participant and used on all other materials including the interview form and audiotape labels, and these materials were stored in a separate locked cabinet on campus. Finally, all materials were destroyed upon completion of the study.

Instruments and procedures

Data were collected through face-to-face meetings during which interviews were conducted. Participants were first asked demographic questions such as gender, education, and ethnicity. Following the demographic questions, participants were asked to describe a time when they were treated differently because of their memory issues. Prompts for those who needed them asked if there were times when the participant was spoken to differently, or if there have been changes in social interactions. Participants were then asked to reflect on the examples provided and share the meaning of the experience from their perspective. A question was asked about changes in roles since the onset of memory problems, with prompts asking about changing expectations or assumptions about abilities. Participants were then asked to share their perception of changes in relationships since the onset of memory problems. These questions were used to establish the experience of Malignant Social Psychology and the meaning attached to the phenomena.

Next participants were asked to identify by first name between one and four friends, and a series of questions were asked about the relationships. For each of the friends named, the participants were asked to identify times when the friend offered help or assistance. Participants were then asked to identify times when they were able to help their friend. Finally, participants were asked to share perceptions of friendship and its meaning in their lives. Appendix B contains the interview guide used for this study.

Analysis

Analysis of the demographic information was conducted using descriptive statistics, including frequencies. The answers to the questions regarding changes in relationships were reviewed to determine the existence of Malignant Social Psychology and to understand the general social environment for the participants in the study.

The data from the set of questions about friendships were analyzed using a phenomenological process that consists of four steps. Following transcription, the responses were first read to get an overall understanding of the discussion taken in its entirety. Second, the responses were reviewed for recurring key themes that indicated perceived meaning for the participants. In the third step, the key themes were analyzed for their significance, and finally the themes were organized into an interpretation of the themes and a description of their meaning as it pertains to the experience of Malignant Social Psychology (Wertz et al., 2011).

Statement of Limitations

A typical sampling of participants assumes that the persons included in the study represent the targeted community (Merriam & Tisdell, 2015). In this study, the assumption was made that members of a dementia support group represent the typical person with memory problems as it pertains to friendship, reciprocity, and the experience of Malignant Social Psychology. The very fact that participants were active members in groups designed to increase social interaction may mean that the sample is comprised of

people who do not represent the average person with a memory problem. (Neuman, 2012). Using the purposive selection method, the selected participants were considered for their personal exposure to the topics discussed, and the meaning of their input was based on the assumption that they stand as experts of the experience of friendship for persons with memory problems (Maxwell, 2013). There remains the possibility that the selected group of participants do not hold ideas that are typical for the dementia community as a whole.

Chapter 4

Findings

Individuals self-identifying as experiencing memory loss were recruited from programs offered by a local chapter of The Alzheimer's Association to participate in a one-time interview to discuss changes in personal relationships and the experience of friendship. Ten individuals were recruited for participation in the study, none were excluded. The responses from one participant who identified herself as having been diagnosed with Alzheimer's disease but was 57 years of age were still included in the analyses. Interviews were conducted at the office of The Alzheimer's Association after consent was obtained from both the participant and a family member or caregiver. While at times the spouse remained in the room and offered information or insight, the focus remained on the participant as the primary authority and source of information. This chapter will provide the findings from the interviews that includes demographic data, an interpretation of the experience of Malignant Social Psychology for the participants, and an explanation of the themes that were revealed following a qualitative phenomenological review of the discussions.

Demographic Data on the Participants

   The first part of the interview consisted of demographic information about each participant. Six men and four women were interviewed. The majority of the participants were White and had an average age of 76 years. Nine of the participants had some college, with three holding advanced degrees (beyond a four-year college degree). All ten were community-dwelling; nine were living with a spouse and one with an adult daughter. All participants reported their health as good or very good. Table 1 contains the complete demographic data for the participants in this study.

Table 2 Demographic characteristics of the participants

N=10

Variable	Group	N	%
Gender			
	Female	4	40%
	Male	6	60%
Age			
	<60	1	10%
	60-70	1	10%
	70-80	5	50%
	80+	3	30%
Ethnicity			
	Hispanic/Latino	1	10%
	Not Hispanic/Latino	9	90%
	American Indian or Alaska Native	0	-
	Asian	0	-
	Black/African American	1	10%
	Native Hawaiian/Other Pacific Islander	0	-
	White	9	90%
Years of schooling			
	High School	1	10%
	Some college	2	20%
	College graduate	4	40%
	Advanced degree	3	30%
Self-reported health			
	Excellent	0	-
	Very good	3	30%
	Good	7	70%
	Fair	0	-
	Poor	0	-
Living situation			
	Lives with spouse	9	90%
	Lives with adult child	1	10%

Findings on the Presence of Malignant Social Psychology

Following the demographic information, participants were asked two questions in the interview to establish the existence of behaviors that are consistent with Malignant Social Psychology. Participants were first asked to describe a time when they were treated differently than they might have been before their memory issues began. The second question asked whether they felt that their role in relationships had changed because of memory problems. In all cases both questions were answered the same way. In other words an affirmative or negative answer to the first question in all cases resulted in the same answer to the second.

Seven of the participants indicated that they did not feel that they were treated differently because of their memory problems and their relationships had not changed. One participant attributed the lack of changes to familiarity and disclosure: "I guess that's because I've known them and I, I do tell them that I do forget." Another participant conceded that changes may have occurred in his relationships that he is unable to detect. He was quite frank about his diagnosis, and asserted that openness is crucial to the success of his relationships. "Most folks that I interact with are aware that I have memory problems. So, when I would display lapses of memory…then they're not surprised by…and some of the problems that I would probably incur, I don't because of that." Other than occasionally questioning her, another participant indicated that there were few changes in her personal relationships related to her memory problems. When asked about the meaning the lack of change has for her, she indicated that "it means that I'm still

normal." Others said that the lack of change in relationships made them "feel good" and "blessed".

Three participants did notice changes in their relationships. One individual shared that he finds people talk to him differently, often speaking loudly as if he is hard of hearing. He felt that he interacted less with people since his memory problems began and that his reliance on others "bothers the hell out of me." Another participant found that people questioned him more, "sometimes rightly sometimes wrongly" but he expressed an understanding of their motivation. "It makes me sad," is how another person described the experience of changing relationships. **"**I've let people know that I have memory problems and most of them are fine with it but I do find some people saying, you know, backing off and don't want to talk to me because they're uncomfortable." Sometimes people helped her when she didn't need it, to which she reacted, "usually it frustrates me because I want to do what I can do."

Findings Related to Friendship

The third portion of the interview asked questions about existing friendships. Participants were asked to identify between one and four friends that they had retained or made since the onset of memory problems. There were 37 friends identified by the 10 participants in the study. The source of the friendship varied, with family members comprising the largest group, followed by church friends, friends with common interests and work associations. With only two exceptions, all of the friends were of the same sex.

There were shared characteristics among the family members who were considered friends by the participants. All of the family members were of the same generation as the participant in the study. The most common relative relationship was that of sister, followed by spouse. In all cases that family members were included as friends, participants were able to justify their choice because of the quality of the relationship, such as shared interests or companionship, and not based on a familial obligation.

Table 3 Types of friends

Family	10
Church friend	7
Common interest friends	7
Co-worker/retiree group	6
Childhood friendship	4
Neighbor	3
Total = 37	

The data from the set of questions about friendships were analyzed using phenomenological methods. Five key themes were identified as having meaning for participants in the study. This section will describe each of the five themes, including examples of key words and phrases and examples as they were presented in the interviews.

1. **Recognizing the importance of longevity in friendship**

Participants chose close friendships to discuss during the interview, opting to consider fewer than four friends over naming acquaintances or lesser friendships. Length of the relationship was not asked as part of the interview, but the majority of the friends identified were long-term in nature. When asked to explain the value of a given friendship, several participants cited longevity with comments such as "it's a good feeling to know someone...for a long time," "we both have long time memories together," "we've known each other for eons" and "we've known each other forever." One participant compared his life filled with many long-term friends to that of his brother, who moved across the country to be near family. He felt that his brother suffered from loneliness and lack of support because he was unable to call on established friends. When describing the aspects of friendship that are necessary to provide support, he stated, "it takes a long time to build friendships usually," offering the explanation that "you get to know each other better and understand each other better" over time. Another individual felt that longevity made communication and understanding easier: "the closer the friendship some things are a lot easier," he shared.

Friendships built over time were considered important because time allows for the establishment of loyalty and trust. "He's just a loyal friend and I like him," was how one participant summed up his friendship. One participant with diminished verbal capabilities felt that his childhood friend was appreciated because he could be trusted to know when help was needed and was willing to step in. When asked to describe the value in a

childhood friend, another participant felt that loyalty was a paramount consideration, indicating that the presence of that factor meant "he's a good friend." For another individual, trusting in the loyalty of a friend meant that "he's somebody that I'm able to…talk to about fairly…significant personal issues." One participant listed four childhood friends that he met in elementary school. In each case, when asked to describe the value of the relationship, longevity and loyalty were cited. When describing the last of his four childhood friends, he said he valued "the same thing I do with the others, they're loyal and… he's…been a good friend for years." One gentleman felt that the trust he had in his friends made it easier for him to talk about problems and concerns and stated, "sometimes it's easier to discuss, you know, things with a friend than family…friends are somehow a little bit easier to discuss it with or to share it with."

2. Helping one another is a normal part of friendship

"Whenever we do something for each other," explained one participant, "it's just a normal thing to do." It was common for participants to explain that give and take is a normal component that is expected of friendship. Diminishing memory and cognitive abilities did not erase the understanding that friendship involves reciprocity. "In my mind," said an individual, "that's kind of the role somebody should play in life…" while another shared, "it just seems to be a natural you know, an element… of friendship or of close personal association." Still another shared:

I think friendship is…kind of two way… you know, you get things from each other…somebody may need more on one side and the other on the lesser side…it's working together and it's understanding and it's continuing growth too…it really is because I mean as we all age, everything changes so, you know, the growth part of it is good.

When asked what meaning the help of a friend brought to one participant, the response was "that means she's a true friend." Another participant said that mutual aid is "a sign of a good friendship." Describing the help that his wife gives to him, one participant said "it means that she's caring."

3. Feeling "alive" through the give and take of friendship

When asked to describe the meaning that she gets from the ability to help her friend, one participant explained, "it means a lot because it makes me feel good, it makes me feel like I am still active, I'm still alive (laughs) I'm alive obviously (laughs) but I, you know, I'm not sitting in a corner being sad…." Another explained that volunteering was important because "it means that I was doing something with my life." Helping each other with work at church was satisfying for another individual because it was an opportunity to share the load: "we don't really consider it work because we're doing it together."

Helping friends was considered important because it provided a chance to show appreciation and affection. "It meant a lot to me because they are dear to me and I was happy to do something for them" and "it makes me feel good that so I can do something

for him" were two responses. For one participant who continued his involvement in a legal society after serving as an attorney and judge, the ability to contribute his knowledge and experiences, especially as his social interactions began to "wane", allowed him to still feel connected to his peers and "contribute my experiences in the community." This same participant made a point of looking for opportunities to contribute: "I've become more vividly aware of these kinds of things and try to develop things that I can share." Another individual felt that the assistance that she was able to give to her husband was important as a form of repayment for his sacrifices because, as she explained, "he is probably losing his chance at friendships with other people because he's with me pretty much 24/7." Helping a friend was seen as a positive benefit for another participant, who stated, "I…think it is, you know, good for my self-esteem to be assisting him, you know, to the extent that I can assist him."

Receiving help from friends had value as well. When describing her friend's assistance, one participant said, "it makes me feel good because she helps me" and of another friend's help, "it meant the world to me." One participant appreciated his friend's help because it meant "that he likes me a little bit." When describing a friend's efforts to spend time together, even when it meant a long commute to drive him to lunch, one gentleman expressed his appreciation, sharing "at this point in time it means a lot."

4. Knowing somebody is there for them

Not every friendship discussed included recent or ongoing acts of give and take, but they all contained the *potential* for reciprocal exchanges. In many cases, participants remembered times when assistance was given in the past. One participant discussed the financial help that his friend had given during college in the 1950s, while another appreciated the help that a former co-worker gave while the two were assigned to work out of town decades in the past. Knowledge of past acts of assistance served as assurance that future requests will be honored. The security derived from a history of mutual assistance was described by one participant, "well, it's been…a long friendship and … you know, she's … helped me recently but … beforehand I helped her so it's kind of a give and take and… I just know…she's there for me." Other participants expressed these feelings with comments such as "they would do anything to help me" and "I know that they would be there for me." When describing the thing he found important with his friendship, one participant explained, "well, I guess if I were in trouble of whatever sort…that they… would come to me," while another said, "I know… they would do anything for me, they would." Knowing that a friend is there when needed, and that the help is given willingly, was esteemed in friendship: "and they do it with genuineness … they are there to help me." The assurances offered through the knowledge of potential aid in the future was valued by participants and considered something that made their relationships stronger. "It means a lot to me," shared one individual.

5. **Seeking security through friendship**

The need to feel secure often came up during the discussions about friendships. The individuals interviewed were aware of their diminishing abilities and feared rejection, stigma and abandonment. One participant, when discussing his recent diagnosis of Alzheimer's disease said, "that's something that I was very concerned about when I … first had the diagnosis and I didn't want to hide it particularly but I also at the same time felt, you know, very reluctant to tell people." Another shared, "I'm afraid that people will not want to talk to me." A third participant indicated that he interacted with friends less frequently than he used to, explaining, "see that's another part of my… my memory I, I get confused very easily…and maybe subconsciously I don't want my friends to know that I get confused."

Friendships that continue after the onset of memory problems offer the hope of comfort and security. One participant, when describing her friendships, explained, "they are a comfort to you and feel like you have a place in the world with the friends that you have and it's comforting to know," while another valued her friendship because she knew "there will always be somebody with me." When asked what it meant to have a friend to turn to in time of need, another participant responded, "oh it gives me a feeling of security I guess, you know, having them to rely on." Another said of her friends, "when I have difficulty getting around like I do today, I can call on any one of them to help me."

Summary

Ten individuals were recruited to discuss up to four friends and share their perspectives on the importance of their friendships and opportunities to help one another. All ten of the participants were able to identify friendships that they considered to be important in their lives. The friends who were selected tended to be long-term in association, which was important because it allowed for the development of loyalty and trust. The give and take of friendship was seen by participants to be a normal part of friendship and not something that goes away because of diminishing abilities. Opportunities to provide help and support to friends made participants feel alive and useful. Receiving help from friends was considered a mark of true friendship and appreciated by the participants. Past acts of assistance established a history that led to confidence in future help if needed. The knowledge that friends can be trusted in times of need provided participants with a sense of security and belonging that allayed fears of abandonment and rejection.

Chapter 5

Discussion

The purpose of this study was to examine friendship for persons with dementia, and identify whether opportunities exist in such relationships for reciprocal behavior that might influence the experience of Malignant Social Psychology. This chapter will offer a discussion of the five themes outlined in the previous chapter. The findings of this study will be compared to previous research found in published literature. Limitations of this study will be presented and recommendations regarding further study will be made.

Discussion of the Findings on the Presence of Malignant Social Psychology

Malignant Social Psychology refers to 17 behaviors, including shunning and stigmatization, that when present threaten a person's identity (Kitwood, 1997; Kitwood et al., 2007). Behaviors that are identified as Malignant Social Psychology create a negative social condition for persons with dementia that can damage a person's self-image and lead to reactionary behaviors in order to maintain control over a positive social identity – a process known as Social Positioning (Sabat et al., 2004).

Seven of the ten participants denied changes in their relationships or experiencing behaviors that would be considered Malignant Social Psychology. The lack of change in

personal relationships, or the lack of the *perception* of changes by the participants, raises questions about the social environment constructed by the individuals interviewed for this study. A possible explanation for the lack of Malignant Social Psychology in the lives of the participants is that a selection process was performed to eliminate friendships that pose a threat through negative social exchanges. The assessment of friends is an important process following a diagnosis of dementia, and one that may offer protective benefits against Malignant Social Psychology. Assessment often results in the termination of relationships that have little in the way of emotional attachment, or that have the potential to be negative (Carstensen, 1992; Carstensen, Isaacowitz, & Charles, 1999; Femlee & Muraco, 2009). This is especially true of friendships, which are mutually voluntary and therefore easier to end than family ties (Huxhold et al., 2014). Individuals, even those experiencing memory loss, can actively decide how to manage their friendships to their advantage (Finchum & Weber, 2000). If the number of friends is decreased, but the relationships that remain are mostly positive and supportive, the overall experience of remaining socially active following the onset of cognitive decline can be used to preserve a positive sense of social identity (Kruse & Schmitt, 2012), and may even be more helpful than at any other time in life (Huxhold et al., 2014).

Two of the three participants who reported experiences of Malignant Social Psychology were younger and more recently diagnosed than the rest of the group. It is possible that these individuals had not completed the process of winnowing out their social ties to create a "buffer" against Malignant Social Psychology (Huxhold et al., 2014; Kruse & Schmitt, 2012), while the older participants had already finished this

process. Recently diagnosed at the age of 63, one participant described the changes he was making in his relationships, "transitioning past" the isolation of his diagnosis and unexpected retirement into a social reality where he could be surrounded by people that he can trust. He decided that he needed to actively pursue positive social engagement, explaining, "I think there's a certain degree of depression and inertia that goes with this particular diagnosis…and I think that it's important to, you know, be interacting with people on a very regular basis."

When discussing the lack of changes in their personal relationships, a number of participants credited disclosure of their memory problems as an important coping strategy that minimized misunderstanding and prevented changes in friendships. Disclosure can be beneficial for a person with dementia, beginning a process in which the realities of cognitive decline are accepted and folded into a new identity (Weaks, Wilkinson, & McLeod, 2015). Harris (2011) supports the benefits of disclosure as an important step in the maintenance of friendships, because it eliminates confusion regarding unexpected or changed behaviors. It is possible that the participants in the study, through a combination of friendship selection and the passage of time, had established a new social identity that accounted for changes in friendship dynamics. If this were the case, asking a person with dementia whether changes have occurred may not result in the desired information, as the social environment would not be perceived as altered.

Finally, it is possible that the individuals interviewed did in fact experience negative social behavior that would be considered Malignant Social Psychology, but

chose not to divulge such experiences. If this were in fact the case, it would be an example of Social Positioning in action.

Discussion of the Findings Related to Friendship

As indicated in Chapter 4, five themes emerged from the interviews with the participants. These themes relate to the experience of friendship and what is valued in friendship for a person with dementia.

1. Recognizing the importance of longevity in friendship

When asked to share the value of a friendship, longevity was frequently cited by the participants. Longevity of a friendship was esteemed for the shared memories and experiences, but was also closely tied to the ideas of trust and loyalty. Several participants explained that trust and loyalty took time to establish, and were key to meaningful relationships. This is consistent with the studies by de Medeiros et al. (2011) and Harris (2013) that found that loyalty and trust were important components of friendship and may support the idea that older adults make decisions about the friendships that remain as they age, with priority given to the relationships that are considered "emotionally satisfying" (Warner, Schuz, Wurm, Ziegelmann, & Tesch-Romer, 2010). These findings are consistent with Social Constructionist Theory and Social Positioning Theory, both discussed in Chapter 1, supporting the idea that the

preservation of identity is dependent upon others to create a positive social position that minimizes the experience of Malignant Social Psychology (Kelly, 2009; MacRae, 2010; Sabat et al., 2004).

2. Helping one another is a normal part of friendship

This theme is supported by the findings of Kontos (2011) and Harris (2011, 2013) that cognitive decline does not eliminate the knowledge of social obligations. An appreciation of the reciprocal nature of friendship remained intact for the participants. All of the individuals interviewed expressed opinions consistent with the idea that reciprocity is an expected obligation of the friendship dynamic, and that the presence of cognitive losses did not exonerate them from giving back to their friends. This is also consistent with studies which have noted that reciprocity, along with reliability, loyalty and common interests are key elements of friendship (de Medeiros et al., 2011; Harris, 2011).

3. Feeling "alive" through the give and take in friendship

The participants in this study both appreciated the help that their friends offered, and found satisfaction in the opportunity to help others. They conveyed an understanding that helping their friends provided the opportunity to maintain balance in their relationships. In addition to contributing to equality in a friendship, reciprocity can be instrumental in maintaining a positive sense of identity increasing feelings of self-esteem

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and happiness (Harris, 2011; Warner et al., 2010). One participant in the current study stated that helping others made her feel that she was still socially alive, while another said that volunteering meant that she was still contributing. The findings of this study are consistent with de Medeiros et al (2011) who concluded that persons with dementia benefit from a positive self-image when they are provided with opportunities for reciprocal exchange.

4. Knowing somebody is there for them

Participants in the study recalled past instances of help from friends, but equally valued the knowledge that friends could be called upon in times of need going forward. Anticipated support gives an older adult a sense of belonging and reassurance (Krause, 1997). With the knowledge that one is not alone, persons with dementia experience heightened levels of confidence and a greater sense of control in their lives (Newsome & Schulz, 1996; Warner et al., 2010), which preserves independence through the knowledge that a strong support network exists (Frazer et al., 2011; Krause, 1997; Schwarzer & Knoll, 2007). This finding is supported by Harris (2013) who found that a social network protects a person with dementia from psychological and social dysfunction, and by Sabat (2011) who promoted friendship and social exchanges as a preventative measure against isolation and distress. The participants in this study shared these feelings of resilience and credited the potential for help from others as a direct benefit of their friendship networks.

5. Seeking security through friendship

The participants in this study communicated their will to remain socially active and relevant. Persons with dementia work to maintain an identity that is free of the stigma of "irreversible devastation and threats of complete self-annihilation" (Beard, Knauss, & Moyer, 2009, p. 234). Fear of stigma and unsupportive reactions are often a barrier to the disclosure of cognitive decline (Weaks et al., 2015). While some participants in this study were fearful that disclosure of their memory problems would result in negative reactions, most expressed relief in how their friends reacted and satisfaction with the friendships that remain in their lives. The security of friendship was reassuring to the individuals in this study. One participant described the experience of supporting a friend through a serious illness. He found the experience of supporting each other to be "mutually reassuring." Another individual explained that the simple knowledge that her friend remembers to call and "ask me what's going on" gave her a sense of reassurance that she remained relevant. Having friends to turn to provided comfort for another participant because she could be honest with them.

All of the reviewed studies (de Medeiros et al., 2011; Harris, 2011, 2013; Kontos, 2011; Sabat & Lee, 2011; Ward et al., 2011) supported the idea that Malignant Social Psychology presents a barrier to healthy friendships. The present study found that individuals with cognitive decline fear negative reactions to their memory problems and actively seek friendships that offer equity and security. The ten individuals interviewed

for this study were aware of the potential for isolation and abandonment, and were universally thankful for the friends who remained in their lives.

Limitations of the Current Study

In qualitative research, the trustworthiness of the findings rests on four concepts: conformability, credibility, dependability, and transferability (Elo et al., 2014). These requirements have been satisfied if the findings are unbiased, consistent with the real world, logical given the data available, and can be generalized to apply to another sampling of individuals (Elo et al., 2014; Merriam & Tisdell, 2015). Trustworthiness is the benchmark of research, determining whether the study has value in spite of inevitable limitations.

Because the emphasis in phenomenological research is on the experience of a phenomenon as understood by the research participant, the researcher must put aside personal experiences and perceptions, a process that is known as bracketing (Merriam & Tisdell, 2015). This is done to ensure that conformability is maintained through unbiased analysis of the data. In this study, personal assumptions about friendship, reciprocity and the experience of Malignant Social Psychology were consciously set aside so that they did not prejudice the analysis of the interviews. While every effort was made to set aside assumptions, there remains the possibility that personal prejudices and suppositions were inadvertently applied during the analysis.

There were few variations in the descriptions of friendships, or in what was valued in the identified relationships, which would imply that the sample size of ten individuals had achieved the goal of reaching saturation. Saturation occurs in data collection when the answers provided by participants become redundant, with no new insight forthcoming (Guest, Bunce, & Johnson, 2006; Merriam & Tisdell, 2015). The validity of the themes regarding friendship can be considered to be met, adding to the credibility of the findings and their transferability to other studies that seek to understand the perception of friendship in persons with dementia.

There were variations in the experience of Malignant Social Psychology, however, as well as variations in the explanation for the presence or absence of negative social exchanges. It is possible that additional participants would have yielded new information and that saturation had not been achieved as it pertains to Malignant Social Psychology. Consequently, the credibility of the data on Malignant Social Psychology may be questionable (Merriam & Tisdell, 2015). This would indicate that additional study is warranted to understand why some individuals experience Malignant Social Psychology while others do not.

The ten individuals included in this study were similar with respect to geographical region, ethnicity, active social lives and high levels of education. It is up to the reader to decide whether the findings of this research can be justifiably applied or transferred to other similar settings or situations. This study could be replicated with individuals with memory loss from other geographical regions, socio-economic statuses,

or ethnic backgrounds to determine whether their experience of friendship is the same or different.

Conclusions and Recommendations for Further Study

This study has helped to understand how persons with memory loss interpret reciprocity as it occurs in friendship. Five themes related to what community dwelling individuals with mild to moderate dementia value in friendships emerged from the data: 1) recognizing the importance of longevity in friendship, 2) helping one another is a normal part of friendship, 3) feeling "alive" through the give and take in friendship, 4) knowing somebody is there for them, and 5) seeking security through friendship. The study was unable to ascertain whether reciprocal friendships have an effect on the experience of Malignant Social Psychology, however, since the majority of the participants did not acknowledge these behaviors, including stigmatization or disempowerment. It was evident that the participants with memory loss in this study had a clear understanding of what friendship meant in their lives. Each was able to identify their significant friendships and explain why the relationship was valuable. Consistent with the findings of previous studies, the participants retained an understanding of friendship and viewed their friends as an essential component of their lives, particularly elements of loyalty and trust that grow over time (Femlee & Muraco, 2009; Newsome & Schulz, 1996). The give and take of friendship was considered a normal part of friendship, and obligations of mutual aid continued after the development of memory

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loss. Reciprocity, including anticipated help, was valued by all the individuals

interviewed, and identified as a source of comfort, empowerment and security.

Opportunities for further research into the importance of friendship as it pertains

to feelings of positive identity and usefulness exist. The possibility that control over

friendship selection and maintenance can have a positive effect on the experience of

Malignant Social Psychology is understudied and warrants further investigation. The

behaviors Kitwood identified as Malignant Social Psychology are related to loss of

control over social networks. As the symptoms of cognitive decline progress, control over

social selection is relegated to family, caregivers and the living environment. Enabling

persons with dementia to have continued input regarding friendships and social

engagement promotes a sense of control and participation. Indeed, the 10 positive social

behaviors that Kitwood identified, which include negotiation, collaboration, validation,

and emotional support, are impossible if the person with dementia is a passive member of

their social environment (Kelly, 2009; Kitwood, 1997). While not the focus of this study,

the ten behaviors that promote a positive identity were encountered through interaction

with participants, and their advantages merit further study. If a person with dementia

makes the choice to end or limit contact with people that present a threat to healthy

interactions, the experience of Malignant Social Psychology may be diminished or even

eliminated (Huxhold et al., 2014; Kruse & Schmitt, 2012).

Using the themes revealed in this study to understand the benefits that friendship

provides, and ways to encourage the continuation of existing supportive friendships, will

allow professionals and caregivers insight into ways to offer enriching, fulfilling experiences for persons with dementia. Activities such as game nights and luncheons designed exclusively for persons with dementia and their friends may provide individuals with the opportunity to catch up, vent, and reinforce friendship bonds. Engaging in creative activities may provide a reciprocal opportunity as friends assist each other in the completion of a project. The collection of life histories through recollection between long-term friends is an example of a creative activity that requires interaction from both members of the friendship dyad. Local chapters of The Alzheimer's Association may want to include such activities to their enrichment program with the aim of providing social opportunities for members as well as respite breaks for caregivers who need not attend. Programs and activities that promote the regular involvement of friends in addition to family members, especially when they contain opportunities for mutual support, should be developed so that persons with dementia maintain opportunities to engage in reciprocal relationships.

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Appendix A

Characteristics of Included Studies

Authors	Type	Level of diagnosis	Participants	Setting	Focus	Findings
e Medeiros t al. (2011)	Qualitative ethnographic study	Moderate to severe	31 residents of a long-term care facility (21 women, 10 men) and 14 staff members at the same facility	A 20-bed assisted living residential care unit exclusively housing people diagnosed with moderate to severe dementia	The importance of friendships in long-term care and the ways that staff interactions impact friendships.	Persons with dementia are able to engage in meaningful friendships and to express satisfaction in their relationships. Staff members were not adept at identifying friendships because of stereotypes and misinterpretations of behavior. Staff perceptions and actions may interfere with the possibility of organic friendships.
Harris (2012)	Qualitative phenomenological	Early stage dementia	8 participants of a larger study looking at the overall experience of early stage dementia. All selected members were women aged 59-85.	Members of an Alzheimer's Association early stage dementia program	Identifying factors necessary for the retention of friendship and the importance of friendships to the experience of early stage dementia	Friendships, while difficult to maintain for persons with dementia, are important to health and well-being. Friendships that survive the dementia experience require key factors, one of which is a sense of reciprocity.
Harris (2013)	Qualitative phenomenological	2 persons with mild, 1 person with moderate, and 1 person with late-stage dementia	four women diagnosed with dementia and four corresponding friend. All friendships were long-term (20 years or more).	Members of an early stage advisory board of an Alzheimer's Association chapter	Does the diagnosis of dementia impact friendship? What qualities are necessary for friendships to survive?	Friendships can survive a diagnosis of dementia, and friendships for persons with dementia are more varied that generally believed.
Kontos (2011)	Qualitative phenomenological	Moderate to severe levels of dementia	13 participants aged 65 years or older (3 men, 10 women)	Long-term care facility located in Ontario, Canada	Do cultural and communication traits that are habitual assist persons with dementia in social situations?	Even in the later stages of the disease, the ability to recognize social norms such as manners and empathy remain.
Sabat & Lee (2011)	Qualitative phenomenological	Moderate	No members were recruited, the study is based on observations of all participants	An adult day care center for persons with central nervous system problems including dementia	How do people diagnosed with dementia engage in positive social interactions?	Persons with dementia are able to communicate with others and to interpret social situations. Assessment tests may not be true indicators of real-life abilities, and therefore subjects should be given the benefit of the doubt regarding social skills necessary in the creation and maintenance of friendship.
Ward et al. (2012)	Case studies using personal narrative and qualitative phenomenological methods	Mild to moderate stages of dementia	Case 1: an 80-year old male diagnosed Case 2: participants in a peer group	Participants in a self-facilitated community peer group for community dwelling persons with dementia	What meaning does friendship have for people who have been diagnosed with dementia? Can "facilitated friendship" fill the same roles as organic friendships?	Friendships are important to persons with dementia. Rejection by friends due to a diagnosis of dementia does occur and can have a negative impact on self-esteem. It is important to provide ongoing opportunities to create new friends and social networks. Peer groups can be effective ways to provide the roles that friendships play in the lives of people who are living with dementia.

Appendix B

Interview Questions

Date and time of interview:

I wanted to visit with you today to learn about the ways your personal relationships may have changed since you started to have memory problems. First I am going to ask a few questions about yourself like your age, where you worked and your education. Then I will ask some questions about friends that you have kept or made since your memory problems began.

I want to know about your opinions, so there are no wrong answers. You don't have to answer any question if you don't want to, and we can stop at any time. If you want to stop or take a break, you can say stop or raise your hand.

Are you comfortable with what I've told you? If yes, begin, if no, allow the participant to ask further questions or end the interview.

Personal Information
---

1. What is your current gender identity?

2. What is your age?

3. Which best describes your ethnicity: Hispanic or Latino or Not Hispanic or Latino?

4. What category would you most identify as belonging to: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander or White?

5. How many years of schooling have you completed?

6. What is/was your occupation?

7. Would you say that in general your health is excellent, very good, good, fair or poor?

8. Do you live alone or with someone else?

Now I'm going to talk about your social life and the ways that you interact with others. You can decline to answer any or all of the questions if you like.

1. Can you describe for me a time when you felt that you were treated differently than you might have been before your memory issues began.

   IF THE SUBJECT CANNOT GIVE AN EXAMPLE, USE THE FOLLOWING PROMPTS:

   • Have there been times when you were spoken to differently?
   • Have there been changes in the way that people interact with you?

   1a. What did/does this mean to you?

2. Do you feel that your role in your relationships has changed because of your memory problems? Please describe.

   IF THE SUBJECT HAS TROUBLE COMING UP WITH AN ANSWER, USE THE FOLLOWING PROMPTS:

   - Do you feel that people have different expectations about the things that you can do since your memory problems began?
   - Do you find that assumptions are made about your abilities?

   2a. What did/does this mean to you?

3. Now we are going to talk about current friends and your relationship with them since your memory problems began. I would like to ask you some questions about up to four of your current friends. First, can you name the friends you'd like to talk about?

   First name of friend 1:
   First name of friend 2:
   First name of friend 3:
   First name of friend 4:

   IF THE SUBJECT HAS TROUBLE THINKING OF FRIENDS, ASK IF THERE ARE PEOPLE THAT THEY SPEND TIME WITH, SUCH AS IN THE SUPPORT GROUP OR AT CHURCH. FRIENDS THAT THE SUBJECT DOESN'T SEE FACE-TO-FACE CAN BE INCLUDED IN THE LIST, AS WELL AS FAMILY MEMBERS.

4. I would like to ask some questions about each of the friends you named.

Friend 1:
How do you know this friend?
What do you do with this friend?
What do you value most about this friendship?
Are there times that this friend helps you?

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What does that help mean to you?
Have there been times that you were able to help your friend, and if so how?
What did that experience mean to you?

> IF THE SUBJECT CANNOT THINK OF AN ANSWER, USE THE
> FOLLOWING PROMPTS:
> * Do these opportunities make you feel more useful?
> * Do these opportunities make you feel more like you used to before your
>   memory issues began?

Friend 2:
How do you know this friend?
What do you do with this friend?
What do you value most about this friendship?
Are there times that this friend helps you?
What does that help mean to you?
Have there been times that you were able to help your friend, and if so how?
What did that experience mean to you?

> IF THE SUBJECT CANNOT THINK OF AN ANSWER, USE THE
> FOLLOWING PROMPTS:
> * Do these opportunities make you feel more useful?
> * Do these opportunities make you feel more like you used to before your
>   memory issues began?

Friend 3:
How do you know this friend?
What do you do with this friend?
What do you value most about this friendship?
Are there times that this friend helps you?
What does that help mean to you?
Have there been times that you were able to help your friend, and if so how?
What did that experience mean to you?

> IF THE SUBJECT CANNOT THINK OF AN ANSWER, USE THE
> FOLLOWING PROMPTS:
> * Do these opportunities make you feel more useful?

- Do these opportunities make you feel more like you used to before your memory issues began?

Friend 4:
How do you know this friend?
What do you do with this friend?
What do you value most about this friendship?
Are there times that this friend helps you?
What does that help mean to you?
Have there been times that you were able to help your friend, and if so how?
What did that experience mean to you?

> IF THE SUBJECT CANNOT THINK OF AN ANSWER, USE THE
> FOLLOWING PROMPTS:
> - Do these opportunities make you feel more useful?
> - Do these opportunities make you feel more like you used to before your memory issues began?

5. Is there anything else you would like to tell me about the experience of friendship for someone with memory problems?