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BEYOND THE OBSERVABLE: EXAMING SELF-REPORTED WELL-BEING IN
PEOPLE WITH DEMENTIA

by

WINGYUN MAK

A dissertation presented to the Graduate
School of Arts and Sciences of Washington University
in St. Louis in partial fulfillment of the requirements
for the degree of Doctor of Philosophy

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ABSTRACT OF THE DISSERTATION

Beyond the Observable: Examining Self-Reported Well-Being in People with Dementia

by

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Doctor of Philosophy in Psychology

Washington University in St. Louis, 2009

Professor Brian D. Carpenter, Chairperson

The well-being of people with dementia is not well understood. Researchers often measure their well-being through observational methods or via proxies, but self-report is rarely used. Recently there is evidence that people with mild to moderate dementia are able to give reliable reports of their well-being, but empirical work in this area is limited. Most dementia-specific measures focus on mood or life satisfaction, and there are few that gauge more existential aspects of well-being (e.g., purpose in life). This study tested the use of a non-dementia-specific well-being measure in people with mild to moderate dementia. The relationship between goal pursuit, a predictor of well-being, and purpose in life, an aspect of psychological well-being, was examined through questionnaire and experimental methods. The moderating effect of dementia severity was also investigated. Results showed that people with mild to moderate dementia were able to provide reliable self-report data on their well-being. A strong association between goal pursuit and purpose in life emerged, but dementia severity did not moderate this relationship. Experimental results were similar in that people who participated in a goal-directed activity reported a greater sense of purpose than those who participated in a goal-

undirected activity. Results from this study illuminate the experience of psychological well-being in dementia and may inform activity programming for this population.

Acknowledgements and Dedication

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CHAPTER 1: REVIEW OF THE LITERATURE

Well-Being

Since the rise of well-being research in the last half-century, two dominant lines of thought have emerged (Ryan & Deci, 2001). Subjective well-being addresses the hedonic aspects of well-being. It is defined as affective well-being, or positive and negative affect, and life satisfaction (e.g., Diener, 1984; Diener, Suh, Lucas, & Smith, 1999). Life satisfaction is an individual's evaluation of the distance between current state in life and desired state, with a smaller deviance indicating greater life satisfaction (Campbell, Converse, & Rodgers, 1976). Psychological well-being addresses the eudemonic components of well-being (e.g., Ryff, 1989a, 1989b, 1989c; Ryff & Keyes, 1995; Waterman, 1984), that is, the happiness that is achieved by living to one's best ability. Psychological well-being is therefore defined by existential issues that reflect human potential: autonomy, environmental mastery, positive relations with others, personal growth, purpose in life, and self-acceptance (Ryff, 1989a, 1989b, 1989c). Occasionally subjective well-being, psychological well-being, and quality of life are used synonymously, but they have also been used distinctively. In this paper, I will use subjective well-being and psychological well-being distinctively and discuss their overlap with quality of life.

There has been much debate between theorists, ancient and contemporary, from both hedonistic and eudemonic perspectives, regarding the definition of well-being, but recent work suggests that well-being may encompass both perspectives. Keyes, Shmotkin, and Ryff (2002) attempted to make sense of the two lines of well-being research, using factor analyses to show that subjective well-being and psychological well-

being share a “related-but-distinct” status (Keyes et al., 2002, p. 1017). They tested six different models of well-being, ranging from complete independence of all the subcomponents of subjective and psychological well-being, to a single factor. The best-fitting model represented subjective well-being and psychological well-being as two oblique factors with self-acceptance and environmental mastery loading on both factors, which suggests that the two types of well-being are associated but conceptually different. Other quantitative (e.g., McGregor & Little, 1998; Ryff & Keyes, 1995) and qualitative studies (e.g., King & Napa, 1998; Waterman, 1993) have also concluded that well-being is composed of not only happiness (a hedonic component) but also meaning and personal growth (an existential component). Because of the conceptual importance of both traditions in well-being research, both subjective well-being and psychological well-being will be discussed.

Subjective Well-Being

Though subjective well-being has been a topic of interest since the third century B.C. (Waterman, 1993), it was not until the 1950s that interest in measuring social progress through the subjective experience of individuals initiated the scientific study of subjective well-being (Andrews & Withey, 1976; Land, 1975). In the post-war era, when food and shelter alone did not constitute happiness, the question of what makes people happy arose (Ryan & Deci, 2001). Psychologists recognized that the absence of negative functioning did not necessarily equal wellness, and they began studying the promotion of positive functioning (Diener, 1984; Diener et al., 1999; Jahoda, 1958). While studying broad areas of social change (e.g., race relations, education, economics, employment), Bradburn (1969) introduced the notion of using mood to measure happiness. His work,

along with his pilot study with Caplovitz, provided some evidence, perhaps fortuitously, for the orthogonality of positive and negative affect (Bradburn, 1969; Bradburn & Caplovitz, 1965), which has been replicated repeatedly (Diener & Emmons, 1984; Watson, Clark, & Tellegen, 1988). The independence of affect and life satisfaction has also been established (Andrews & Withey, 1976; Lucas, Diener, & Suh, 1996). Since then, researchers have often operationalized well-being as the combination of mood and life satisfaction. Bradburn's work was useful in terms of operationalizing happiness, but it was not intended to determine the structure of subjective well-being. As a result some have questioned the validity of using mood and life satisfaction to reflect well-being.

Ryff (1989a), for instance, criticized the subjective well-being literature because of its atheoretical beginnings. She pointed out that studies use subjective well-being as an outcome without first clarifying its definition. Take, for example, Bradburn's (1969) study, one of the first to include subjective well-being. The decision to define subjective well-being as an amalgam of positive and negative affect was intuitively driven rather than theoretically driven. Bradburn applied Herzberg and colleagues' (1959) finding that the absence of factors leading to job *dissatisfaction* did not lead to job *satisfaction* to suggest a parallel in the relationship between positive and negative affect. Though no correlational statistics were offered in the Herzberg et al. study, Bradburn concluded that "[he] would suspect that there would be substantial independence between the two groups [of factors]" (Bradburn, 1969, p.12). The use of life satisfaction as a component of subjective well-being also lacks firm theoretical grounding; however, its independence from affective well-being has been established (Andrews & Withey, 1976; Lucas et al., 1996).

The scales used to measure subjective well-being also have been problematic. Himmelfarb and Murrell (1983) found questionable reliability (Cronbach's $\alpha = .65$) in the Affect Balance Scale when administered to 279 older adults (mean age 68.63 years) and 109 older adults from a clinical population (mean age 58.43 years). The Life Satisfaction Index has satisfactory reliability (Cronbach's $\alpha = .87$) but poor validity ($r = .07$ to $.73$; Neugarten, Havighurst, & Tobin, 1961). As was the case with the Affect Balance Scale, the goal of creating the Life Satisfaction Index was not to measure life satisfaction per se but to differentiate successfully aging individuals from those who were not successfully aging. Nonetheless, psychologists have continued to use mood and life satisfaction in the hedonic tradition of well-being research (e.g., Biswas-Diener & Diener, 2006).

Correlates of Subjective Well-being

Diener's (1984) review discussed the influence of top-down and bottom-up processes on subjective well-being. Early research focused on how external, or bottom-up, factors like situations, income, and demographics affected happiness. The bottom-up approach was based on Wilson's (1967) point that happiness is achieved when universal human needs are met. For example, if a person is hungry, satiating that hunger will produce happiness. The presence of factors that prevent satiating that hunger will reduce happiness.

There is some evidence in support of the bottom-up approach. Stallings and colleagues (1997) found that pleasant and unpleasant life events were relatively good predictors of positive and negative affect across time in a multigenerational sample. Overall, however, these bottom-up factors explained less than 20% of the variance in

subjective well-being (also see Andrews & Withey, 1976; Campbell et al., 1976; Ryff, 1995). For example, research has shown that education is weakly correlated with subjective well-being, except in poorer countries (Argyle, 1999). Income may be a mediating factor between education and subjective well-being, but the research on income and subjective well-being is not definitive either. In third-world countries the relationship between income and subjective well-being is statistically significant (Howell, Howell, & Schwabe, 2006), which makes sense because a certain level of income is needed to meet basic needs. In first-world countries, however, this relationship disappears. After examining two independent data sets with a combined total of over 22,000 people of different ages, Diener, Sandvik, Seidlitz, and Diener (1993) found the same level of happiness in both poorer and richer areas of the United States. Income was not a mediating factor between education and subjective well-being. In general, the relationship between income and subjective well-being has been inconsistent (Argyle, 1999; Diener et al. 1999; Pugno, 2007).

Similarly it is not clear that age is related to subjective well-being. Wilson (1967) posited that younger people would be happier than older people because they are physically and psychologically healthier. This age difference held true in Bradburn and Caplovitz's (1965) study of happiness but is generally unsupported in later research. For instance, Gutierrez, Jimenez, Hernandez, and Puente (2005) found an initial negative relationship between age and positive affect that disappeared after controlling for the personality variables extraversion and openness. They also found no relationship between age and negative affect.

Perhaps due to the small effects explained by the bottom-up perspective, researchers began to incorporate a top-down approach in which they explored the effect of internal traits on well-being. One of the most robust top-down predictors is personality. Costa and McCrae (1980) found that positive affect positively correlated with extroversion, and negative affect positively correlated with neuroticism. People who scored higher on neuroticism also reported lower life satisfaction (Rogalski & Paisey, 1987). In addition to replicating these findings, Keyes and colleagues (2002) also found high conscientiousness linked with higher subjective well-being. Taken together, these findings are consistent with the results from other researchers who have found that people who report more anxiety, psychosomatic concerns, and worry tend to be unhappy (Bradburn & Caplovitz, 1965; Veroff, Feld, & Gurin, 1962).

Subjective well-being also may be associated with the extent to which people engage in goal-directed behavior (Brunstein, 1993; Emmons, 1986; King & Hicks, 2007; MacLeod, Coates, & Hetherington, 2008; Sheldon & Elliot, 1999). For example, older adults generally derive a sense of joy and satisfaction from communicating with their grandchildren. Perhaps the only way to see them while talking to them is via the computer. By setting goals towards learning how to use the computer, they may have a greater chance of experiencing those positive outcomes compared with people who do not have a goal in mind. Emmons (1986) found that the more one strives towards a goal, the more positive affect is reported. Regardless of whether the goal is actually achieved, Emmons found that life satisfaction was higher when one pursued more goals.

The relationship between subjective well-being and goal pursuit also may be affected by the relevance of the goal. For example, people who achieve goals that are in

line with their interests are more likely to report a boost in their well-being (Sheldon & Elliot, 1999). Furthermore, goals may affect some aspects of subjective well-being and not others. Setting goals for acquiring material resources correlates with greater life satisfaction, whereas having social goals or performing altruistic acts have been related to greater overall subjective well-being (Diener & Fujita, 1995; Lyubomirsky, King, & Diener, 2005). Subjective well-being may be affected differentially depending on the goal's implications for the individual.

Psychological Well-Being

In contrast to the hedonistic approach to well-being, others have argued that well-being is achieved by engaging in meaningful activity and reaching one's potential (Ryan & Deci, 2001). Aristotle (350 B.C./1947) first classified this type of well-being as eudemonia. The prefix, "eu," means good or true, and "demon," means inferior deity, or the intermediary between human and the divine. Though it is often translated as "happiness," the original meaning of eudemonia refers to the pursuit towards the best version of oneself.

Psychological well-being was not a term that was frequently used until the 1980s, but Keyes and colleagues (2002) pointed out that themes of personal growth and development have been discussed by many developmental theorists in the past. For example, Jung's (1933) notion of individuation suggested that each person's life is a journey towards self-discovery. Erikson's (1959) eight-stage model outlined healthy psychological development across the lifespan, stating that developmental stagnation is harmful to mental health. Rogers's (1961) discussion of full functioning as a means to having "the good life" emphasized openness to growth and fulfilling one's potential.

Maslow's notion of self-actualization emphasized "the desire to become more and more what one is, to become everything that one is capable of becoming" (Maslow, 1943, p. 382). Because many of these theories were not translated into clearly operationalized constructs, their role in well-being research was limited (Keyes et al., 2002).

Ryff (1989a, 1989b) recognized the commonalities in these developmental theories and saw the need for a definition of psychological well-being that incorporated optimal functioning. From the developmental literature, she took recurring features that she then defined as the six dimensions of psychological well-being: self-acceptance, personal growth, positive relationships, purpose in life, autonomy, and environmental mastery. In the following subsections I will describe these dimensions of psychological well-being.

Self-Acceptance

Across the developmental literature it appears that self-perception is one of the main aspects of well-being. Whether positive or negative, the recognition of one's nature seems to be important for well-being (Jung, 1933). Likewise, Jahoda noted that "positive mental health should be sought in the attitudes of an individual toward his own self" (Jahoda, 1958, p. 23). Self-acceptance is especially important in older age as people evaluate their identity and past experiences (Erikson, 1959). Without achieving self-acceptance, Maslow (1968) argued, people cannot reach their full potential.

Positive Relationships

Also important to well-being are meaningful relationships. In a nationally representative sample the majority of people stated that having a spouse, raising children, and having close friends contribute to their well-being (Ryff, 1989a). This finding is

consistent with Erikson's (1959) sixth stage of development, intimacy vs. isolation, which emphasized the healthy experience of close interpersonal relationships, whether romantic, platonic, or filial. Affection is something most people innately value (Rogers, 1959) because it provides a sense of belonging and acceptance (Maslow, 1968). Without interpersonal relationships there is a greater risk for psychological maladjustment (Maslow, 1968).

Personal Growth

Regardless of age or life situation, optimal development requires the continued development of the self in response to changing environments. Deeming growth one of the criteria for positive mental health, Jahoda (1958) posited that degree of growth is a reflection of the state of a person's mental health. Essentially mirroring Maslow's (1968) notion of self-actualization, Rogers (1959) said that all people naturally aim to enhance themselves in positive ways. This serves as the motivation behind all human activity. Even in old age, when there may be more physical or social limitations, Allport deemed it a "social waste in cutting older people off, through retirement or isolation, from their directions of growth" (Allport, 1961, p. 296). He argued that mental growth might occur independent of physical ability.

Purpose in Life

Another aspect of well-being is having purpose in life. Having purpose infuses one's life with meaning and worth. It also facilitates personal growth; without purpose a person may find it harder to progress because his or her efforts are not directed. For example, people lacking purpose may be less likely to engage in behaviors that would provide them with rewarding experiences. Allport (1961) stated that maturation includes

understanding purpose in life and having intentionality about fulfilling that purpose, whether that includes a single goal or many goals. Setting goals seems to be the manifestation of the desire to work towards fulfilling one's purpose. A person's mental health is so dependent on having a purpose in life (Jahoda, 1958) that lacking purpose may result in suicide (Allport, 1961, p. 295). After controlling for neuroticism, depression, and social hopelessness, purpose in life is still a significant predictor of suicidal ideation (Heisel & Flett, 2004). In regards to the increasing limitations that come with age, Frankl (1959) strongly advocated for the right to pursue meaning and purpose in life regardless of one's situation.

Autonomy

Psychological well-being also includes the ability to think and act independently of the demands of the environment. Maslow (1943) suggested that the autonomous person is able to act in accordance to interior rewards (e.g., self-growth) rather than exterior rewards (e.g., monetary wealth, political power). Achieving autonomy allows people to fulfill their innate need to become the best version of themselves (Rogers, 1959). Even in cases where physical limitations may limit autonomy in some areas of life, Neugarten (1973) suggested that one can still experience autonomy through communication.

Environmental Mastery

Having some control over one's environment (physical, social, and emotional) also contributes to well-being. For example, a person who can adapt to novel situations and maintain meaningful interpersonal relationships while balancing work and play has mastered the environment (Jahoda, 1958). Inability to interact with the external world

prevents a person from moving towards maturation (Allport, 1961), which is inherent in achieving psychological well-being.

Measuring Psychological Well-Being

None of the developmental theories discussed in the previous sections were translated into reliable and valid instruments for measurement. To remedy this problem, Ryff (1989b) drew from the developmental theories as the foundation for constructing a scale to measure psychological well-being. She began, in the formative stages of scale construction, by writing bipolar definitions for each of the six dimensions (Table 1). Subsequently, three individuals independently created approximately 80 items for each dimension. Through an iterative process of evaluation, including gathering reliability and validity statistics based on large samples, a final version of 20 items per subscale had acceptable internal consistency ($\alpha = .86 - .93$) and test-retest reliability over 6 weeks ($r_s = .81$ to $.88$). Currently there are multiple shortened versions of this scale (3-item subscales, 9-item subscales, 14-item subscales), though Ryff does not recommend using the 3-item subscales, noting low internal consistency (personal communication, April 13, 2008).

Table 1. Definitions of Theory-Guided Dimensions of Well-Being

Self-acceptance

High scorer: Possesses a positive attitude toward the self; acknowledges and accepts multiple aspects of self including good and bad qualities; feels positive about past life.

Low scorer: Feels dissatisfied with self; is disappointed with what has occurred in past life; is troubled about certain personal qualities; wishes to be different than what he or she is.

Positive relations with others

High scorer: Has warm, satisfying, trusting relationships with others; is concerned about the welfare of others; capable of strong empathy, affection, and intimacy; understands give and take of human relationships.

Low scorer: Has few close, trusting relationships with others; is isolated and frustrated in interpersonal relationships; not willing to make compromises to sustain important ties with others.

Autonomy

High scorer: Is self-determining and independent; able to resist social pressure to think and act in certain ways; regulates behavior from within; evaluates self by personal standards.

Low scorer: Is concerned about the expectations and evaluations of others; relies on judgments of others to make important decisions; conforms to social pressure to think and act in certain ways.

Environmental mastery

High scorer: Has a sense of mastery and competence in managing the environment; controls complex array of external activities; makes effective use of surrounding opportunities; able to choose or create contexts suitable to personal needs and values.

Low scorer: Has difficulty managing everyday affairs; feels unable to change or improve surrounding context; is unaware of surrounding opportunities; lacks sense of control over external world.

Purpose in life

High scorer: Has goals in life and a sense of directedness; feels there is meaning to present and past life; holds beliefs that give life purpose; has aims and objectives for living.

Low scorer: Lacks a sense of meaning in life; has few goals or aims, lacks sense of direction; does not see purpose of past life; has no outlook or beliefs that give life meaning.

Personal growth

High scorer: Has a feeling of continued development; sees self as growing and expanding; is open to new experiences; has sense of realizing his or her potential; sees improvement in self and behavior over time; is changing in ways that reflect more self-knowledge and effectiveness.

Low scorer: Has a sense of personal stagnation; lacks sense of improvement or expansion over time; feels bored and uninterested with life; feels unable to develop new attitudes or behaviors.

Note Source: Ryff, C.D. (1989a).

Correlates of Psychological Well-Being

Many studies have identified important factors that are associated with psychological well-being. In terms of age, Ryff (1989b) found that middle-aged adults scored higher than older adults in purpose in life and higher than young adults in autonomy. Middle-aged and older adults scored higher on environmental mastery than young adults. Young adults and middle-aged adults tended to report more personal growth than older adults. There were no age differences in self-acceptance and positive relations with others. Similar findings have been replicated in other samples (Clarke, Marshall, Ryff, & Rosenthal, 2000; Clarke, Marshall, Ryff, & Wheaton, 2001; Ryff, 1991; Ryff & Keyes, 1995). The major purpose of these studies was to highlight the age-related trends in psychological well-being, but the reasons underlying these trends are vague. Ryff (1995) has preliminary data showing that older adults do not lose the desire for growth and purpose but instead may have limited access to opportunities for development. Longitudinal studies are needed to understand whether age-related differences stem from developmental or maturational processes or from cohort effects.

As with subjective well-being, personality is also a strong correlate of psychological well-being. Neuroticism and extraversion appear to be the strongest predictors. Using the NEO-PI-R (McCrae & Costa, 1992), Siegler and Brummett (2000) found 23 significant correlations (out of 24) between facets of neuroticism and self-acceptance, environmental mastery, positive relations, and purpose in life; 22 significant correlations (out of 24) between facets of extraversion and the same well-being dimensions. People who were higher on neuroticism tended to be lower in these aspects of well-being. The strongest relationships with neuroticism and extraversion were seen

with self-acceptance and purpose in life. Schmutte and Ryff (1997) also investigated the relationship between personality and psychological well-being. Like Siegler and Brummett (2000), they found neuroticism and extraversion to be the strongest correlates, but incorporating affect produced somewhat more complex results.

Because of the potential overlap between personality, affect, and psychological well-being, Schmutte and Ryff (1997) examined their relationships with each other. Conceptually, psychological well-being does not include affect, but the definition of psychological well-being overlaps with some personality items. For example, Ryff's (1989a, 1989b) definition of a person with positive relations with others is quite similar to McCrae and Costa's (1992) definition of a person scoring high on agreeableness. Results showed that after controlling for mood, personality was still a significant predictor of psychological well-being. Though these results did not clarify whether personality is a valid predictor of psychological well-being or just another aspect of psychological well-being, Schmutte and Ryff (1997) argued that the two are separate constructs because personality precedes life events, and psychological well-being is a consequence of life events.

Another predictor of psychological well-being is goal pursuit or the extent to which people pursue goals to shape their situation (Brandtstädter & Renner, 1990). Goals serve as a vehicle for experiencing meaning and structure in daily life (e.g., Klinger, 1977; Pervin, 1989). In addition to navigating life more efficiently, setting goals may allow an individual to feel a sense of accomplishment when the goal has been reached. In sports-related activity, for instance, setting goals can organize needs and

partially determine the amount of effort that is put forth towards goal achievement (Smith, Ntoumanis, & Duda; 2007).

Frazier, Newman, and Jaccard (2007) introduced a multivariate model of psychosocial outcomes across the lifespan that highlighted the strength of the relationship between goal pursuit and psychological well-being. They included factors such as age, feared and hoped-for possible selves, goal pursuit, goal adjustment, and four personal control variables to understand how these may function as predictors of the six aspects of psychological well-being. Of the factors that were related to psychological well-being, goal pursuit was the strongest predictor with a path coefficient of .53. Other factors that were related to psychological well-being were hoped-for possible self ($\beta = .09$), goal adjustment ($\beta = .44$), and selective primary control ($\beta = .29$). Frazier and his colleagues suggested that goal adjustment may be more important in old age, as older adults may find more success in adapting their goals to their capabilities, but their results suggested that goal pursuit is just as important, if not more. In general, this study confirmed the notion that pursuing goals is associated with enhanced psychological well-being.

Well-Being in Older Adulthood

Well-being has become a popular outcome of interest in social science, especially in the growing field of gerontology. Because of the relative absence of theory-guided definitions of well-being, a variety of definitions are used. The definitions of subjective well-being and psychological well-being, as reviewed in previous sections, are not consistently applied, which has made the summarization of research findings difficult. In this section I will discuss the most frequently used definitions of well-being in late life research.

Neugarten, Havighurst, and Tobin (1961) were early investigators of well-being in older adults. They created the Life Satisfaction Ratings scale (LSI; more commonly known as the Life Satisfaction Index) to identify successfully aging individuals. Their operational definition of well-being, derived from examining previous well-being scales, had five components: zest, resolution of life issues, congruence between desired and achieved goals, positive self-concept, and mood tone. This definition taps components of both subjective and psychological well-being, which shows that the challenges of operationalizing well-being also exist in the literature specific to late life.

Quality of life is a construct that has often overlapped with well-being in the aging literature. Lawton's (1983, 1991) multidimensional definition of quality of life included psychological well-being as a subjective indicator, along with perceived quality of life and two objective indicators, behavioral competence and objective environment. Psychological well-being, in this case, reflected "the person's evaluations of life as a whole, including the self, in both cognitive and affective terms, as well as the purely subjective aspects of mental health" (Lawton, Kleban, & diCarlo, 1984, p. 69). Lawton and colleagues were concerned with determining the dimensions of psychological well-being using all aspects of subjective and psychological well-being described in the literature. They included a measure of happiness (Gurin, Veroff, & Feld, 1960), life satisfaction (Campbell et al., 1976), affective states (Bradburn, 1969), self-esteem (Rosenberg, 1965), and psychological distress (National Center for Health Statistics, 1970) to characterize psychological well-being. They also included self-rated health, personal adjustment, and residential satisfaction indices from the Philadelphia Geriatric Center Multilevel Assessment Instrument (MAI; Lawton, Moss, Fulcomer, & Kleban,

1982). Though their two-component solution accounted for 46% of the variance, it remained unclear why certain variables grouped together. For example, the first component, which was termed Neuroticism, included indices such as negative affect, self-esteem, self-rated health, satisfaction with family, and social anxiety. Conceptually it is ambiguous why these indices loaded onto the same component, but no one has attempted to clarify this finding. Overall, the quality of life literature includes a variety of definitions for quality of life, and the overlap with subjective and psychological well-being has made it difficult to study effectively these two conceptually different types of well-being.

Since the late 1980s there has been a growing interest in understanding the eudemonic aspects of well-being in late life. Ryff (1989a, 1989b, 1989c) proposed that there was more to well-being than affective well-being and life satisfaction (i.e., subjective well-being). Thus she created a six dimensional definition of psychological well-being as described earlier (see Table 1). Low correlations between measures of subjective well-being and Ryff's scales offered initial evidence of the independence of psychological well-being and subjective well-being, a finding that was confirmed in a subsequent principal components analysis (Ryff, 1989a). More important, many interesting age-related differences in psychological well-being surfaced. As noted in a previous section, older adults were more likely to report less purpose in life and personal growth than middle-aged individuals. Older adults were also more likely to have less sense of environmental mastery and personal growth than younger adults. A detailed explication of these findings was not included, but the role of health and functional limitations has been mentioned in other studies as an explanation for age-related

decrements in psychological well-being (Clarke et al., 2000; Clarke et al., 2001). Also, with the onset of retirement the number of roles a person holds decreases, which may also affect one's sense of purpose in life and growth. A more parsimonious explanation for these decrements simply may be that older adults have fewer opportunities to enhance well-being (Ryff, 1995). Although many of these studies are purely descriptive, their results have implications for intervention.

Activity and Well-Being in Older Adults

Carver and Scheier (1998) stated that activity is what sustains life. Activity is the medium through which people experience well-being. Without activity, none of the subcomponents of subjective well-being or psychological well-being could be enhanced. Activity theory first suggested that continued activity in old age would help maintain social roles and promote successful aging through productivity (Havighurst, 1968), a notion that was reflected in Rowe and Kahn's (1997) definition of successful aging. Indeed there has been a great deal of support for these theories (e.g., Lampinen, Heikkinen, Kauppinen, & Heikkinen, 2006; Lawton, Winter, Kleban, & Ruckdeschel, 1999; Moen, Dempster-McClain, & Williams, 1992; Musick, Herzog, & House, 1999).

Some would suggest a more complex relationship between activity and well-being. Everard (1999) found that the number of activities was not as important as the reasons for the activity participation. After compiling a list of 44 activities from a focus group of six older adults, Everard asked a separate group of older adults (N = 220) to mark which ones they participated in and for what reason (i.e., fun, mental, social, passes time, obligatory, physical). In a hierarchical regression analysis she found that activities that were done to pass time and for social reasons were significantly associated with

enhanced mood after controlling for various demographic variables and the number of engaged activities. Everard's findings indicate that the type of activity may differentially affect well-being.

The existence of an activity hierarchy (i.e., some activities may be better than others for well-being) is supported by the late life productive engagement literature. Morrow-Howell (2000) stated that "productive activity is any activity that produces goods or services...These activities are clearly a subset of activities in which older adults engage, and they have a common element: they have social benefit, benefits that extend beyond the individual" (Morrow-Howell, 2000, p. 1). Volunteerism has been associated with lower levels of depressive mood in older adults (Musick & Wilson, 2003). In a longitudinal sample of 2,812 older adults, Glass, de Leon, Marottoli, and Berkman (1999) found social and productive activities, regardless of their potential to enhance physical fitness, increased the rate of survival in older adults.

A common theme throughout the productive engagement literature is role theory, which states that social roles greatly affect self-perception and behavior (Cottrell, 1942). Losing a role equates to loss of activity because having a role links a set of activities to the person. For example, the label *mother* assigns a set of activities to a woman. Her role affects not only the way she acts, but it also affects her perception of her purpose. Through interactions with her child she has more opportunity to feel that she is serving a purpose as a mother. In extreme cases, people without any roles may question their own purpose as there would be no reason for their activities. Participating in activities that fulfill a role or purpose may lead to greater well-being. This seems likely to be true even among people with cognitive deficits.

Well-Being in Persons With Dementia

There have been many lines of research to improve the well-being of people with dementia, but there has been relatively little focus on the experience of dementia from the perspective of people with the disease (Downs, 1997; Phinney, 2002; Phinney, Chaudhury, & O'Connor, 2007). Challenges of studying well-being in people with dementia include their diminished insight and communication abilities. Consequently, many well-being measures for people with dementia use observational methods (e.g., Lawton, Van Haitsma, et al. 1999) or proxies (e.g., Albert et al., 1996; Rabins, Kasper, Kleinman, Black, & Patrick, 1999; Teri & Logsdon, 1991).

Lawton, Van Haitsma and colleagues (1999) created the Apparent Affect Rating Scale (AARS) as an observational method of gauging emotional expression (pleasure, anger, anxiety/fear, depression/sadness, interest) of moderately to severely demented people. Trained observers made observations at set times throughout the day and rated whether they saw signs of the aforementioned emotions and for how long.

Teri and Logsdon's (1991) Pleasant Events Schedule for people with Alzheimer's Disease (PES-AD) measures well-being by asking the caregiver to report on the person with dementia's activity. In some instances of mild dementia, Teri and Logsdon noted that the person with dementia could be involved in rating items. Albert et al. (1996) also measured mood and level of activity in people with dementia, but from the perspective of the main caregiver. They noted that, although there was no gold standard for determining validity, comparing family caregiver reports with institutional caregivers provides a check for consistency. As dementia severity increased, quality of life, reported

observationally, decreased, as reflected in mood and reduced activity participation and enjoyment. The Alzheimer's Disease-Related Quality of Life (ADRQL; Rabins et al., 1999) requires caregivers to make judgments regarding the care recipient on domains of social interaction, awareness of self, enjoyment of activities, feelings and mood, and response to surrounding. Although observational and proxy methods may offer some information regarding the well-being of people with dementia, establishing validity is difficult because the people with dementia themselves are not given an opportunity for self-report.

Whereas observational and proxy measures may be appropriate for people with dementia who are no longer able to communicate about their well-being, there is growing evidence that individuals with mild to moderate dementia are able to rate their well-being reliably (Brod, Stewart, Sands, & Walton, 1999; Logsdon et al., 2002; Ready, Ott, Grace, & Fernandez, 2002). The Dementia Quality of Life Instrument (DQoL; Brod et al., 1999) is one of the few measures administered directly to people with dementia. It is designed to assess positive and negative moods, feelings of belonging, self-esteem, and sense of aesthetics. Reliability is acceptable (Cronbach's $\alpha = .67$ to $.89$, test-retest $r = .64$ to $.90$), and mean ratings were similar among mild to moderately demented people (Ready & Ott, 2003). Though this finding suggests that quality of life is the same across different stages of dementia severity, Zank and Leipold (2001) found that subjective well-being is rated higher in more severe cases of dementia ($r = -.40$) as measured by the Mini Mental State Exam (MMSE). Convergent validity of the DQoL has been established by moderate correlations ($rs = -.42$ to $-.64$) between its subscales and the Geriatric Depression Scale (GDS; Sheikh & Yesavage, 1986).

Logsdon, Gibbons, McCurry, & Teri (2002) designed the Quality of Life in Alzheimer's Disease Scale (QoL-AD) to measure general mood, memory, functional abilities, interpersonal relationships, activity participation, financial situation, physical condition, and global self-assessment through patient and caregiver reports. They found good internal consistency (Cronbach's $\alpha = .83$ to $.90$) among both caregiver and patient reports. Convergent validity was also established through correlations with the GDS ($r = -.41$ to $-.65$) and the PES-AD ($rs = .18$ to $.51$). Though they found weak correlations between caregiver and patient reports ($rs = .14$ to $.39$), they suggested that "the correlation between patient and caregiver reports likely reflects a real difference in the way they perceive the patient's QoL rather than a lack of reliability of the measure itself" (Logsdon et al., 2002, p. 518).

The Cornell-Brown Scale for Quality of Life in Dementia (CBS; Ready, Ott, Grace, & Fernandez, 2002) was designed to assess global quality of life through measuring positive and negative affect, physical and psychological satisfaction, self-esteem, and experience of negative events as reported by both patient and caregiver. Reliability was good (Cronbach's $\alpha = .81$, interrater $r = .90$), and a positive correlation between CBS scores and separate positive mood ratings (Spearman $\rho = .63$) indicated criterion validity. All of these measures have attempted to understand the well-being of people with dementia, but the specific area of eudemonic well-being remains unmeasured in this population.

Activity and Well-Being in People with Dementia

If activity is a means by which people can experience well-being, and if people with dementia can offer self-report data regarding their well-being, a logical step is to

look at the relationship between activity and well-being in people with dementia. There is some evidence suggesting that activity can enhance the well-being of people with dementia. For example, Phinney et al.'s (2007) qualitative study revealed that people with dementia derived a sense of meaning from normal everyday activities. Participants reported that engaging in leisure and recreational pastimes, household chores, social events, and work-related activities allowed them to find meaning by experiencing a sense of identity and belonging, enjoyment, and some level of autonomy. Brooker and Duce (2000) compared engagement in goal-directed activities (i.e., reminiscence therapy pictures, objects, crafts, games) with goal-undirected activities (i.e., unstructured time) and observed that the former type of activity produced a higher sense of well-being in people with dementia. In addition to enhanced well-being, Kolanowski, Buettner, Costa, and Litaker (2001) found that participating in activities can reduce the number of behavioral disturbances. An important consideration in this process, however, is that activity must be consistent with the preferences of the person with dementia or it may not be beneficial (Phinney et al., 2007).

In an effort to enhance the well-being of people with dementia, adult day service centers typically structure their day around different activities that promote social, physical, and cognitive engagement. Compared with the isolation that can occur in nursing homes or other living situations, attending an adult day service center seems to help people with dementia. For example, in a study where adult day service center participants ($n = 43$) were compared with matched controls ($n = 40$) at three different times across 15 months, day service center participants showed improvements in observable depression and self-reported life satisfaction (Zank & Schacke, 2002). Day

service center participants also were more likely to recognize more words on the Nuremberg Aging Inventory (Oswald & Fleischmann, 1982) and exhibit fewer instances of agitation than control participants.

An additional benefit of attending an adult day service center is reduced caregiver burden (Gitlin, Reever, Dennis, Mathieu, & Hauck, 2006; Zank & Schacke, 2002; Zarit, Stephens, Townsend, & Greene, 1998) and reduced patient institutionalization (Harder, Gornick, & Burt, 1986). Though it seems that day service centers benefit psychosocial outcomes (Gaugler & Zarit, 2001), it is not understood what drives this effect. Most of the programs seem to be modeled on other adult day service centers or created intuitively, without reference to theory or empirical data. The purpose of this study is to generate empirical evidence about well-being in dementia and how understanding predictors of well-being may inform program development in these adult day facilities.

Theoretical Rationale and Hypotheses

As the field of psychology has shifted towards understanding what promotes adaptive or positive functioning rather than merely reducing negative functioning, the promotion of positive functioning in demented individuals seems fitting. Few studies have examined more existential facets of positive functioning in people with dementia, and fewer still have used self-reports to explore these constructs. The purpose of this study was to determine whether goal pursuit is positively related to one aspect of psychological well-being, purpose in life, in people with dementia. I tested this relationship using experimental and questionnaire methods. Additionally the role of dementia severity was explored.

Existing measures of well-being in people with dementia tend to emphasize subjective well-being more than psychological well-being. In fact, there is little empirical evidence to describe how psychological well-being functions in people with dementia, and no one has examined Ryff's definition of psychological well-being in people with dementia. Examining whether aspects of psychological well-being can be (a) measured and (b) enhanced will contribute to our understanding of the experience of demented populations and suggest opportunities for effective day services programming.

In a qualitative study that aimed to define well-being from the perspective of people with dementia, one of the most frequently mentioned aspects of well-being was having a purpose in life (Dröes et al, 2006). Surprisingly, having a purpose was one aspect of well-being that caregivers did not mention. Two implications of this study are that (a) having a purpose in life is still important to people with dementia and (b) it is necessary to let them voice their opinions, as their perspectives may not be captured by observational methods or proxy reports.

Just as psychological well-being is poorly understood in people with dementia, so too are its predictors. Goal pursuit is a well-known predictor of subjective well-being, but researchers are just beginning to note its relationship to psychological well-being. Frazier et al. (2007) conducted one of the first studies to look at the relationship between goal pursuit and psychological well-being, and they found that goal pursuit was strongly associated with purpose in life. Theoretically many developmental psychologists have proposed this relationship. For example, Rogers used terms like "forward-moving forces" (Rogers, 1951, p. 195), Berne suggested a personal life plan (Berne, 1964), and Erikson suggested pursuing activities that would lend purpose and meaning to behavior

(Erikson, 1959). All three were referring indirectly or directly to the idea that goal-directed behavior would be beneficial, but this relationship remains untested in people with dementia.

The relationship between dementia severity and well-being (including psychological well-being) is also relatively undefined. One might presume that well-being suffers as dementia severity increases, based on the loss of abilities; however, the few studies that have examined the effect of dementia severity on aspects of well-being reveal inconsistent trends. In the area of subjective well-being the progression of dementia is accompanied by improvement in self-reported subjective well-being (Zank & Leipold, 2001). In the quality of life literature Albert et al. (1996) found that as dementia severity increased mood, activity participation, and enjoyment deteriorated. On the DQoL (Brod et al., 1999), which measures a mixture of aspects of subjective well-being and psychological well-being, people with more severe dementia did not differ from people with milder dementia (Ready & Ott, 2003). Because there is a greater degree of overlap between quality of life and psychological well-being than between subjective well-being and psychological well-being, findings from quality of life studies may be a better source for predictions regarding the relationship between dementia severity and aspects of psychological well-being.

One method of testing the relationship between goal-directed behavior and sense of purpose in life for people with dementia would be to adapt an existing adult day service center activity such that goal pursuit would be manipulated to investigate its differential effects on sense of purpose in life. In this study I examined the relationship between goal pursuit and purpose in life in people with dementia. All participants

completed both an experimental and questionnaire portion of the study. In the experimental portion of the study, people with dementia participated in either a goal-directed or goal-undirected activity and then made ratings of their immediate sense of purpose. This part of the study tested whether the average immediate sense of purpose was greater in people with dementia who participated in a goal-directed activity compared with those who did not. In the questionnaire portion of the study, people with dementia were asked about their tendency towards goal pursuits and their purpose in life. This part of the study was meant to quantify the degree to which goal pursuit and purpose in life are related in people with dementia.

Hypotheses

Hypothesis 1: People with dementia who engage in a goal-directed activity will have a higher immediate purpose score than those who engage in a goal-undirected activity.

Hypothesis 2: The effect of a goal-directed activity on immediate purpose will be moderated by level of dementia severity, such that within the goal-directed condition people with more severe dementia will have lower mean immediate purpose scores than people with less severe dementia.

Hypothesis 3: People with dementia who have a greater sense of goal pursuit will have a greater sense of purpose in life.

Hypothesis 4: The relationship between level of goal pursuit and sense of purpose in life will be moderated by level of dementia severity such that greater dementia severity will weaken the relationship between goal pursuit and sense of purpose in life.

CHAPTER 2: METHODS

Power

To calculate an appropriate sample size for the current study, I used results from Frazier and colleagues (2007), which to my knowledge is the only previous study that examined the relationship between goal pursuit and purpose in life. They reported a correlation of .46. In my study, I added an additional variable, dementia severity, to examine its effects on the relationship between goal pursuit and purpose in life. Therefore, for my power analysis I have used a more conservative effect size ($R^2 = .1$). According to Cohen (1977), there will be an 80% chance of detecting effects of goal pursuit and dementia severity on purpose in life ($p < .05$) with an effect size of $f^2 = .11$ and a sample size of 90 participants.

Participants

Ninety-one community-dwelling people with dementia were recruited from local adult day service centers and the Alzheimer's Association (St. Louis chapter) for participation. Interest and eligibility were determined in person with the participant on site at local adult day service centers (consent process detailed in the Procedure section). People with all types of dementia were eligible to participate as long as they were able to give consent themselves. If interested in participating, people first completed the 15-item Geriatric Depression Scale (GDS; Sheikh & Yesavage, 1986) as a screening instrument; they had to score five or below so that depression would not be a confounding variable (Korner et al., 2006; Wright & Persad, 2007). Everyone scored within this parameter, and thus no one was excluded. Participants with aphasia, severe vision loss, and the loss of use of hands were excluded. This was determined by staff recommendations.

Materials

Demographic Variables

A short demographic questionnaire included questions regarding age and gender (see Appendix A).

Dementia Severity

The modified Telephone Interview for Cognitive Status (TICS-m; Welsh, Breitner, & Magruder-Habib, 1993) consists of 12 questions with a point total of 50 (see Appendix B). A score of 36 or higher suggests the absence of dementia, a score between 19 and 35 suggests mild to moderate dementia, and a score below 19 suggests moderate to severe dementia. The TICS-m is designed to be a relatively quick method of gauging a person's cognitive status by testing memory, orientation, arithmetic, language, attention, and problem solving. This instrument has excellent interrater reliability ($r = .97$; Brandt et al., 1993). Moylan and colleagues (2004) observed that it functions similarly when administered in person and by telephone, noting that its greater difficulty (i.e., it contains a delayed memory recall component) possibly makes it a more sensitive measure than the Mini Mental State Examination. Barber and Stott (2004) found a strong correlation (.86) between the TICS-m and the revised version of the cognitive part of the Cambridge Examination for Mental Disorders of the Elderly (de Koning, Dippel, van Kooten, & Koudstaal, 2000), indicating good convergent validity.

Depression

The Geriatric Depression Scale (GDS; Sheikh & Yesavage, 1986) consists of 15 yes or no questions and is designed to be a time-efficient screening tool for depression in older adults (see Appendix C). Items are summed to produce an overall score ranging

from 0 to 15, with higher scores indicating a greater level of depression. It has high internal consistency (Cronbach's $\alpha = .80$; Chattat, Ellena, Cucinotta, Savorani, & Mucciarelli, 2001). With a cut point between four and five, sensitivity, specificity, positive predictive, and negative predictive rates are 93%, 65%, 83%, and 83%, respectively, compared with the International Classification of Diseases-10 diagnostic criteria for a Major Depressive Episode, and 97%, 55%, 70%, and 94% respectively, compared with Diagnostic and Statistical Manual of Mental Disorders-IV (Almeida & Almeida, 1999). The GDS has been used with demented populations. Korner and colleagues (2006) found sensitivity and specificity are 81% and 72% compared with the International-10 diagnostic criteria when using a cut point of four. They also find that the GDS is highly correlated with the Cornell Scale for Depression in Dementia ($r = .77$), the Hamilton Depression Rating Scale ($r = .77$), and the Clinical Global Impression ($r = .75$).

Goal Pursuit

The Tenacious Goal Pursuit scale (Brandtstädter & Renner, 1990; Appendix D) consists of 15 items that measure an individual's self-described tendency to pursue goals (e.g., "The harder a goal is to achieve, the more appeal it has to me."). Responses to each item are made on a 5-point Likert scale, ranging from 0 (*strongly disagree*) to 4 (*strongly agree*). Items are averaged to produce an overall score ranging from 0 to 60, with higher scores indicating greater goal pursuit tendency. The scale has adequate internal consistency (Cronbach's $\alpha = .80$; Brandtstädter & Renner, 1990; Heyl, Wahl, & Mollenkopf, 2007) and construct validity. Brandtstädter and Renner (1990) reported a negative correlation ($r = -.24$) between goal pursuit and depression and a positive

correlation between goal pursuit and life satisfaction ($r = .26$). This scale has not been used previously in people with dementia.

Purpose in Life

Ryff's (1989a) Purpose in Life scale (Appendix E) is a 14-item subscale from her psychological well-being scale. Responses follow a 6-point Likert format: 1 (*strongly disagree*), 2 (*moderately disagree*), 3 (*slightly disagree*), 4 (*slightly agree*), 5 (*moderately agree*), 6 (*strongly agree*). Negatively-worded items are reversed in the scoring procedures and then the items are summed producing scores that range from 14 to 84 with higher scores indicate greater purpose in life. Ryff reported good internal consistency ($\alpha = .88$) and also noted that the 14-item version strongly correlates with its 20-item parent version ($r = .98$). This scale has not been used previously in people with dementia.

Because there are no existing scales to measure an individual's immediate sense of purpose, for the experimental portion of this study, the Purpose in Life subscale was modified to assess participants' perception of purpose in their experimental activity (see Appendix F). It consists of 8 items, again rated on 6-point Likert scales, producing scores that can range from 8 to 48, with higher scores indicating greater immediate sense of purpose.

Experimental Condition and Pilot Studies

Half of the participants (experimental group: $n = 46$, 9 males) were randomly assigned to participate in a goal-directed activity that involved creating a card for either a sick child or a soldier away from home. Participants chose for whom they wanted to create a card. The experimenter provided some background information on the selected

card recipient and explained how receiving this card would affect the person (see Appendix H for activity script). The card had a few stenciled objects on the front (e.g., an ocean scene, an American flag) and contained a simple message inside (for the child: “Dear Ashley, Sending warm wishes your way.”; for the soldiers: “Dear Soldier, Thank you for your service to our country.”). Participants used markers to add their own words and creative design to the card.

Participants in the goal-undirected activity group (control: $n = 45$, 12 males) were given a sheet of construction paper with a similarly stenciled ocean scene or American flag. Participants used markers to add their own creative design. In both conditions participants were provided with the same types of markers and paper materials. All participants had 10 minutes to work on the drawing activity.

I tested these drawing activities in a pilot study in order to determine whether people would perceive a difference between the goal-directed and goal-undirected activities. Eleven participants were recruited from local adult day service centers and randomly assigned to either the goal-directed or goal-undirected condition. The groups did not differ in terms of dementia severity as measured by the TICS, $t(9) = -0.15$, $p > .05$, or depression as measured by the GDS, $t(9) = -0.65$, $p > .05$. The control group included 3 men and 2 women, and the experimental group included 3 men and 3 women. After the drawing activity participants were asked to rate how useful, difficult, worthwhile, tiring, enjoyable, and pleasant the activity was on a 5-point scale ranging from 1 (*not at all*) to 5 (*very*). They also were asked whether the activity had a goal. If they answered affirmatively, they were asked what the goal was. They were also asked

whether the purpose of the activity was clear (yes or no). Lastly they were asked whether they would engage in this activity again.

In general, participants tended to find the goal-directed drawing activity to be more useful ($M = 3.67, SD = 1.75$) than the goal-undirected activity ($M = 1.75, SD = .96$), $t(9) = -1.98, p = .08$. There were no group differences on ratings of difficulty, how worthwhile, tiring, enjoyable, and pleasant the activity was. It should be noted, however, that participants in the goal-directed condition had a higher mean rating for how worthwhile the activity was (3.83 vs. 2.80 on the 5-point scale). These results are summarized in Table 2.

Table 2. Means Ratings of Activities in the Pilot Study

Rating of activity	Goal-directed activity group	Goal-undirected activity group	<i>t</i>
Useful	3.67 (1.75)	1.75 (0.96)	-1.98*
Worthwhile	3.83 (1.47)	2.80 (1.48)	-1.16
Difficult	1.67 (1.21)	1.20 (0.45)	-0.81
Tiring	1.67 (1.21)	1.20 (0.45)	-0.81
Enjoyable	4.00 (1.26)	3.67 (0.89)	-0.59
Pleasant	4.17 (0.98)	4.40 (0.89)	0.41

* $p < .10$

All participants in the goal-directed condition were able to acknowledge the existence of a goal and affirm its clarity, compared with 1 of the 5 participants in the goal-undirected condition. These results are summarized in Table 3. Both groups unanimously reported that they would engage in their respective activities again.

Table 3. Responses from Participants in Goal-directed and Goal-undirected

Groups in the Pilot study

Response	Goal-undirected	Goal-directed
Did the task have a goal?		
Yes	1	5
No	4	0

Was the goal clear?		
Yes	1	5
No	4	0

Procedure

I administered the protocol at the adult day service center in a room where participants would not be distracted. Participants completed a written consent form. If the participant was unable to provide consent (i.e., unable to answer comprehension questions as detailed in the script in Appendix G), they were excluded from the study. Once consent was obtained, the experimenter administered the GDS, demographic questionnaire, TICS-m, Goal Pursuit questionnaire, Purpose in Life questionnaire, the drawing activity, and then the measure of perceived purpose. A third party (either a caregiver or a worker at the adult day services center) confirmed the participant's age. All questionnaires were administered orally with printed response scales placed in front of the participant to facilitate response. Upon completion of the research protocol, participants were debriefed and paid \$10 as remuneration (for a summary of the procedure refer to Figure 1).

Procedural Flowchart

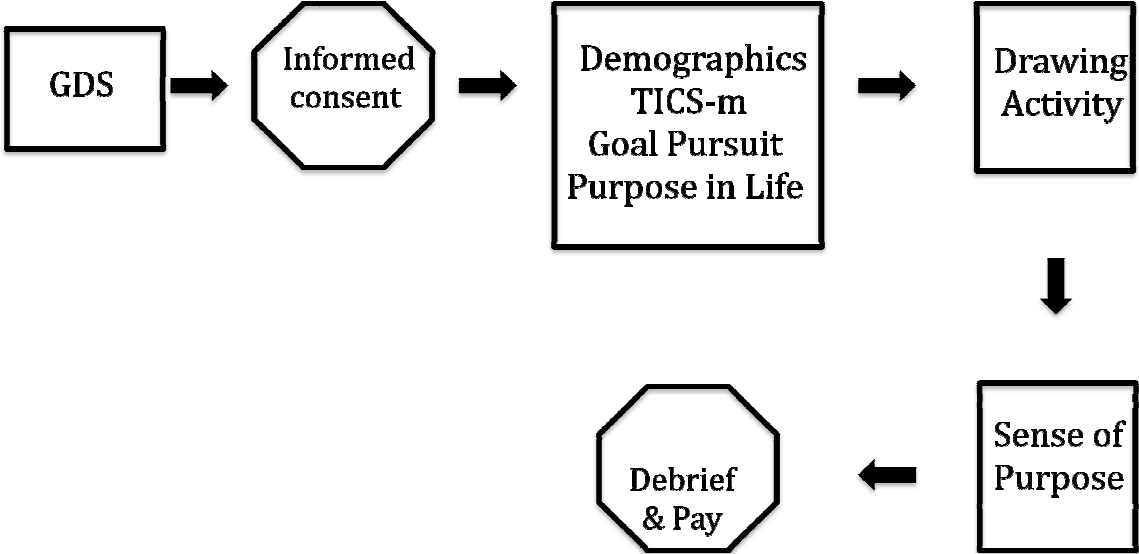


Figure 1. Procedural Flowchart

CHAPTER 3: RESULTS

The Perceived Purpose, Tenacious Goal Pursuit, and Purpose in Life scales have not been used with people with dementia, therefore reliability analyses for each of those scales are presented first. Subsequently, results addressing the experimental portion of the study are presented. Those results address the effect of goal condition on perceived purpose and the moderating role of dementia severity. The last section includes results addressing the relationship between goal pursuit and purpose in life and the moderating effect of dementia severity.

Across all analyses there were no effects of age, gender, or ethnicity. Thus, these variables were not included in the following analyses. In addition, prior to the analyses univariate normality assumptions for each variable were tested and met.

Reliability Analyses

Reliability analyses were conducted to examine the internal consistency reliability of these scales in this sample. Cronbach's α for the Perceived Purpose scale was .87, and the average inter-item correlation was .48 ($SD = .13$). All items correlated with the total score (mean $r = .64$, $SD = .10$, range = .13 to .66), and Cronbach's α did not increase significantly with the removal of any one item from the scale (mean difference = .01, $SD = .01$). Internal consistency was lower but still acceptable for the Tenacious Goal Pursuit scale (Cronbach's $\alpha = .70$) compared with a previously reported value (.80; Brandtstädter & Renner, 1990). The average inter-item correlation was .13 ($SD = .13$), and the mean item correlation with the total score was .30 ($SD = .12$, range = -.13 to .49), though Cronbach's α did not increase much with the removal of any one item from the scale (mean difference = .02, $SD = .01$). Cronbach's α for the Purpose in Life scale was .73,

which was also lower than a previously reported value (.90; Ryff, 1989a). The average inter-item correlation was .17 ($SD = .13$), the mean item correlation with the total score was .35 ($SD = .12$, range = -.12 to .49), and Cronbach's α did not substantially increase with the removal of any one item from the scale (mean difference = .02, $SD = .01$). Further replication may reveal whether lower Cronbach's α values for both of these scales are the result of applying non-dementia scales to people with dementia.

Goal-directed Activity and Perceived Purpose

Groups in the experimental portion of the study were comparable in terms of dementia severity (see Table 4; $t(89) = -0.92, p > .05$). To test Hypothesis 1 activity condition was coded as a dichotomous variable (0 for undirected, 1 for directed). A linear regression was conducted in which the 8-item Perceived Purpose scale was the dependent variable and activity condition was the independent variable. Goal condition accounted for 59% of the variance in perceived purpose ($r = .77, p < .001$). As illustrated by the means for the two groups shown in Table 4, participants who completed a goal-directed activity were more likely to perceive purpose in the activity compared with participants who completed a goal-undirected activity.

Table 4. Means and Standard Deviations for Age, the TICS-m, and the Perceived Purpose Scales by Goal Condition

Scale (total points)	Goal directed			Goal undirected		
	<i>Mean</i>	<i>SD</i>	<i>Range</i>	<i>Mean</i>	<i>SD</i>	<i>Range</i>
Age	76.57	8.83	64-92	74.12	9.54	57-90
TICS-m (50)	19.26	6.17	6-32	18.04	6.43	7-33
Perceived Purpose (48)	40.46	6.21	26-48	25.38	6.44	10-42

Note. TICS-m = Telephone Interview for Cognitive Status – modified version.

An item on the Perceived Purpose scale was considered endorsed if the respondent selected *strongly agree*, *somewhat agree*, or *slightly agree*. Table 5 contains the overall endorsement percentages, along with percentages of those who endorsed *strongly agree* for each item. Items in the table are organized by those that were positively worded and those that were negatively worded. The endorsement of a positive item produced a higher score on the Perceived Purpose scale, whereas the reverse was true for the endorsement of a negative item. Higher scores reflect a greater sense of perceived purpose.

Regardless of goal condition, most people agreed with item 1 (*I feel good when I think of what I've done with this drawing activity.*; overall endorsement = 89%). Item 3 (*I have a sense of direction and purpose for this drawing activity.*) was the most highly endorsed positive item by goal-directed participants. One hundred percent of participants in the goal-directed activity endorsed this item, with 67% rating it *strongly agree*, compared with 40% of participants in the goal-undirected activity who endorsed this item, with 7% rating it *strongly agree*. The item that was least endorsed overall was item 4 (*This drawing activity seems trivial and unimportant to me.*). Most (89%) people in the goal-directed condition did not agree with this item, whereas a majority (62%) of the people in the goal-undirected condition agreed with this item.

Table 5. Endorsement Percentages for Items on the Perceived Purpose Scale by Goal Condition

Item	Overall endorsement		Strong endorsement	
	Goal directed	Goal undirected	Goal directed	Goal-Undirected
Positive items				
I feel good when I think of what I've done with this drawing activity.	98%	80%	76%	20%
I have a sense of direction and purpose for this drawing activity.	100%	40%	67%	7%
This activity has been more a source of satisfaction than frustration to me.	89%	76%	61%	22%
I find it satisfying to think about what I have accomplished through this drawing activity.	96%	64%	54%	18%
Negative items				
I do not think about how this drawing activity will affect the future.	17%	78%	4%	47%
This drawing activity seems trivial and unimportant to me.	11%	62%	4%	29%
I don't have a good sense of what it is I'm trying to accomplish through this drawing activity.	37%	76%	15%	37%
I'm not so sure that my drawing adds up to much.	22%	69%	0%	13%

Note. Overall endorsement = Strongly, somewhat, or slightly agreed with the item. Strong endorsement = Strongly agreed with the item. Data presented in percentages for ease of understanding. Statistical tests are based on interval-level Likert scores, not percentages.

The second regression tested whether the relationship between goal condition and perceived purpose was moderated by dementia severity (see Table 6). There were significant bivariate correlations between dementia severity and perceived purpose ($r = .27, p < .01$) and goal condition and perceived purpose ($r = .77, p < .001$), but not between dementia severity and goal condition ($r = .10, p > .05$). At Step 1 dementia severity was a significant predictor of perceived purpose ($R^2 = .07, p < .05$). People with higher TICS-m scores (i.e., more cognitively intact) showed greater perceived purpose. After controlling for dementia severity in Step 2, goal condition contributed an additional 56% of explained variance in perceived purpose. Those in the goal-directed condition reported greater perceived purpose than those in the control condition. Although dementia severity was also significant at Step 2 ($\beta = .20, p < .01$), there was no interaction between goal condition and dementia severity at Step 3 ($\Delta R^2 = .01, p > .05$). In summary, there were main effects of dementia severity and goal condition on perceived purpose, but there was no interaction. The relationship between goal condition and perceived purpose was not moderated by dementia severity.

Table 6. Hierarchical Regression Analysis Predicting Perceived Purpose by Dementia Severity and Goal Condition

	<i>B</i>	<i>SE B</i>	β	ΔR^2
Step 1				.07*
Dementia Severity	.42	.16	.27*	
Step 2				.56***
Dementia Severity	.31	.10	.20**	
Goal Condition	7.35	.64	.75***	
Step 3				.01
Dementia Severity	.31	.10	.20**	
Goal Condition	4.51	1.99	.46*	
Dementia Severity \times Goal Condition	.15	.10	.31	

* $p < .05$. ** $p < .01$. *** $p < .001$.

Though not originally planned, I asked participants whether they enjoyed the activity (i.e., the drawing activity) at the end of each session. A yes or no was recorded. Across both conditions, 74% of the sample enjoyed the activity; the remaining 26% did not. An additional regression was performed to investigate the effect of this activity preference (see Table 7). The nonsignificant interaction between dementia severity and goal condition was omitted from the regression, adding activity preference at Step 3 instead. In addition to the main effects of dementia severity and goal condition, there was a main effect of whether participants enjoyed the activity such that those who enjoyed the activity were more likely to report a higher sense of perceived purpose, controlling for dementia severity and goal condition. There were no significant interactions.

Table 7. Hierarchical Regression Analysis Predicting Perceived Purpose by Dementia Severity, Goal Condition, and Enjoyment.

	<i>B</i>	<i>SE B</i>	β	ΔR^2
Step 1				.07*
Dementia Severity	.42	.16	.27*	
Step 2				.56***
Dementia Severity	.31	.10	.20**	
Goal Condition	7.35	.64	.75***	
Step 3				.04**
Dementia Severity	.23	.10	.15*	
Goal Condition	7.19	.61	.73***	
Enjoyment	2.23	.71	.20**	

* $p < .05$. ** $p < .01$. *** $p < .001$.

Goal Pursuit and Purpose in Life

The results from the questionnaire portion of the study paralleled those of the experimental part. All 91 participants completed measures of goal pursuit, purpose in life, and dementia severity. Means and standard deviations of these measures are shown in Table 8. As anticipated by Hypothesis 3, people who scored higher on goal pursuit tended to score higher on purpose in life ($r = .53, p < .001$). There were also significant correlations between goal pursuit and dementia severity ($r = .42, p < .001$) and between dementia severity and purpose in life ($r = .35, p < .001$).

Table 8. Means and Standard Deviations for the Tenacious Goal Pursuit scale, Purpose in Life scale, and the TICS-m.

Scale (total points)	Mean	SD	Range
Tenacious Goal Pursuit (60)	38.78	8.75	19-57
Purpose in Life (84)	63.45	10.29	31-84
TICS-m (50)	18.66	6.29	6-33

In the last regression (Table 9) the role of dementia severity on the relationship between goal pursuit and purpose in life was tested (Hypothesis 4). Dementia severity was a significant predictor of purpose in life at Step 1 ($R^2 = .12, p < .01$). At Step 2, after controlling for dementia severity, goal pursuit explained an additional 18% of the variance in purpose in life ($p < .001$). At Step 3, however, there was not a significant interaction between dementia severity and goal pursuit ($\Delta R^2 = .00$). This signifies that

the relationship between goal pursuit and purpose in life was not moderated by dementia severity.

Note that the β value for dementia severity becomes nonsignificant at Step 2 with goal pursuit, which may indicate multicollinearity, although the magnitude of the tolerance statistic (.89) would suggest otherwise. To summarize, people who scored higher on the Tenacious Goal Pursuit scale were more likely to score higher on the Purpose in Life scale, regardless of dementia severity.

Table 9. Hierarchical Regression Analysis Predicting Purpose in Life by Dementia Severity and Goal Directedness.

	<i>B</i>	<i>SE B</i>	β	ΔR^2
Step 1				.12**
Dementia Severity	.58	.16	.35**	
Step 2				.18***
Dementia Severity	.26	.16	.16	
Goal Pursuit	.55	.12	.47***	
Step 3				.00
Dementia Severity	.59	.72	.36	
Goal Pursuit	.71	.36	.60	
Dementia Severity \times Goal Pursuit	-.01	.02	-.28	

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

In the Tenacious Goal Pursuit questionnaire, higher scores reflect greater goal pursuit tendencies. Greater endorsement of positively worded items leads to higher scores, and endorsement of negatively worded items yields lower scores. Two items that had the highest average ratings were the positively worded Item 5 (*Even when things seem hopeless I keep on fighting to reach my goals.*) and Item 14 (*I stick to my goals and projects even in face of great difficulties.*). On a Likert-scale ranging from 0 to 4, the mean rating for Item 5 was 3.43 ($SD = .87$) and the mean for Item 14 was 3.31 ($SD = .88$). Two items that were rated lowest were Item 4 (*To avoid disappointment, I don't set my goals too high.*) with a mean of 1.69 ($SD = 1.48$) and Item 9 (*Life is much more pleasurable when I don't expect too much from it.*) with a mean of 1.77 ($SD = 1.59$). Overall, participants seemed to score higher on items relating to tenacity and lower on items related to high expectations (see Table 10 for a summary).

Table 10. Means and Standard Deviations for the Tenacious Goal Pursuit Scale

Items	<i>Mean</i>	<i>SD</i>
Positive items		
The harder a goal is to achieve, the more appeal it has for me.	2.89	1.15
I can be very obstinate in pursuing my goals.	2.84	1.27
When faced with obstacles, I usually double my efforts.	2.99	1.07
Even when things seem hopeless, I keep on fighting to reach my goals.	3.43	.87
Even when a situation seems hopeless, I still try to master it.	3.00	1.23
I stick to my goals and projects even in face of great difficulties.	3.00	.88
Negative items		
To avoid disappointments, I don't set my goals too high.	1.69	1.48
I tend to lose interest in matters where I cannot keep up with the others.	2.59	1.41
I find it easy to give up on a goal if it seems difficult to achieve.	2.86	1.27
When I run up against insurmountable obstacles, I prefer to look for a new goal.	2.10	1.49
Life is much more pleasurable when I do not expect too much from it.	1.77	1.59
When I have tried hard but cannot solve a problem, I find it easy just to leave it unsolved.	2.14	1.47
I avoid grappling with problems for which I have no solutions.	2.31	1.51
If I find I cannot reach a goal, I'd prefer to change my goal than to keep struggling.	2.22	1.53
Faced with a serious problem, I sometimes simply pay no attention to it.	2.74	1.48

Note. The range of each item score is 0 – 4. For positive items, higher scores reflect greater goal pursuit. The negative items have been reverse scored such that higher scores also reflect greater goal pursuit.

With a scoring structure similar to the Tenacious Goal Pursuit scale, higher scores on the Purpose in Life scale reflect a stronger sense of purpose in life, and negatively worded items are reversed scored such that endorsement yields lower scores. Items 1 (*I feel good when I think of what I've done in the past and what I hope to do in the future.*) and 13 (*I find it satisfying to think about what I have accomplished in life.*) were both strongly endorsed ($M = 5.23, SD = 1.10, M = 5.22, SD = 1.22$, respectively). Most participants also felt they had a sense of purpose in life (Item 4: $M = 5.01, SD = 1.29$) and that they played an important role in carrying out the plans they set for themselves (Item 9: $M = 5.04, SD = 1.24$). Item 2 (*I live life one day at a time and I don't think about the future.*) had the lowest mean ($M = 3.31, SD = 1.78$). Participants tended to rate higher items related to life review compared to items related to future plans (see Table 11 for summary).

Table 11. Means and Standard Deviations for the Purpose in Life Scale

Items	<i>Mean</i>	<i>SD</i>
Positive items		
I feel good when I think of what I've done in the past and what I hope to do in the future.	5.23	1.11
I have a sense of direction and purpose in life.	5.01	1.29
I enjoy making plans for the future and working to make them a reality.	4.79	1.43
I am an active person in carrying out the plans I set for myself.	5.04	1.24
Some people wander aimlessly through life, but I am not one of them.	3.81	1.96
My aims in life have been more a source of satisfaction than frustration to me.	4.90	1.54
I find it satisfying to think about what I have accomplished in life.	5.22	1.22
Negative items		
I live life one day at a time and don't really think about the future.	3.31	1.78
I tend to focus on the present, because the future nearly always brings me problems.	4.16	1.62
My daily activities often seem trivial and unimportant to me.	4.47	1.70
I don't have a good sense of what it is I'm trying to accomplish in life.	3.75	1.87
I used to set goals for myself, but now that seems like a waste of time.	4.37	1.61
I sometimes feel as if I've done all there is to do in life.	4.68	1.83
In the final analysis, I'm not so sure that my life adds up to much.	4.69	1.52

Note. The range of each item score is 1 – 6. For positive items, higher scores reflect greater purpose in life. The negative items have been reverse scored such that higher scores also reflect higher purpose in life.

CHAPTER 4: DISCUSSION

The goal of this study was to determine whether a relationship exists between goal pursuit and purpose in life in people with dementia, whether immediate sense of purpose is greater after engaging in a goal-directed activity than a goal-undirected activity, and whether dementia severity operates as a moderator in either case. In nondemented populations, goal pursuit has been a good predictor of purpose in life (Frazier et al., 2007), but it was unknown whether this relationship would replicate in a dementia sample. As hypothesized, in this group of people with mild-moderate dementia there was a significant relationship between goal pursuit and purpose in life such that people who reported greater goal pursuit also reported greater purpose in life. Similarly, people who completed a goal-directed activity perceived a greater sense of purpose than those who completed a goal-undirected activity. Dementia severity did not influence this relation.

Past studies looking at well-being in people with dementia have typically focused on external indicators such as mood and behavioral disturbances in part to avoid dealing with presumably unreliable self-report data (e.g., Lawton, Van Haitsma, et al., 1999; Parpura-Gill & Cohen-Mansfield, 2006; Rabins et al., 1999). Although external indicators of well-being are important, internal states, insofar as they can be measured, are important as well. In Dröes et al. (2006) people with dementia defined well-being with abstract concepts such as positive social relationships, freedom, and purpose in life, all of which are challenging, if not impossible, to measure solely based on external indicators. The results of this study show that people with significant cognitive impairment are able to provide reliable information regarding their internal state. The

average TICS-m score across 91 participants was 18.66, which suggests that the participants had significant cognitive impairment (Moyle et al., 2004), but all of them were able to complete the protocol and appeared to understand the questions they were asked and the meaning of the activity they completed. Furthermore, they provided internally consistent responses on both the Purpose in Life and Perceived Purpose scales, lending more evidence to the Logsdon et al. (2002) finding that self-reported quality of life is quantifiable in people with cognitive impairment.

The Relationship Between Goal Pursuit and Purpose in Life

The significant correlation between goal pursuit and purpose in life in the current study of people with dementia replicates a portion of the model of psychosocial outcomes in Frazier et al. (2007) using the same scales with a group of people without dementia. The similarity in the magnitude of correlation between goal pursuit and purpose in life in this study ($r = .53$) and Frazier and colleagues' ($r = .46$) suggests that goal pursuit and purpose in life are related in similar ways, whether or not a person has dementia, at least within the spectrum of disease severity in this study. These findings counter the assumption that people with dementia cannot meaningfully complete some scales designed for people without dementia. More important, they suggest that aspects of well-being beyond those that are observable still exist in people with dementia. It may be the general case that people who are motivated to pursue goals may sense more purpose in life regardless of dementia severity (within the boundaries tested in this study). Although this result is tentative, as it has not been replicated, it does beg the question of whether there are other aspects of well-being or other predictors of well-being that could be measured quantitatively in people with dementia.

The many ways in which well-being has been measured in people without dementia could be explored in people with dementia. For example, the dichotomy of subjective versus psychological well-being has never been investigated. Within subjective well-being (i.e., mood and life satisfaction), dementia researchers have looked at mood using observational methods (Lawton, Van Haitsma, et al., 1999), via proxy (Albert et al., 1996), and via standard self-report (Brod et al., 1999), or using simplistic happy or sad faces (Tappen & Barry, 1995); life satisfaction items have been included on various quality of life measures that involve both self-report and proxy methods (Logsdon et al., 2002; Ready et al., 2002). Yet aspects of *psychological* well-being (i.e., self-acceptance, positive relationships, personal growth, purpose in life, autonomy, and environmental mastery) have been less studied in people with dementia, though there are several scales that include related items. For example, the DQoL scale (Brod et al., 1999) taps feelings of belonging and self-esteem, and the QoL-AD scale (Logsdon et al., 2002) includes items regarding the quality of interpersonal relationships. Clearly there are still many aspects of psychological well-being that have not been quantified in dementia, and results from the current study suggest that it may be worthwhile to investigate a more comprehensive model of well-being in people with dementia incorporating their own self-reports.

To my knowledge, this is one of the only studies where the relationship between goal pursuit and purpose in life has been quantitatively explored by self-report in people with dementia. Successful replication of a portion of the Frazier et al. (2007) model of psychosocial outcomes provides a foundation for the future study of how different portions of their model operate in people with dementia. Formally testing scales made

for people *without* dementia using people *with* dementia may help define the limits of self-report in the latter population. Reliability and validity data may reveal what structural or content-related adjustments would be needed for people with dementia. If reliability and validity are achieved, existential aspects of well-being, such as purpose in life, could be quantified and explored, with the additional benefit of cross-population comparison (i.e., with older adults without dementia).

The Relationship Between Goal Condition and Perceived Purpose

Results from the experimental portion of my study also are consistent with the finding that goal pursuit is related to sense of purpose. This portion of the study suggests that a drawing activity can be manipulated to have different goal valences and that participation in an activity with a stronger goal valence can affect a person's immediate sense of purpose. Half of the participants created a card that would benefit another person while the other half was free to draw anything they wanted: one condition clearly had a goal whereas the other did not. Using the same materials in both conditions, a simple modification in the framing of the activity changed the way participants experienced it. As a result, people who made a card for someone else felt a greater sense of purpose after the activity than those who engaged in free drawing. Anecdotally, many participants in the goal-directed condition expressed a sense of accomplishment after doing something to help another person, whereas those in the control condition questioned what the activity was meant to do. These results suggest it is possible to enhance a person's sense of purpose through a simple, goal-directed drawing activity.

The results of this study used self-reports to extend the observational findings of Brooker and Duce (2000) in which they found enhanced well-being in people with

dementia during goal-directed activities. In their study they used Dementia Care Mapping (DCM; Kitwood & Bredin, 1994), which measures well-being using a trained “mapper” who observes the participant during short intervals across a period of several hours. Although DCM provides information regarding the participant’s general state (e.g., number of positive events, well- or ill-being), including self-report measures of more specific constructs whenever possible could capture the participant’s well-being more comprehensively by incorporating the first-person perspective. The fact that participants in this study were, on average, able to respond to a goal-directed activity suggests that (a) people with dementia are sensitive to the types of activities they engage in, and (b) the effect of activity on psychological well-being in dementia is quantifiable.

The Role of Dementia Severity

This study also investigated the role of dementia severity in the relationship between goal pursuit and purpose in life. Contrary to prediction, dementia severity did not moderate the relationship between goal pursuit and purpose in life. In other words, level of cognitive impairment, at least in this sample, did not dampen or enhance the relationship between goal pursuit and purpose in life. There is some evidence to suggest that aspects of well-being do not differ dramatically between people with mild dementia compared with those with more severe dementia (Ready & Ott, 2003); however, there are also contradictory data that support both the decline (Albert et al., 1996) and incline (Zank & Leipold, 2001) of well-being with the progression of dementia. There may be a host of explanations for these discrepant results, including differences in operational definitions of well-being and sampling. Additionally, none of these studies included a goal pursuit variable as a predictor; they merely addressed levels of well-being at

different stages of dementia. At the moment, there is not enough evidence to discount the possibility that goal pursuit and purpose in life might operate similarly across a broad spectrum of dementia severity.

In the current study it is also plausible that dementia severity did not moderate the relationship between goal pursuit and purpose in life because of a multicollinearity problem. In the current data dementia severity was a significant predictor of purpose in life by itself, but when goal pursuit was added into the regression the beta weight for dementia severity becomes nonsignificant. The bivariate correlation between goal pursuit and dementia severity was significant ($r = .42$), as was the correlation between goal pursuit and purpose in life ($r = .53$). Consequently, there may be overlap in the proportion of explained variance in purpose of life as predicted by goal pursuit and dementia severity. A relationship between these two latter variables has been hypothesized in the past. Grigsby, Kaye and Robbins (1995) suggested that with the progression of dementia comes the decline of executive functioning, which renders people with dementia increasingly less able to set or pursue goals. Furthermore, Grigsby and his colleagues suggested that behavioral disturbances in people with dementia occur because they are unable to participate in goal-directed or meaningful activity. Despite the plausibility of this explanation, the notion of a goal is very broad, and their findings do not preclude the possibility that people with cognitive impairment could, if given the opportunity, set manageable goals for themselves or engage in goal-related behaviors that are fitting for their abilities.

Though purely speculative, it may be the case that the desire to pursue (or not pursue) goals never disappears, but the ability to act upon it is impeded with the

progression of dementia. Grigsby and colleagues (1995) suggest that with the decline of executive functions, goal pursuit is hampered, but this does not address whether the desire to pursue goals is gone. In fact, if it is true that the *desire* to pursue goals is generally stable even as the *ability* to pursue goals becomes unstable with growing cognitive impairment, this discrepancy may help explain why dementia severity did not affect the relationship between goal pursuit and purpose in life. The self-reported responses to the questionnaires may reflect desire rather than ability, and as long as verbal comprehension of the questions is intact, it may be possible to detect a relationship between goal pursuit and purpose in life using self-reports. In this study, administering the questionnaires in an interview format and repeating questions as needed might have facilitated the process of comprehension and response from participants. By contrast, in a sample of people in whom verbal comprehension was more impaired, the relationship between goal pursuit and purpose in life might have been weakened. Whether a weakened relationship between goal pursuit and purpose in life is an artifact of verbal comprehension problems or whether it is representative of the true state will be difficult, but important, to answer.

The null moderating effect of dementia severity in the experimental portion of the study is consistent with my speculation that responses of people with dementia may function similarly to people without dementia if verbal comprehension still exists. It seems that participants in this study were able to understand the setup of their activity and respond accordingly. The participants did not appear to have severe communication deficits, and though repetition of questions and comments was common, participants demonstrated good comprehension of the directions for their respective activity. Those

in the goal-directed condition would often provide feedback to indicate that they knew their card would be sent to encourage someone or that they felt good to help someone. Conversely, those in the goal-undirected condition would often question what the purpose of their activity was. These observations suggest that if an activity has an obvious enough goal, even people with significant cognitive impairment recognize that goal and can benefit from the activity.

Individual Scale Items

In addition to looking at the relationships among the variables, closer examination of the item performance on the Tenacious Goal Pursuit and the Purpose in Life scales may provide interesting information about the sample because these scales have never been used with people with dementia. In the Tenacious Goal Pursuit scale, the items rated most highly, indicating greater goal pursuit, were all related to tenacity in times of difficulty (e.g., *Even when things seem hopeless, I keep on fighting to reach my goals.*, *Even when a situation seems hopeless, I still try to master it.*, *I stick to my goals and projects even in face of great difficulties.*). The items with the lowest means, indicating lesser goal pursuit, carried the theme of avoiding high expectations (*To avoid disappointments, I don't set my goals too high.*, *Life is much more pleasurable when I do not expect too much from it.*). The contrast between these groups of items may be related to the stage of life the participants have reached. When they think about their tendencies to get through great difficulties, they may draw upon past and present circumstances and feel as if they have persevered and still continue to persevere. When asked whether they should set high goals and expectations for their lives, however, they may feel the need to be more realistic about their pursuits. Many disagreed with the need to have high

expectations or difficult goals at this point in life. This may not indicate the lack of drive in pursuing goals as much as it points to the process of goal adjustment, which works in tandem with goal pursuit.

Brandtstädter and Renner (1996, p. 118) discussed the relationship between goal pursuit and goal adjustment as “offensive and defensive.” They proposed that pursuing goals may benefit one’s purpose in life, but there is the potential for harm if the goal is unattainable. Though pursuing goals in general may enhance life satisfaction (Emmons, 1986), pursuing unrealistic goals may lead to repeated failures or slowed progress and depression (Street, O’Connor, & Robinson, 2007). Goal adjustment is therefore important in calibrating the fit between the person’s abilities and the goal. In the psychosocial outcomes model of Frazier and colleagues (2007), goal adjustment was also related to psychological well-being, though the magnitude of the relationship was lower than that between goal pursuit and well-being. Based on the finding that items related to tenacity were rated higher than items related to life expectations, a next step may be to test both goal pursuit and goal adjustment as predictors for purpose in life. This result also highlights the need for age-based norms for scales where performance might vary depending on life stage.

In the Purpose in Life scale, items rated highest were those regarding life review (*I feel good when I think of what I’ve done in the past and what I hope to do in the future., I find it satisfying to think about what I have accomplished in life.*). It appears that my sample had relatively positive evaluations of their life. This may be because recruitment took place at adult day care centers where well-being might be higher than among people who are in nursing homes or isolated at home (McKee, Harrison, & Lee,

1999), or perhaps my sample was characterized by people high in optimism. In the case of adult day services centers, reminiscence groups are frequently held to facilitate life review and help participants recall positive experiences in their lives, as was the case at the day care centers I visited. Even when negative experiences were discussed, reminiscence group leaders usually helped participants restructure the way they thought of that experience, for example, highlighting the wisdom gained from it. Especially in late life, there may be health-related benefits to positive life review (Peck, 2001).

The themes of the lowest rated items were future planning (*I live life one day at a time and don't really think about the future.*) and purpose (*I have a sense of direction and purpose in life.*). Low scores on these two items may reflect the shift towards a phase of life when strenuous goal pursuit has tapered. When asked to think about their future, most participants quickly responded that they did not think extensively about their future. They expressed that they felt like they no longer needed to accomplish significant things like they used to when they were younger. From my interactions with them it seemed that the statement, "I have a sense of direction and purpose in life," caused participants to think of lofty goals and pursuits that were no longer relevant to them. Yet despite low ratings on this item, it did not seem as if participants had little purpose in life. Ninety out of 91 participants thought it was wonderful to be alive (GDS, item 11), which suggests that most had some reason for living. I speculate that having a "direction and purpose in life," in a macro sense, may be less relevant to the participants in this sample. All of them were retired and felt like this was their time to enjoy life. Though many were parents and grandparents, it is unclear whether they defined these roles as a means for having direction in their lives. Similarly, most participants also had active hobbies, but

they did not consider these to provide life direction. In general, interpretations based on both the Tenacious Goal Pursuit scale and the Purpose in Life scale would especially benefit from developing population-specific norms and validity testing.

Application for Community Settings

The findings from this study may provide some helpful suggestions for adult day programming. First, activities for people with dementia could be structured with a clear goal. Based on the findings of this study, tasks that involve an unmistakable, altruistic objective facilitate feelings of purpose and meaningfulness for participants. This is not surprising as older adults who have regular altruistic involvement report high life satisfaction (Dulin, Hill, Anderson, & Rasmussen, 2001). Even beyond altruistic activities, it seems that activities with the objective of giving meaning to life and facilitating personal growth contribute to well-being (Carpenter, Van Haitsma, Ruckdeschel, & Lawton, 2000; Kalis, van Delden, & Schermer, 2004). Sometimes this merely means participating in everyday activities. People with dementia have reported that as long as activities are enjoyable and promote a sense of belonging, autonomy, and identity, even very ordinary activities (e.g., cleaning the house, reminiscing, gardening) can be meaningful (Phinney et al., 2007). Though this study would support the use of goal-directed activity, it is apparent that this is only one among many effective methods in providing purpose for people with dementia. Also important to keep in mind is that any single activity usually involves more than one way of providing purpose for people (e.g., social, goal-related, physical benefits). Within reason and depending on the circumstances, it may possible to develop activities that can provide multiple benefits at once.

Second, the finding that the enjoyment of the drawing activity was related to whether people had a higher sense of perceived purpose speaks to the importance of tailoring activities towards the preference of the individual. Even though goal condition played a significant role in determining perceived purpose, enjoyment of drawing also predicted perceived purpose in the drawing activity (see Figure 2). Deci and Ryan (2000) noted that “people will become more or less interested in activities as a function of the degree to which they experience need satisfaction while engaging in those tasks” (p. 233). If a task does not seem fulfilling, it is likely that the person will either lose interest or not benefit from participating. There are measures that specifically gauge the activity preferences in older adults (e.g., Activity Card Sort, Baum, 1995; Preferences for Everyday Living Inventory, Carpenter et al., 2000) and those of people with dementia (e.g., Pleasant Events Schedule-Alzheimer’s Disease, Teri et al., 1991) that could be completed together by caregivers and care recipients to identify activities that will maximize enjoyment. In cases of severe dementia, researchers have systematically assessed preferences for different types of sensory stimulation, like the brightness of lights or types of smells and sounds, to provide a pleasing multisensory environment (see Stahl, Pickney, & Roane, 2003, for a review). Taking preferences into account can facilitate participation, enjoyment, and sense of purpose (LeBlanc, Cherup, Feliciano, & Sidener, 2006).

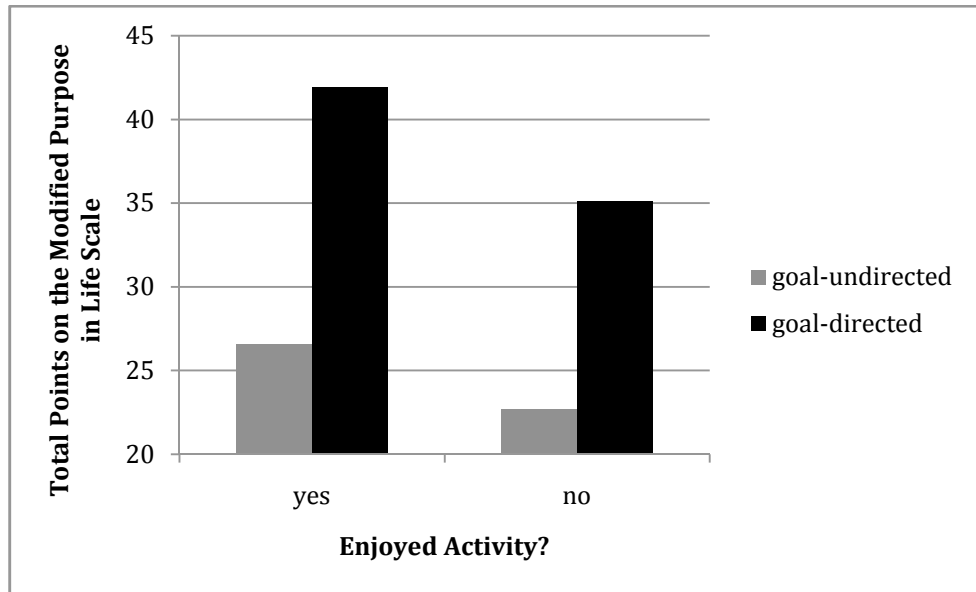


Figure 2. Perceived Purpose as a Function of Goal Condition and Enjoyment.

Limitations

There were some limitations in this study. Regardless of goal condition, the use of drawing as the activity in the experimental portion benefited those who appreciated that activity more than those who did not in terms of perceptions of purpose. The latter group would report a lower sense of purpose, regardless of goal condition. Drawing activities may not be for everyone, but the inclusion of one in this study provided some ecological validity as many adult day service centers incorporate drawing into activity programming.

Another limitation of this study is that the experimental portion only addressed the benefits of an altruistic goal-directed activity. The manipulation used in this study involved an altruistic goal, which was selected for its potential health and well-being benefits (Post, 2005), but there are numerous ways of setting up a goal-directed activity that could differentially affect well-being. For example, the majority of participants at one of the day services centers looked forward to playing bingo everyday. Playing bingo likely does not enhance one's sense of purpose yet one could label it as a goal-directed activity because it involves a clear end goal of winning. As I watched them play, however, it was very clear that part of the enjoyment was derived from reaching the goal but a larger part of it was derived from the social exchange that occurred during the games. This observation was a reminder that, although factors like goal pursuit and purpose in life might be related, they typically do not operate in isolation. In the case of bingo, the social nature of the game seemed to trump the importance of the goal-directedness of the game. Realistically, there are many variables that may function within an activity that could alter outcome benefits.

The generalizability of these results is also limited by the sample characteristics. Presumably those who attend an adult day service center and are willing to participate in a research study are more agreeable and perhaps higher functioning than those who do not attend an adult day service center or those who are unwilling to participate. Also, the characteristics of this sample may not necessarily reflect those living in nursing homes or private residences. Like any other research study it is a challenge to include a fully representative sample, but these results establish more reason to pursue this type of work in the broader community.

Last, my results and interpretations are limited by the fact that little is known regarding the functioning of self-report well-being scales in people with dementia. For example, the limits of self-report in dementia are unknown. There is no definitive point at which self-report is known to be invalid or unreliable. Furthermore, existential aspects of well-being are rarely studied using quantitative methods. Given the general lack of empirical evidence in the study of well-being in dementia, my conclusions should be considered tentative until further replication.

Future directions

Well-being is a multifaceted construct, and we are far from understanding it in dementia. A more complex and representative model of well-being may be developed by expanding its definition, the methods of measurement, and the study of its predictors. Expanding the definition may include more qualitative studies where people with dementia are asked to define well-being. Equally important would be the translation of these qualitative data into scales that could be empirically tested for reliability and validity. Based on growing evidence that people with dementia are able to provide self-

reports of their internal states (Brod et al., 1999; Logsdon et al., 2002; Ready et al., 2002), our understanding of well-being in dementia may benefit from creating more self-report measures along with using traditional methods (i.e., observational, proxy-reported). This study also suggests that people with dementia are able to provide reliable data on measures not specifically designed for people with dementia. Replication in a sample with a broad spectrum of dementia severity would help define the boundaries of using non-dementia specific measures and also the boundaries of self-report in dementia. Certainly the findings in this study require replication; however, using existing measures of well-being on people with dementia also may be a good step towards understanding differences between people with and without dementia and what adjustments need to be made on measures of well-being for the former group.

Establishing the relationship between goal pursuit and purpose in life is only a starting point for understanding well-being and its predictors in people with dementia. In this study, greater goal pursuit was associated with greater purpose in life, but an extreme level of goal pursuit typically is not beneficial either. Setting unreasonable goals without taking physical and cognitive constraints into account may prevent successful goal achievement. A potential next step would be to investigate the tandem processes of goal pursuit and goal adjustment (Brandstädter & Renner, 1990) as it relates to purpose in life. This type of study would provide a more multidimensional approach to understanding how goal-related behavior is associated to purpose in life.

Also of interest is personality as a predictor of well-being in people with dementia. In normal populations, personality has been tied to both subjective (Costa & McCrae, 1980; Lyubomirsky & Tucker, 1998) and psychological well-being (Schmutte &

Ryff, 1997). For example, Costa and McCrae (1980) found that greater extraversion was associated with more positive affect and greater life satisfaction whereas greater neuroticism was associated with more negative affect and lower life satisfaction. Schmutte and Ryff (1997) found an inverse relationship between neuroticism and all six aspects of psychological well-being (i.e., self-acceptance, environmental mastery, purpose in life, personal growth, positive relations with others, autonomy). Extraversion and conscientiousness were positively correlated with psychological well-being. Based on these findings it would be interesting to see whether goal pursuit or goal-related activity have additional benefits on well-being over and above that which is already accounted for by personality. Given the evidence that people with dementia may score higher on neuroticism and lower on conscientiousness, extraversion, and openness (Duchek, Balota, Storandt, & Larsen, 2007; Siegler, Dawson, & Welsh, 1994; Strauss, Pasupathi, & Chatterjee, 1993), those who have high levels of subjective and psychological well-being may be the exception to this finding. Of note is also the fact that the results of Duchek et al. (2007) are based on both self and informant reports, not just the latter.

Last, in regards to developing activities for people with dementia, social interaction may be an important factor to consider. Many activities likely would not provide the same amount of stimulation and enjoyment if they were done in isolation (i.e., bingo). The drawing activity in this study was done individually to minimize noise and isolate the effects of goal-directedness, but in a community setting activities done in isolation are rare. It would be revealing to gauge the beneficial effects of social interaction during activity participation to see whether there is a synergistic effect on well-being when people are engaged in communal versus solitary activities. Group

settings allow for the development of positive social relationships, which is part of psychological well-being (Ryff, 1989a, 1989b, 1989c) and may reduce feelings of loneliness and depression while increasing life satisfaction (Nezlek, Richardson, Green, & Schatten-Jones, 2002). Despite the benefits of social activity, preferences for solitary activity must be taken into consideration as well. Understanding how multiple factors (e.g., goal pursuit, preferences, personality, social interaction) operate *together* during activity participation to affect well-being may have the most useful implications for clinical and community settings.

Conclusion

Being able to maintain a high level of purpose in life may alleviate some of the challenges people with dementia experience as their cognitive or physical capacities are compromised. Though this dissertation identifies one method of enhancing an immediate sense of purpose in people with dementia, other methods are yet to be investigated. The variance in purpose in life accounted for by goal pursuit indicates the latter is important, but the remaining unexplained variance suggests that having a sense of purpose requires more than just having strong goal pursuit tendencies or engaging in goal-directed activities. Further development of a model of psychosocial outcomes in people with dementia that accounts for the effect of dementia severity may provide a more comprehensive understanding of their well-being and in turn help refine care and services for this population.

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Appendix A: Demographic Questionnaire

1. When were you born? (Or what is your age?) _____

2. What is your gender? _____

8. Repetition.

Please repeat after me: NO IFS ANDS OR BUTS

Please repeat after me: Methodist Episcopal _____

9. President's and Vice President's full names.

What is the president's first name?

What is the president's last name?

What is the vice-president's first name?

What is the vice-president's last name? _____

10. Finger tapping.

Please tap five times on the phone. (2pts.) _____

11. Word opposites.

What is the opposite of east?

West

What is the opposite of generous?

Stingy/etc _____

12. Delayed recall.

Please tell me as many words from the list of 10 words I read earlier?

Cabin

Pipe

Elephant

Chest

Silk

Theater

Watch

Whip

Pillow

Giant

Appendix C: Geriatric Depression Scale Short Form (15-item) (Sheikh & Yesavage, 1986)

Choose the best answer for how you have felt over the past week:

1. Are you basically satisfied with your life? YES / **NO**
2. Have you dropped many of your activities and interests? **YES** / NO
3. Do you feel that your life is empty? **YES** / NO
4. Do you often get bored? **YES** / NO
5. Are you in good spirits most of the time? YES / **NO**
6. Are you afraid that something bad is going to happen to you? **YES** / NO
7. Do you feel happy most of the time? YES / **NO**
8. Do you often feel helpless? **YES** / NO
9. Do you prefer to stay at home, rather than going out and doing new things? **YES** / NO
10. Do you feel you have more problems with memory than most? **YES** / NO
11. Do you think it is wonderful to be alive now? YES / **NO**
12. Do you feel pretty worthless the way you are now? **YES** / NO
13. Do you feel full of energy? YES / **NO**
14. Do you feel that your situation is hopeless? **YES** / NO
15. Do you think that most people are better off than you are? **YES** / NO

TOTAL: _____/15

Answers in bold indicate depression. A score > 5 points is suggestive of depression. Scores > 10 are almost always depression.

Appendix D: Tenacious Goal Pursuit (Brandtstädter & Renner, 1990)

- (+) 1. The harder a goal is to achieve, the more appeal it has to me.
- (+) 2. I can be very obstinate in pursuing my goals.
- (+) 3. When faced with obstacles, I usually double my efforts.
- (-) 4. To avoid disappointments, I don't set my goals too high.
- (+) 5. Even when things seem hopeless, I keep on fighting to reach my goals.
- (-) 6. I tend to lose interest in matters where I cannot keep up with others.
- (-) 7. I find it easy to give up on a goal if it seems difficult to achieve.
- (-) 8. When I run up against insurmountable obstacles, I prefer to look for a new goal.
- (-) 9. Life is much more pleasurable when I do not expect too much from it.
- (+) 10. When I have tried hard but cannot solve a problem, I find it easy just to leave it unsolved.
- (-) 11. I avoid grappling with problems for which I have no solutions.
- (-) 12. If I find I cannot reach a goal, I'd prefer to change my goal than to keep struggling.
- (-) 13. Faced with a serious problem, I sometimes simply pay no attention to it.
- (+) 14. Even when a situation seems hopeless, I still try to master it.
- (+) 15. I stick to my goals and projects even in face of great difficulties.

Response format: 0=strongly disagree, 1=disagree, 2=neutral, 3=agree, 4=strongly agree

- (+) indicates positively scored items
- (-) indicates negatively scored items

Total: _____ /60

Appendix E: Purpose in Life Scale (Ryff, 1989a)

- (+) 1. I feel good when I think of what I've done in the past and what I hope to do in the future.
- (-) 2. I live life one day at a time and don't really think about the future.
- (-) 3. I tend to focus on the present, because the future nearly always brings me problems.
- (+) 4. I have a sense of direction and purpose in life.
- (-) 5. My daily activities often seem trivial and unimportant to me.
- (-) 6. I don't have a good sense of what it is I'm trying to accomplish in life.
- (-) 7. I used to set goals for myself, but that now seems like a waste of time.
- (+) 8. I enjoy making plans for the future and working to make them a reality.
- (+) 9. I am an active person in carrying out the plans I set for myself.
- (+) 10. Some people wander aimlessly through life, but I am not one of them.
- (-) 11. I sometimes feel as if I've done all there is to do in life.
- (+) 12. My aims in life have been more a source of satisfaction than frustration to me.
- (+) 13. I find it satisfying to think about what I have accomplished in life.
- (-) 14. In the final analysis, I'm not so sure that my life adds up to much.

Response format: 1=strongly disagree, 2=disagree somewhat, 3=disagree slightly, 4=agree slightly, 5=agree somewhat, 6=strongly agree

- (+) indicates positively scored items
- (-) indicates negatively scored items

Total: _____ /84

Appendix F: Perceived Purpose Scale

- (+) 1. I feel good when I think of what I've done with this drawing activity.
- (-) 2. I do not think about how this drawing activity will affect the future.
- (+) 3. I have a sense of direction and purpose for this drawing activity.
- (-) 4. This drawing activity seems trivial and unimportant to me.
- (-) 5. I don't have a good sense of what it is I'm trying to accomplish through this drawing activity.
- (+) 6. This activity has been more a source of satisfaction than frustration to me.
- (+) 7. I find it satisfying to think about what I have accomplished through this drawing activity.
- (-) 8. I'm not so sure that my drawing adds up to much.

Response format: 1=strongly disagree, 2=disagree somewhat, 3=disagree slightly, 4=agree slightly, 5=agree somewhat, 6=strongly agree

- (+) indicates positively scored items
- (-) indicates negatively scored items

Total: /48

Appendix G: Consent Script

[done while looking at the Informed Consent form]

First we are going to look at the consent form so that you know exactly what you will be doing today. We would like to invite you to participate in this study titled, Activities for Persons With Dementia. The overall purpose of this research is to explore the experience of activity in people with dementia. During this study you may be asked to draw something and answer some questions about the activity and yourself. This will take less than 45 minutes, and you will receive \$10 for your time.

Does this make sense? Do you have any questions?

There are no risks or benefits associated with this research. Your participation is voluntary and you may choose to stop at any point. You will not be penalized in any way, and you will still be compensated. Your privacy is important to us, so your identity and information will be kept private.

Does this make sense? Do you have any questions?

At the bottom of this sheet are names of people you may contact if you have more questions after you leave.

If you don't have any questions, does this sound like something you'd like to participate in?

[Yes] Ok, great. Go ahead and sign your name on this line [pointing].

[No] Ok, great. Thank you for your time today, and I will bring you back outside to join the group.

[If the person seems not to fully understand what you have gone over, use these additional questions to gauge what they understand.]

Q: Do you understand what we are asking you to do today?

Can you tell me a little bit about what you think you will do for this research?

Does this project have any risks? Benefits?

Will you have to answer some questions about yourself?

Will all of this information be kept private?

Q: Does this project sound like something you would like to participate in?

[If the person cannot fully verbalize what he/she will do for the study, you will terminate their participation and move on to the next participant.]

Appendix H: Activity Script

For this next activity, you'll be creating a greeting card for someone else. As you may know, receiving a greeting card from someone else is really nice. Have you ever gotten a nice card from a friend a family member? How did it make you feel? Good. In this case, you will be the one who will send a person some warm wishes. Does this make sense so far?

Ok, now would you prefer sending your card to a child patient at Children's Hospital or would you prefer sending your card to a soldier stationed in the Middle East? Both of them will equally appreciate and enjoy your card. Do you have a preference?

Ok.

.....
This following information is real, and your card will be sent in the mail.

You will be creating a card for a **soldier** who has been stationed in the Middle East for the last 10 months. He is in a town called Rustimayah, which is a few miles southwest of Baghdad, Iraq. Being so far away from his family and friends has made him long for things that remind him of home. Receiving this card would really bring a smile to his face, and it'd be the best part of his day. He would really appreciate this card, because it would remind him of home and all the people who care for him and are grateful for his service. Do you understand what I just described?

Ok, please use these markers and crayons to decorate this card. Please know that the soldier appreciates your sentiment over your artistic ability. Receiving your card will really lift his spirits, because he will know you are supporting him from home. I will leave you alone for about ten minutes to work on this project. Do you understand what you have been asked to do?

This following information is real, and your card will be sent in the mail.

You will be creating a card for a **young girl**, Ashley, who has been a patient at Children's Hospital for the last ten months. She has Hodgkin's disease, which is a type of cancer that spreads in the lymphatic system. The radiation and chemotherapy she has had to endure has made her very tired and weak. Receiving a card from you would really make her smile. It would be the highlight of her day. She would really appreciate this card because it would remind her of all the people who care for her and are thinking about her. Do you understand what I just described?

Ok, please use these markers and crayons to decorate this card. Please know that Ashley will appreciate your sentiment over your artistic ability. Receiving your card will really lift her spirits, because she will know you are supporting her. I will leave you alone for about ten minutes to work on this project. Do you understand what you have been asked to do?

Ok, now I'm going to give you a piece of paper and some drawing instruments. I will leave you alone for 10 minutes, and you may draw whatever you choose.