

PRESERVING IDENTITY AND PLANNING FOR ADVANCE CARE (PIPAC):
AN INTERVENTION TO INCREASE COPING IN THE
EARLY STAGES OF DEMENTIA

by

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A DISSERTATION

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ABSTRACT

The current study examined the feasibility and limited efficacy testing of the newly developed Preserving Identity and Planning for Advance Care (PIPAC) intervention. This intervention combined one self-adjusting component and one self-maintaining component to maximize coping and enhance quality of life in individuals in the early stages of dementia. Blocked randomization stratified by race and gender was used to assign participants and a family contact to either the: (a) multi-component intervention group, or the (b) minimal support phone contact control group. Of the 19 dyads randomly assigned to group 18 completed post-treatment assessment (i.e., 10 intervention and 8 control). Individuals with dementia were $M = 82.8$ ($SD = 6.46$) years old; six (31.6%) were men and 13 were women (68.4%). Participants were predominantly White/Caucasian (94.7%) with one Black/African American (5.3%) individual with dementia. Family contacts were $M = 70.14$ ($SD = 12.16$) years old and were predominantly spouses (47.4%) or adult children (42.1%). They were 84.2% White/Caucasian and 12.5% Black/African American. Feasibility data, including a focus group with research staff, demonstrated successful implementation, acceptability, and practicality of the intervention package. Furthermore, limited efficacy testing using between subjects ANCOVAs to control for baseline values revealed clinically meaningful differences (i.e., medium to large effect sizes) between groups at post-treatment for depression, quality of life, indicators of health-related quality of life, and decisional conflict. Higher levels of coping and awareness were also observed post-treatment in intervention group individuals. Overall, the PIPAC intervention shows promise as a brief, manualized, psychosocial treatment for individuals in the early stages of dementia.

DEDICATION

To the loving memory of my maternal grandparents, Bob and Betty Lyons

“Papa D and Mama B.”

To my fiancée, Shane, who has generously supported me in all of my endeavors.

And to my family, who are my biggest cheerleaders and the most dedicated
consumers of my research.

LIST OF ABBREVIATIONS AND SYMBOLS

ANCOVA	Analysis of covariance
ANOVA	Analysis of variance
d	Cohen's measure of sample effect size for comparing two sample means
EMM	Estimated marginal mean
F	F distribution, Fisher's F ratio
GLM	General linear model
M	Sample mean, arithmetic average
n	Number of cases (generally in a subsample)
N	Total number of cases
η_p^2	Partial eta squared estimate of effect size
p	Probability associated with the occurrence under the null hypothesis of a value as extreme as or more extreme than the observed value
<	Less than
=	Equal to

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CONTENTS

ABSTRACT.....	ii
DEDICATION.....	iii
LIST OF ABBREVIATIONS AND SYMBOLS.....	iv
ACKNOWLEDGMENTS.....	v
LIST OF TABLES.....	vii
LIST OF FIGURES.....	viii
1. INTRODUCTION.....	1
2. METHOD.....	25
3. RESULTS.....	52
4. DISCUSSION.....	69
REFERENCES.....	91
APPENDICES.....	105

LIST OF TABLES

1. Comparing rate of recruitment across studies.....	34
2. Sample characteristics by group.....	35
3. Demographic characteristics by living arrangement for dyads that completed study.....	37
4. Selected quotes from the Project Evaluation completed at post-treatment assessment....	55
5. Treatment implementation data for intervention families.....	56
6. Raw means for patients and family contacts that completed PIPAC.....	64
7. Estimated treatment effects at post-treatment assessment.....	68

LIST OF FIGURES

1. Stress process model in early dementia (SPM-ED).....	11
2. Legacy patient engagement by cognitive status.....	15
3. Designing the PIPAC intervention.....	20
4. Study design and summary of sample size.....	32
5. Raw scores of depressive symptomatology at baseline and post-treatment assessment by group.....	66

Chapter 1. Introduction

As longevity of the population increases, so does the prevalence of age-related disorders such as Alzheimer's disease. The Centers for Disease Control and Prevention estimates prevalence rates of Alzheimer's and related disorders (ARD) in the United States at nearly 4.5 million with expected escalation between 11 and 16 million by the year 2050 (Alzheimer's Association, 2008; Hebert, Scherr, Bienias, Bennett, & Evans, 2003). Over half of these individuals will suffer from significant depressive symptoms during the course of the disease (Starkstein, Jorg, Mazrahi, & Robinson, 2005) placing them at an increased risk for institutionalization and mortality (Verkaik, Nuyen, Schellevis, & Francke, 2007). Research on dementia has long suggested that one of the greatest fears associated with a diagnosis of dementia is the eventual *"loss of self,"* which is thought to be characteristic of later stages of the disease (e.g., Orona, 1990; Ronch, 1996). Second to a loss of identity is the guilt and anxiety associated with dependency and *fears of becoming a burden* to loved ones. These two uncertainties can contribute to depression, anxiety, social withdrawal, and decreased quality of life in the early stages of the disease. However, most intervention research targeting individuals in the early stages has not addressed these aspects of living with dementia, focusing instead on memory skills training or other cognitive aspects of the disease (e.g., Bates, Boote, & Beverley, 2004).

Qualitative studies describing the lived experience of individuals early in the disease process (e.g., Pearce, Clare, & Pistrang, 2002; Preston, Marshall, & Bucks, 2007; Steeman, Godderis, Grypdonck, de Bal, & de Casterle, 2007) have suggested that individuals typically

cope with the uncertainty of the disease in two primary ways. The first is to engage in behaviors that promote a connectedness to their past without the disease, termed *self-maintaining*. Second is the tendency to engage in behaviors that coincide with acknowledgement of the disease and its likely course, termed *self-adjusting* or reappraisal. A central aspect of coping with any stressor, like a dementia diagnosis or changes in functional abilities, is the awareness at some level that the stressor exists. Additional research is needed to incorporate these elements into existing models of the stress process for those with early or mild dementia. Using this model as a conceptual framework, the Preserving Identity and Planning for Advance Care (PIPAC) intervention was designed to address one self-maintaining component (i.e., reminiscence-based project) and one self-adjusting or future planning component (i.e., patient-centered advance care planning interview) to maximize both types of coping in the early stages of dementia.

The following review describes current research on symptomatology and treatment of individuals in the early or mild stages of dementia, qualitative research on coping and awareness, and a modified stress-process model that incorporates qualitative findings early in the disease process. Furthermore, it outlines existing empirically supported interventions for individuals in the early stages of dementia and other clinical populations facing similar mental health needs and proposes a new intervention entitled “Preserving Identity and Planning for Advanced Care.” In summary, the current study is the first step in establishing a newly developed, manualized treatment for individuals in the early stages of dementia and as such aimed to assess the feasibility of the PIPAC intervention as well as examine the likely impact of the intervention on emotional and health-related outcomes.

Background and Significance

Psychological symptoms of dementia. Depression and anxiety are recognized psychosocial indicators of distress in the early stages of dementia (Teri et al., 1999). Starkstein and colleagues (2005) collected depressive symptomatology data from 670 Alzheimer's disease patients spanning the spectrum of disease stages from mild to severe. Their results revealed that over half of individuals with dementia ($n = 493$) met diagnostic criteria for minor depression (26%) or major depressive disorder (26%). Depression rates were relatively similar across stages of the disease, suggesting that interventions targeting depression in the early stages of the disease should be as much of a priority as treatment of depression later in the disease progression. Similarly, a prevalence study on anxiety in individuals with dementia found that 70% of individuals experienced significant symptoms, with 54% experiencing comorbid depression and anxiety (Teri et al., 1999).

Although some studies have suggested that cognitive training can reduce disability thereby improving well-being (Clare & Woods, 2004), a more targeted approach to relieve symptoms of depression, anxiety, and other psychological indicators of distress is warranted. Among existing emotion-oriented approaches, many focus exclusively on individuals later in the disease process (e.g., Finnema, Dries, Ribbe, & van Tilburg, 2000) and target symptoms such as disruptive vocalization, agitation, and behavioral disturbances as primary outcomes of interest (e.g., Logsdon, McCurry, & Teri, 2007). In a review of existing interventions focused on emotional outcomes, Finnema and colleagues noted that most of the 23 studies reviewed were either qualitative or quasi-experimental designs targeting institutionalized individuals with dementia. Despite methodological limitations, emotion-oriented approaches (e.g., validation therapy or simulated presence therapy) appear to be most effective in increasing positive affect

such as well-being and social interaction (although behavioral problems are also consistently decreased). Therefore, as more clinical outcomes research in this field is developed, it will be important to include positive affect (i.e., quality of life, meaning, and social engagement) in conjunction with indicators of distress as outcomes of interest (Logsdon, Gibbons, McCurry, & Teri, 2002).

Awareness and coping in early dementia. There is growing evidence that the degree of insight into memory loss that a person with dementia demonstrates affects his/her well-being and support needs, as well as the well-being and support needs of family members and caregivers. For example, when people with dementia have a high level of awareness, their caregivers report feeling less stressed, burdened, and depressed (Marková, Clare, Wang, Romero, & Kenny, 2005). Likewise, when people with dementia engage in rehabilitation interventions, those with higher levels of awareness experience better outcomes (Clare & Woods, 2004). Higher levels of awareness can also have a downside: these individuals appear to experience more depression and emotional distress (Clare, 2004). With an increasing emphasis on understanding the perspective of the person with dementia alongside that of family members and paid caregivers, the issue of awareness emerges as an important factor when considering how people with dementia view and appraise their own quality of life.

Clare (2003) explored the relation between awareness of deficits and identity in individuals with early stage Alzheimer's disease (AD). Using a sample of individuals representing a broad spectrum of awareness, from "unaware" to "very aware" of their illness, Clare concluded that individuals responded to awareness of memory problems along a continuum from self-maintaining to self-adjusting. Clare's preliminary model described differences in the integration of knowledge in terms that parallel the more broad identity process

perspective outlined by Whitbourne (1996, see preliminary studies section below). As described by Clare, a self-maintaining stance refers to a tendency to normalize memory problems in an attempt to maintain a sense of self that is consistent with previously held beliefs. In contrast, self-adjusting coping is characterized by a tendency to challenge or adapt the self-concept based on difficulties with one's memory. By conceptualizing the relation between awareness and identity along a continuum (i.e., self-maintaining to self-adjusting), Clare also allows for fluidity within a given individual across domains or situations. In other words, self-maintaining and self-adjusting coping strategies can be used simultaneously within the same individual depending on the situation or target event. For example, an individual may be willing to relinquish bill-paying responsibilities to a family member, adjusting to memory change in one social role, but may not have adjusted beliefs in another domain, such as driving or medication management.

In another notable study, Pearce, Clare, and Pistrang (2002) identified specific coping strategies in men diagnosed with early AD through interviews with the patients and their spouses. Their results supported the management of self by balancing self-maintaining strategies and the reappraisal or reconstruction of the self. The most frequently identified themes of self-maintaining (i.e., occurring in more than two-thirds of participants) included perceiving their memory problems as having a "limited impact;" attributing them to "normal memory loss and aging;" reporting efforts to compensate such as to "try a bit harder;" "making the most of things;" and "reliance on wife" for emotional and social support. The most frequent themes indicated by participants for reappraising the self were a sense of "loss," "uncertainty," and a tendency to "downgrade expectations." Pearce and colleagues concluded that the desire to make sense of difficulties with memory (and integrate them into self-beliefs) is experienced as tension with the need to protect and preserve a prior sense of self.

Interventions targeting challenges to identity. Intervention research that focuses directly on distress related to uncertainty about the future and the sense that identity is *slipping away* (Cohen-Mansfield, Parpura-Gill, & Golander, 2006) can promote positive affect and decrease negative affect simultaneously by promoting meaning-based coping (e.g., Folkman, 1997). Even in the absence of awareness of changes in memory, changes in functional status and social roles can be a source of distress (Woods, 1999). The psychological distress of being confronted with illness is often entangled with existential issues and future care needs (Chochinov, 2004).

Self-adjusting: Focusing on the future. While experiencing loss and uncertainty in light of changes in cognitive functioning can lead to negative affect, it can also be an opportunity for important conversations about planning for current and future care (Husband, 2000). Across populations, concerns about autonomy, independence, comfort, maintaining abilities, and living free of pain are common themes (e.g., Chochinov et al., 2004; Hu & Gruber, 2008; Low, Molzan, & Kalfoss, 2008; Woods, 1999). Addressing uncertainty about future care and feelings of burden associated with increasing health-related dependence can result in positive outcomes for both the individual with dementia and their family members. One aspect of planning for future care that has demonstrated benefit from a patient-centered approach is advance care planning (ACP; Briggs, Kirshoff, Hammes, Song, & Colvin, 2004). By focusing on decision-making that is consistent with the individual's wishes, dignity and arguably aspects of the individual's identity are preserved (Chochinov et al., 2004). Wishes may include not becoming a burden to families, or the more generative wish of caring for future generations (e.g., children or grandchildren) by making one's own plans. Furthermore, most individuals in Western cultures prefer to be the one making decisions rather than having family or doctors decide on their behalf

(Karel, Moye, Bank, & Azar, 2007). Briggs and colleagues (2004) define patient-centered care in the context of advance care planning as a “partnership to design patient-specific education and support to assist in making decisions that are respectful of the patient’s needs and wishes” (p. 48). However, Briggs (2004) cautions that despite the overwhelming probability that individuals with dementia and their families will be faced with decisions regarding life-sustaining treatments; the proportion of individuals with advance care plans in place is minimal compared to other terminal diseases such as cancer. Briggs cites three primary reasons for this discrepancy: (a) physicians often do not recognize dementia as a terminal disease; (b) research on appropriate therapeutic interventions (i.e., feeding tubes, etc.) in the context of dementia is limited; and (c) health care proxies and individuals with dementia do not receive adequate support in the face of these decisions. Perhaps simple interventions that have been shown to increase satisfaction, decrease decisional conflict, and increase the likelihood that an individual’s wishes are followed could be employed with families earlier in the disease process (e.g., Allen, Allen, Hilgeman, & DeCoster, 2008; Caplan, Meller, Squires, Chan, & Willett, 2006).

Understanding values, wishes, and fears of the individual making health care decisions has received attention in light of evidence that suggests communication regarding these topics results in the most consistent and representative decision-making (Karel et al., 2007). Even when plans are open to change or agreement regarding future health care decisions does not improve, engaging in conversations about health care desires often results in increased satisfaction with the decision-making process (Ditto et al., 2001). In the past an emphasis on surrogate decision makers and agreement as an outcome of interest overshadowed efforts to describe the benefits and challenges of involving individuals with compromised capacity in the process (Ditto et al.). In a sense, there has been a fundamental shift to a more patient-centered approach to end-of-life

care and advance care planning as a whole, even in the context of dementia. New outcome variables such as empowerment, social engagement, autonomy, and reduced decisional conflict have replaced previous notions about the best way to plan for future care (e.g., Allen, et al., 2003; Hilden, Honkasalo, & Louhiala, 2007; Schamp & Tenkku, 2006; Wilkinson, 2001).

Karel and colleagues (2007) conducted a study examining the tools, motivations, and reactions to decision making in individuals with and without dementia. In their sample of 165 older adults, 97.3% of individuals in their sample over the age of 75 and 87.3% of those younger than 75 reported that they were concerned about becoming a burden. Their results revealed that participants with mild dementia were as able as normal elderly controls to answer both open-ended and forced-choice questions about quality of life, advance care planning, and “how general concerns about quality of life might translate to more specific beliefs and preferences regarding medical treatment decisions,” (Karel et al., 2007, p.144). The current study targeted concerns about becoming a burden by addressing not only the link between quality of life and advance care planning, but also by underscoring that one way of coping with changes in functioning and memory in the context of dementia may be to plan for future care.

Self-maintenance: Remembering the past. Across a series of nursing home studies, Cohen-Mansfield and colleagues (Cohen-Mansfield, Golander, & Arnheim, 2000; Cohen-Mansfield et al., 2006) explored the maintenance of self-identity or personhood in individuals with moderate to severe dementia. Specifically, close-ended questionnaires from individuals with dementia, their formal caregivers, family members, and when appropriate, a review of the resident’s chart were used to develop personalized interventions with the goal of maintaining self-identity. The interviews targeted four broad roles or domains of identity: (a) family membership, (b) work, (c) leisure activities, and (d) identity related to group membership, traits,

or achievement. In the initial phase of this research, Cohen-Mansfield and colleagues (2000) found that older individuals with dementia reported the following identity roles most frequently, in order of prevalence: (a) family heritage, (b) success of a relative, (c) academic achievement, (d) occupations, (e) traits, and (f) survival. Notably, better cognitive functioning was consistently related to greater saliency of identity roles in their sample of moderately to severely impaired individuals (Cohen-Mansfield et al., 2000).

From information learned in the initial interviews, Cohen-Mansfield et al. (2000) refined the Self-Identity in Dementia Questionnaire and piloted it with 93 older persons with dementia with an average Mini-Mental State Exam score of 10.58 (Cohen-Mansfield et al., 2006). Interventions were then developed to help maintain identity-salient roles by engaging participants in interactions related to their role identities. For example, some individuals prioritized family roles such as being a father or grandfather as most important, while others chose professional roles (e.g., educator, pilot, etc.), or leisure related roles (e.g., athlete, gardener, etc.). Therefore, the *first step* was the determination of role-identity salience. The person with dementia's cognitive function impacted the priority ratings of different aspects of self-identity such that moderately impaired individuals' input was weighed more heavily than those who were more severely impaired. Role-identity salience was determined by considering: (a) how important the role was rated; (b) whether the role maintained importance over time; and (c) whether the role was mentioned by all three informants (i.e., participant, family member, & professional caregiver). The *second step* was the determination of the intervention. In all cases, interventions were designed to match the demographics and cognitive abilities of the person with dementia while still providing purposeful or meaningful activity. For example, activities in the family-social role realm included creating a family tree out of photographs, listening to

audiotapes of family members, or engagement in prompted reminiscing. Individuals in the Self-Identity treatment group showed a significant increase in interest, pleasure and involvement with activities, fewer agitated behaviors, and increased orientation during the treatment period (Cohen-Mansfield et al., 2006). The intervention was designed to prioritize and target particularly salient aspects of the person with dementia's self-identity. Awareness of deficits was not considered by Cohen-Mansfield and colleagues in this study.

Life review in the nursing home as an intervention for self-esteem and self-integration, quality of life, and modification of problematic behavior was recently reviewed by Moos and Bjorn (2006). Across 28 studies, Moos and Bjorn noted that the individuals with mild to moderate dementia appeared to benefit most in the five interventions that targeted self-integration. However, Moos and Bjorn note several methodological concerns across studies including inadequate information on the staging of dementia, limitations of content as a result of group formatted sessions, and poor documentation of unprompted or spontaneous recall of memories or events.

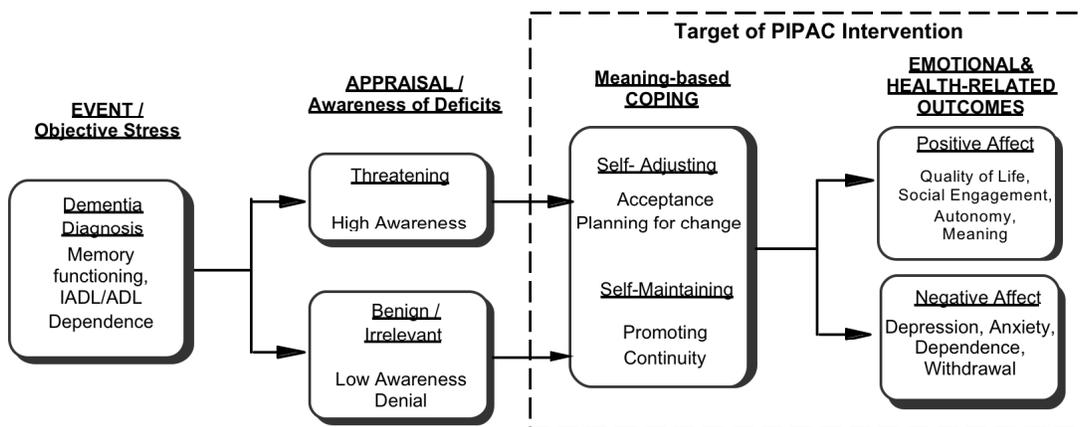
The notion of maintaining a sense of self or "continuity" as a means of coping is not unique to individuals with a dementia diagnosis. Chochinov's (2004) research has suggested that individuals coping with a terminal illness often face similar challenges. In a recently developed working model of dignity in the terminally ill, Chochinov describes illness-related concerns in themes of independence and themes of symptom distress. Similarly, Chochinov's description of the internal mechanisms or working cognitive model that conserves or maintains dignity (i.e., the "Dignity Conserving Repertoire") consists of the following components: (a) continuity of self, (b) role preservation, (c) generativity/legacy, (d) maintenance of pride, (e) autonomy/control, and (f) acceptance, among others (Chochinov, 2004, p. 138). The conceptual model for the current

PIPAC project shares many of Chochinov’s underlying constructs as the basis for the current project (e.g., as depicted in the modified stress process model, described below). Furthermore, Chochinov’s Dignity therapy, which focuses on preserving dignity through interventionist-guided interviews served as a theoretical and methodological predecessor to the Legacy Project (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008), described in detail in the preliminary studies section.

Proposed Conceptual Model

Lazarus and Folkman (1984) laid the foundation for understanding the relation between stressful events and coping in individuals facing adversity, including illness. In the original model and in the current modification (i.e., Stress Process Model- Early Dementia; Figure 1), individuals are continually appraising events (i.e., objective stressors: in this case, instances related to their memory) in their environment as either *stressful and threatening* or *benign and irrelevant*. Individuals may assess events as non-threatening for a number of reasons, including an absence of *awareness* or denial regarding their level of impairment.

Figure 1. Stress process model- early dementia.



When this occurs, individuals will likely depend more on self-maintenance coping, which can lead to poor planning and communication about future care needs. Individuals low in awareness

have been described by some researchers as being in denial about their deficits (e.g., Macquarrie, 2005); therefore, it is assumed they are not able to consider implications of disease progression. In contrast, events or objective stressors that are appraised as threatening require coping, which can be adaptive problem-focused coping (e.g., planning for future medical care), or what has traditionally been referred to as “nonadaptive,” avoidance-coping. Interestingly, in the context of coping with a dementia diagnosis, a self-maintaining stance or avoidance of incorporating current problems with memory into existing self-schemas can be just as beneficial, or likely to result in positive emotional outcomes as long as it is embraced simultaneously with willingness to engage in problem-solving, future-oriented approaches as well. In fact, some researchers (see Clare, 2004 for review) argue that a lack of awareness is more than a neurological symptom, as once believed, and is influenced by a lifetime of psychosocial influences and patterns of behavior.

The PIPAC intervention combines one self-adjusting, future planning component (i.e., Patient-Centered ACP) and one self-maintaining component (i.e., Legacy based project) to maximize coping and enhance quality of life and well-being in the early stages of dementia (Figure 1). Coping processes lead to an emotional or health-related outcome that is generated through the process of appraisal, coping, and potential resolution of the initial event or objective stressor. In Folkman’s (1997) revision of the stress process model, she introduced the importance of meaning-based coping as a means of maintaining the coping process despite less than desirable outcomes or resolution of events (as might be the case with a progressive dementia). The Legacy component of the PIPAC intervention was designed with meaning-based coping in mind and has successfully increased meaning and reduced symptom distress in individuals in previous projects (e.g., Allen et al., 2008). Application of stress process models to the early

stages of dementia is a logical way to build on the sophistication of the Alzheimer's caregiving literature in more patient-centered research and interventions. Both the Legacy component and the advance care planning component of the current intervention may promote feelings of generativity, of passing on family memories, giving back to someone who has provided care, and a sense of personal growth and dignity (e.g., see Chochinov et al., 2004).

Preliminary Studies

Three areas of preliminary studies conducted within our research group are relevant to the development and rationale of the proposed study: (a) community and nursing home interventions, (b) memory-related threats to self and identity, and (c) advance care planning.

Nursing home and community-based interventions with frail populations. Our research team has extensive experience in dementia-related intervention research (e.g., Hilgeman, Burgio, & Allen, 2009; Hilgeman, Allen, DeCoster, & Burgio, 2007). For example, in one nursing home (NH) based study entitled, "Increasing Effective Communication in Nursing Homes," (R01AG13008) an intervention using communication-prompting memory books effectively increased social engagement in individuals with dementia (Allen-Burge, Burgio, Bourgeois, Sims, & Nunnikhoven, 2001; Burgio et al., 2001) by providing simple pictures or cues that were salient to the individual (e.g., a picture of their previous home, etc.). The creation of a simple, tangible, memory-aid or book facilitated communication with others in their environment in much the same way as Cohen-Mansfield and colleague's (2006) identity-role research with individuals in the later stages of disease progression.

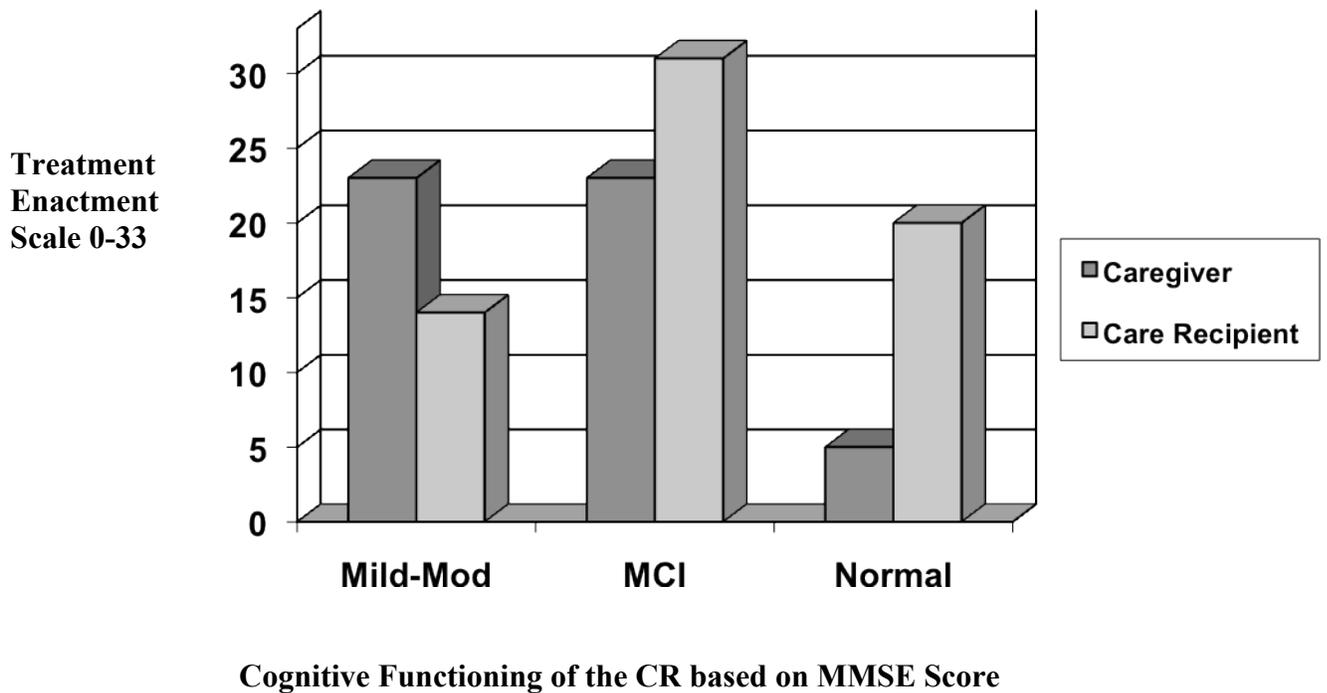
A second study, the Legacy Project, expanded the notion behind the memory books used in the nursing home for application in a community-based intervention. Rather than creating a simple memory book to facilitate communication, the Legacy Project aimed to document, in

detail, aspects of the individual's life story. The Legacy intervention builds on Chochinov's Dignity Therapy (2004) by integrating the role of the family caregiver into an intervention designed to record an aspect of the ill individual's life story. This project used a randomized, contact control group design to examine palliative care patient and family caregiver outcomes. The intervention group received three home visits in which the interventionist used a Participant Notebook (or manualized treatment workbook) to guide the family/dyad to construct a personal Legacy. This family-centered intervention began by guiding the participants through problem-solving exercises designed to select an agreed upon medium for their Legacy, usually a scrapbook with photos or audiotaped stories. Control group families received supportive telephone calls and a one-time "Legacy Highlights" booster session after the post-treatment assessment.

Of the 42 families that entered the Legacy project, 31 families completed follow-up assessments (i.e., the five-contact protocol with the research team) within nine to ten weeks (14 control; 17 intervention; 72% African American) for a retention rate of 74%. Allen and colleagues (2008) found that intervention patients reported decreased breathing difficulty, increased meaning, and greater social interaction. All participants in the intervention group initiated a Legacy activity and reported that Legacy improved family communication. In the current study, the structure and underlying goals of the Legacy Project are retained, although modified for simplicity using aspects of the Cohen-Mansfield and colleagues (2006) identity-role intervention for the newly developed PIPAC intervention (see Appendix). For example, emphasis on problem-solving skills has been omitted from PIPAC for simplicity, yet the underlying structure remains the same.

Although cognitive decline was not a focus of the Legacy Project, 35.5% ($n = 11$) of participants in the original Legacy sample had MMSE scores in the mild to moderate range (i.e., 14-23), while 25.8% ($n = 8$) had MMSE scores in the mild cognitive impairment (MCI) range (i.e., 24-27). Notably, even individuals in the mild to moderate range were able to be actively engaged in the intervention as determined by the treatment enactment data (see Figure 2); however, as participant's cognitive functioning decreased the caregiver seemed to take a more active role in the completion of the family Legacy.

Figure 2. Legacy patient engagement by cognitive status.



It is anticipated that more impaired individuals may require more support from the interventionist or family members in the completion of a Legacy project. Where indicated, the interventionist may choose to match the complexity of the project to the individual's level of functioning, such that more impaired individuals may benefit more from projects similar to those

produced in Cohen-Mansfield and colleagues' work (2006) or the memory-book interventions in skilled long-term care (Allen-Burge et al., 2001; Burgio et al., 2001). Treatment enactment data were collected for participants with dementia as well as the family contact or other individuals that assist with the intervention (see below for details). However, based on the Legacy project data there is no reason to believe that the level of enactment will predict outcomes for the participants.

The Legacy project significantly reduced both caregiver and intervention patients' symptom distress. Specifically, intervention individuals with a life limiting illness reported decreased breathing difficulty and increased religious meaning. Caregivers and patients reported greater social interaction or social-engagement on the part of the patient, and all participants reported that Legacy improved family communication. Themes from our qualitative review of Legacy intervention transcripts (Payne, Allen, Hilgeman, & Ege, 2007) revealed the following themes, salient to both patients and family caregivers: (a) family membership both past and future (e.g., continuity of self in future generations), (b) faith or spiritual beliefs, (c) accomplishments/achievements, (d) generativity or helping others, (e) friendship, (f) food, and (g) lessons in overcoming adversity. These themes are highly similar to the types of roles most frequently endorsed by participants in Cohen-Mansfield and colleagues (2006) identity-role intervention, suggesting the possibility of using the Legacy activity to promote identity or self-maintenance in individuals with mild dementia. Participants in both projects (i.e., Allen et al., 2008; Cohen-Mansfield et al., 2006) endorsed family relationships and roles as the most meaningful for them across the lifespan. Components from the Legacy intervention were incorporated into the identity preservation module of the PIPAC intervention (see Appendix).

Memory-related threats to self and identity. In addition to intervention research facilitating social engagement and meaning, Hilgeman and Allen (under revision), have also explored the impact of *memory-related threats to self-concept* in a sample of 81 independent, community-dwelling older adults. Like the proposed model of coping in early Alzheimer's disease (Figure 1), the relation between objective memory performance and beliefs about memory abilities and self-perceptions were hypothesized to be moderated by a self-maintenance or self-adjusting approach to memory threats. Results indicated that self-adjusting strategies, specifically, Whitbourne's identity accommodation approach (e.g., Whitbourne, 1996; Whitbourne, Sneed, & Skultety, 2002) moderates the relation between objective memory performance and perceived change in memory for healthy aging individuals. In addition, identity balance (a fluid process of self-maintaining and adjusting) and identity accommodation (self-adjusting) predicted memory self-efficacy and self-concept above and beyond depression and subjective health. These findings are congruent with identity process theory; however, the impact of identity assimilation (denial) in this population was unremarkable. The PIPAC intervention builds on this research in two primary ways: (a) exploring self-maintaining and self-adjusting coping in a more cognitively impaired, clinical population; and (b) designing an intervention aimed at promoting adaptive aspects of self-maintenance and self-adjusting behaviors.

Advance care planning. Finally, our lab has a long-standing program of research in advance care planning and communication of treatment preferences (e.g., Allen-Burge & Haley, 1997). Although there are many reasons to discuss and document future health care planning desires, perhaps one of the most frequently researched is the discrepancy between proxy or family member decisions and those of the individual receiving care (Schmid, Allen, Haley, & DeCoster, 2010). In one study, Allen and colleagues (2003) investigated correlates of consent

capacity and possession of advance directives among 78 communicative NH residents (M MMSE = 14.04, SD = 6.50) and their proxy decision-makers (usually family). Capacity assessments revealed that most residents could state a simple treatment preference but a sizable number did not retain capacity to understand treatment alternatives or appreciate the consequences of their choice. Family proxies were more apt to state treatment preferences for their resident that coincided with their personal wishes than those of the resident for whom they provided care. This underscores the importance of discussing treatment wishes before capacity is lost, as is encouraged in the PIPAC intervention targeting individuals in the early to mild stages of the disease.

Most recently, Allen, Allen, Hilgeman, and DeCoster (2008) designed an enhanced information intervention to assist individuals in making decisions about life-sustaining treatments (N = 79 community-dwelling older adults). Allen and colleagues found that even a simple educational information sheet describing the risks, benefits, and treatment alternatives reduces decisional conflict overall and impacts preference for life-sustaining treatment in some groups (i.e., African American participants). This simple information sheet was included in the Appendix of the PIPAC Participant Notebook (see Appendix of the current document) for use with higher functioning individuals who desired more information about treatment preferences.

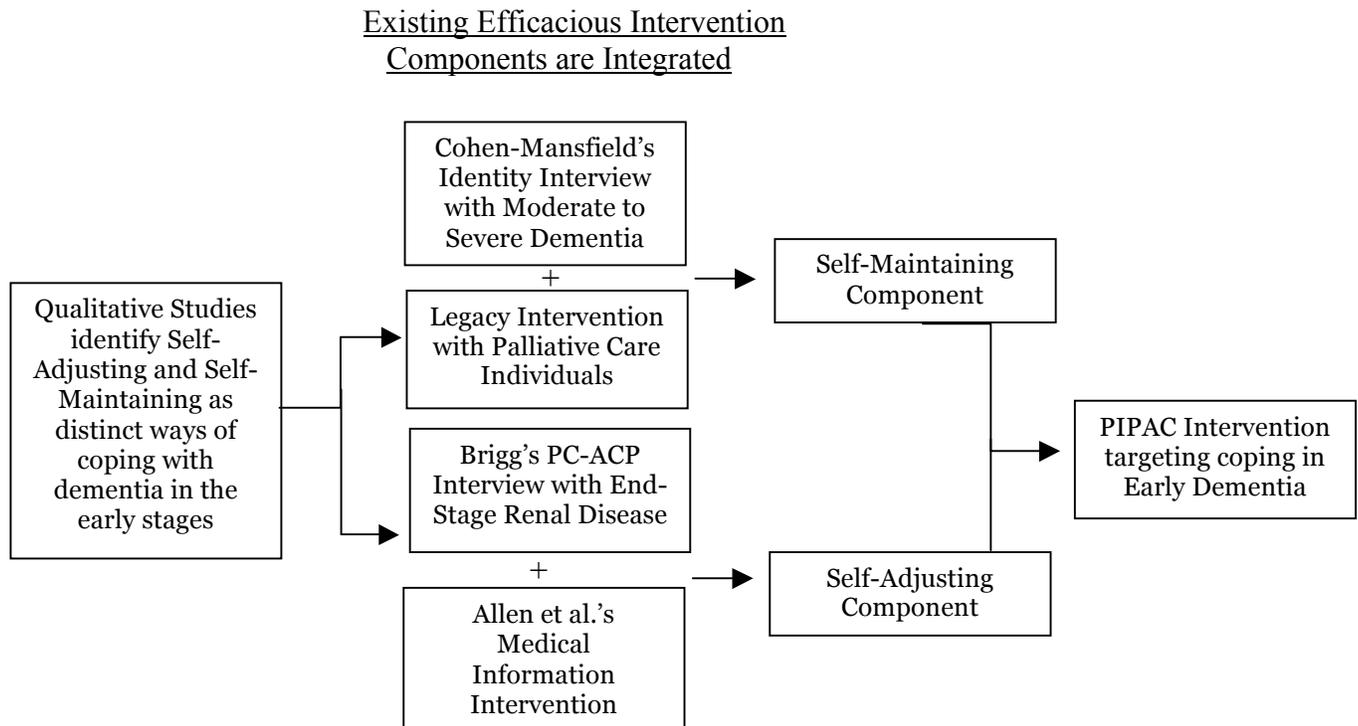
The Current Study

The current study attempted to address both conceptual and methodological gaps in the existing emotion-focused intervention literature. Conceptually, it attempted to take a step toward bridging existing qualitative studies on coping with dementia in the early stages with a well-established model of the stress process used in other disease populations and caregiving literatures (i.e., Lazarus & Folkman, 1984; and Folkman, 1997). In line with these goals,

consideration was also given to the everyday experience of individuals with dementia, the impact of awareness, and the notion that coping within these individuals likely fluctuates between periods of maintaining ties to the past (self-maintenance) and acknowledgment and adjustment to an uncertain future (self-adjusting) for optimal outcomes. The Stress Process Model- Early Dementia reflects these aspects of the coping and stress process early in the stages of the disease.

Methodologically, the PIPAC intervention was designed to build on this conceptual framework by focusing needed attention on interventions targeting positive and negative emotional outcomes of individuals in the early stages of the disease. Despite the attention of qualitative researchers to individuals in the early stages, intervention research most often focuses on family caregivers (e.g., Resources for Enhancing Alzheimer's Caregiver Health, REACH clinical trials, Belle et al., 2007) and individuals in the moderate to severe stages of the disease. Effective meaning-based interventions used to promote quality of life (health-related and general), social engagement, identity preservation, increased communication about future plans, and ultimately decreased depression and anxiety (Allen et al., 2008; Briggs et al., 2004; Chochinov et al., 2004; Cohen-Mansfield et al., 2006) have been merged to create the Preserving Identity and Planning for Advance Care (PIPAC) intervention (see Figure 3).

Figure 3. Designing the PIPAC intervention.



Designing a Feasibility Study

Because this intervention was developed for the purposes of this study and its components have not been tested in this population, a feasibility study sometimes called a “Phase I” or “Phase II” clinical trial was conducted as a logical first step toward the goal of establishing a new evidence-based intervention. As clinical outcomes research has advanced, the phases of clinical trials have been more clearly defined (e.g., Bowen et al., 2009; Green & Glasgow, 2006; Robey, 2004, Schnurr, 2007). Within this movement is the realization that not every newly developed intervention should be promoted and tested for effectiveness, which often involves a costly and time-intensive clinical trial. Feasibility studies, broadly defined, are used to evaluate whether an intervention warrants additional testing and can provide information on ways to modify elements of the intervention protocol. Bowen and colleagues (2009) argue that feasibility

studies are indicated when: (a) “community partnerships need to be established,” (b) there are few published studies using the “specific intervention technique,” (c) the population requires unique considerations in other published research, and (d) previous examinations of the intervention show promise, but have not been tested in a new situation or with a new population (p. 453). The current study meets each of these criteria.

Furthermore, specific goals for evaluating newly developed interventions as well as recommended methodological approaches have been suggested (e.g., Bowen et al., 2009; Schnurr, 2007). Feasibility studies may be more focused on the practical implementation of an intervention in a given setting or with a specific population and the associated constraints that may impact eventual success of that intervention than the highly controlled focus on internal validity that is central to efficacy studies (Green & Glasgow, 2006; Seligman, 1995). Bowen and colleagues (2009) outline eight areas of focus that can be used to shape feasibility study design and outcomes, specifically: (a) acceptability, (b) demand, (c) implementation, (d) practicality, (e) adaptation, (f) integration, (g) expansion, and (h) limited-efficacy testing (p. 453). *Acceptability* describes the importance of determining how satisfied and appropriate the intervention is to those who are delivering it as well as the consumers of the intervention. For example, expressing a continued desire to use the materials or skills learned during an intervention would be one example of an endorsement of the acceptability of the intervention. Second, *demand* refers to the likelihood that the intervention will be embraced by the population or organization that it is targeting. Demand can be measured by assessing interest in the intervention and anticipating future need or desired use. Third, *implementation* refers to the extent that the intervention package can be delivered in a consistent and measurable way and includes indicators such as: preciseness of treatment delivery, resources needed to administer the intervention, and the

success of implementing the intervention in terms of cost effectiveness, quality, etc. Fourth, *practicality* simply refers to the target population's ability to use the intervention package, essentially can they do what is being asked of them in the intervention and does it make sense to do so in terms of risks and benefits to the patient's time and resources. *Adaptation* should be an area of focus for feasibility studies when the intervention has been used successfully in one setting or population and the research team is interested in modifying it for use in a new context. Successful adaptation would be indicated by replicated results of the intervention in the new setting. *Integration* and *expansion* both refer to aspects of the intervention that may have organizational or structural repercussions. Specifically, integration describes the ease or difficulty with which the intervention can be absorbed into existing infrastructure and expansion refers to the ease with which a successfully tested intervention can be broadened to provide new services or effect additional outcomes. Finally, *limited efficacy* refers to the goal of a feasibility study to evaluate whether the intervention "shows promise of being successful with the intended population" (p. 454). Given obvious disadvantages of smaller *n* studies, the researchers (Bowen et al., 2009) recommend using effect-size estimation whenever possible with "small-scale experiments that more closely approximate the clinical or community context of an RCT" (p. 456) to determine the intended effects on potential outcomes of interest. In summary, each of these areas address different facets that can be measured and modified to most efficiently graduate from one phase of clinical outcomes research to the next.

Specific Aims

With these considerations in mind, the current study addressed two primary aims and one exploratory aim:

Aim 1. The primary aim was to evaluate the feasibility of the newly developed patient-centered PIPAC intervention for use with individuals in the early to mild stages of dementia. In order to address this aim, individuals with dementia, their family members, and project staff completed project evaluation forms that assess areas of: (a) acceptability, (b) implementation, (c) practicality and (d) adaptation of the newly developed intervention. System-level or organizational aspects of the intervention's feasibility (i.e., demand, integration, and expansion) can be inferred from other elements, but were not a direct target of this feasibility study as community partnerships were continuing to be developed throughout the project.

Aim 2. The second aim was to conduct limited-efficacy testing of the PIPAC intervention on emotional and health-related outcomes in order to determine appropriate targets of future clinical outcomes research with individuals in the early stages of dementia. Consistent with recommendations for feasibility studies, effect size estimates were the primary statistical indicator used to determine likely promise of the intervention. Using the Stress Process Model-Early Dementia and other reviewed literature as a guide, the following preliminary hypotheses were made:

1. *Self-reported emotional outcomes:* We hypothesized that intervention individuals with dementia would have decreased symptoms of depression and anxiety compared to individuals in the control group. In addition, intervention individuals with dementia were expected to report increased overall meaning, social engagement, and quality of life in comparison to control individuals.
2. *Self-reported health-related outcomes:* We also hypothesized that intervention individuals with dementia would have increased health-related quality of life and satisfaction with the advance care planning process compared to control individuals.

In addition, intervention individuals were expected to report less decisional conflict than control individuals.

3. *Family contact reported emotional outcomes:* For family contacts' ratings of individuals with dementia, we hypothesized that intervention group proxy-report would reflect decreased symptoms of depression and anxiety compared to family contact report for individuals in the control group. In addition, we expected family contacts for intervention individuals with dementia to report greater overall social engagement and quality of life in comparison to family contacts for control individuals.
4. *Family contact reported health-related outcomes:* Family contacts for individuals with dementia in the intervention group were expected to reflect increased health-related quality of life compared to family contact report for control individuals.

Secondary Aim. An exploratory aim was to examine the impact of PIPAC on coping strategies and awareness in the early stages of dementia, which may serve as moderators of intervention effects or targets of future interventions (see SPM-ED, Figure 1). We were also interested in determining whether the patient-centered PIPAC intervention, which makes family contact optional, could have an effect on caregiver stress. Exploratory *hypotheses* related to this aim are:

1. Intervention individuals will report an increase in coping strategies compared to control individuals.
2. No hypotheses were offered about the impact of the intervention on awareness or on the family contact's stress as these factors are not necessarily expected to be impacted by the designed intervention and are truly exploratory in nature.

Chapter 2. Method

Study Design

Eligible dyads that consented to be in the study completed the baseline assessment. Patient data was collected interview-style by a trained assessor, while the family contact measures were completed independently with paper and pencil unless indicated otherwise (e.g., one family contact could not physically complete the measures due to Parkinson's disease). Once baseline data were collected, dyads were randomly assigned to condition. Blocked randomization stratified by race and gender was used to assign participants to either the: (a) multi-component intervention group, or the (b) minimal support phone contact control group. This two-group experimental design was chosen over other approaches (e.g., no comparison group designs, etc.) because it most closely approximates the next level of clinical research (e.g., an efficacy study), which allows for the most directly applicable conclusions. Post intervention assessments were scheduled the week after the last intervention session.

Participants

Recruitment and incentives. Consistent with the feasibility design of this study, community partnerships for recruitment continued to be developed and established over time. Study recruitment was advertised through flyers, community newsletters (e.g., the Alabama Cares newsletter which is sent to caregivers of individuals with dementia-related disorders), community talks, and one-on-one discussions with community liaisons and senior groups at: (a) Capstone Village Retirement Community, (b) Middle Alabama Area Agencies on Aging (M4A),

(c) West Alabama Regional Commission (WARC) and the affiliated West Alabama Area Agency on Aging, (d) Pearlie Duncan's Senior Group at Stillman College, (e) Martinview Assisted Living, (f) Fair Haven Retirement Community, (g) LaRocca Nursing Home & Assisted Living, (h) Morning Pointe Assisted Living, (i) Ashton Gables and Lakeview Estates Senior Living Communities, (j) North River Assisted Living (k) FOCUS on Senior Citizens, and (l) numerous providers in the community with access to older adults with dementia (i.e., Dr. Regina Harrell, Dr. Mark Prohaska, Dr. Mike Parker, Dr. Danny Potts, Dr. Hugh Lee, & Dr. Eugene Marsh). Letters of support were obtained from each recruitment source before potential participants were contacted. "Snowball recruitment" methods were also employed such that current or previous participants could tell friends about the study or make recommendations regarding recruitment. Providers in the Dementia Clinic (i.e., Dr. Sylvia Colon) and the Home-Based Primary Care Service (i.e., Dr. Bettina Schmid) at the Tuscaloosa Veterans Affairs (VA) Medical Center were also interested in partnering with the PIPAC study investigators; however, due to an inability to successfully gain approval from the Tuscaloosa VA Institutional Review Board after several months (July 2008-February 2009), efforts were discontinued given staffing and time constraints of the current study.

In accordance with Health Insurance Portability and Accountability Act (HIPAA) guidelines and the IRB at the University of Alabama, the research team only approached potential participants who had previously expressed interest (e.g., either by attending a talk, mailing in a flyer, or communicating with a community liaison). A recruitment flyer and a longer study description (see Appendix) were used to inform individuals about the study. After individuals received some information and expressed interest in learning more about the study,

project staff contacted participants by phone or in person to expand on the details of the study (i.e., time commitments, eligibility criteria, incentives, etc.).

Participant Incentives. Participants with dementia received a \$20 honorarium at the completion of each assessment phase (i.e., baseline and post-treatment), for a total of \$40 for their participation. In addition, family contacts received a \$10 honorarium for their participation in each assessment (baseline and post-treatment), for a total of \$20. Participants with dementia received a larger honorarium since their time commitment to the project is greater than that of their family contact. In addition, intervention individuals received a small cash amount (i.e., \$20) to offset the costs of the materials for the Legacy project.

Inclusion Criteria. *Dementia patients* were eligible if they: (a) were able to read and speak English, (b) were 55 years or older, (c) had a self-reported or proxy-reported dementia diagnosis (primarily: AD, VD, Mixed) in the early or mild stages of the disease, and (d) in order to ensure reliability of self-report, score either a .5 (very mild dementia) or 1 (mild dementia) on the Clinical Dementia Rating Scale (Washington University Alzheimer's Disease Research Center, 1999). Psychotropic medications including acetylcholinesterase inhibitors (e.g., Aricept), antidepressants, and anxiolytics could have impacted changes in well-being or affect. Therefore, careful documentation of medication history and adjustments were tracked whenever possible to ensure that changes in medications were not responsible for changes in dependent variables of interest. Participants who were not eligible based on their CDR score, and thus were not enrolled in the study, still received appropriate incentives after completing baseline assessment.

Family/friend Contacts were included if they: (1) had regular (at least weekly) contact with the individual with dementia; (2) lived close enough to the dementia patient to participate in an interview at the patient's home or another place of convenience; (3) read and spoke English,

and (4) could be reached by phone. Eligibility for the family contact was determined in the same manner as the individual with dementia (i.e., initially by phone and confirmed during the baseline assessment). Based on previous studies conducted in our lab, cognitive functioning of the family contact is rarely a reason for exclusion (i.e., Legacy Project, Rebecca Allen, PI, $n = 0$ out of 42) and therefore was not included in the eligibility criteria for this study.

No restrictions were placed on gender or race for family contacts or individuals with dementia. Recruitment was expected to reflect the racial/ethnic composition of Tuscaloosa County as measured in the 2008 census (U.S. Census Bureau, 2008), approximately 66.9% Whites/Caucasians and 30.8% Blacks/African Americans. Block randomization for gender and race was used to ensure approximately equal numbers of men and women and Blacks/African Americans and Whites/Caucasians appeared in the experimental and control groups.

Capacity to consent protocol. Individuals with probable Alzheimer's disease were considered to be a vulnerable population so extra cautionary steps were taken to ensure the participant had capacity to consent to the research study. However, diminished cognitive functioning alone was not considered to be synonymous with capacity to consent to research, which is situation-specific (Marson, Schmitt, Ingram, & Harrell, 1994). Moye and Marson's (2007) article on assessment of decision making capacity in older adults points out that consenting to research is a fairly specific, "narrow cognitive task" (p. P4). Furthermore, capacity to consent to any given study is based on the complexity of the task and the level of risk involved. Applebaum & Grisso (2001) suggest that complex medical or clinical trials may be more difficult for individuals with mild levels of impairment than psychosocial research (see also Jefferson et al., 2008; ABA/APA Workgroup, 2008).

Informed consent procedures were conducted in accordance with the consensus recommendations for research with cognitively impaired populations (Alzheimer's Association, 2004), described in detail below. Proxy consent and participant assent was only collected when the participant was willing to assent for the study but was determined by the capacity assessment at the time of consent to be lacking in capacity. Family contacts also completed informed consent for the use of their information in the study. Although the emphasis of the intervention was on the individual with dementia, family contacts provided their perspective of the individual with dementia's functioning and therefore had to complete a separate informed consent procedure for the use of their assessment data in the study. Informed consent was completed at the beginning of the baseline assessment visit.

Researchers who conducted the baseline assessment were trained to assess capacity to consent prior to the first assessment. Consent procedures were supervised by Dr. Rebecca Allen, a licensed clinical psychologist with experience in civil capacity assessment, and the principle investigator (MH). Dr. Allen and Ms. Hilgeman have experience with the Geropsychology Consultation Service in accordance with The University of Alabama's Elder Law Clinic (ELC) directed by Hugh Lee, JD. Only specifically trained research assistants (36% of those working on the study) completed baseline assessments.

In order to determine capacity to consent, the researcher assessed the participant's ability to: (a) understand the nature of the research and of his/her participation (e.g., by asking the participant to repeat back in their own words what the study is about); (b) appreciate the consequences of the participation, including personal consequences (e.g., was the participant able to spontaneously provide both negative and positive potential consequences of participating in the study); (c) understand alternatives, including the option not to participate (i.e., do they

understand that participation is voluntary); and (d) to make a reasoned and consistent choice (e.g., are they providing logical reasons for wanting to participate and were they consistent over time in their expressed desire to do so).

Researchers were trained to use both orally presented and visually presented information and the participant was offered a copy of the informed consent for their records (Alzheimer's Association, 2004). The researcher also stopped several times during the consent procedure to test for understanding and requested that the participant "put it into their own words," before moving forward. A capacity to consent checklist was developed to aid in assessment and documentation of capacity procedures in accordance with requests made by the UA IRB (see Appendix). If participants were unable to complete the four steps outlined above and expressed interest in participating, participant assent and proxy consent was completed. Participant assent and proxy consent was completed for 1 of the 22 dyads that completed baseline (4.5%). However, if the participant dissented for any reason or at any time participation was discontinued.

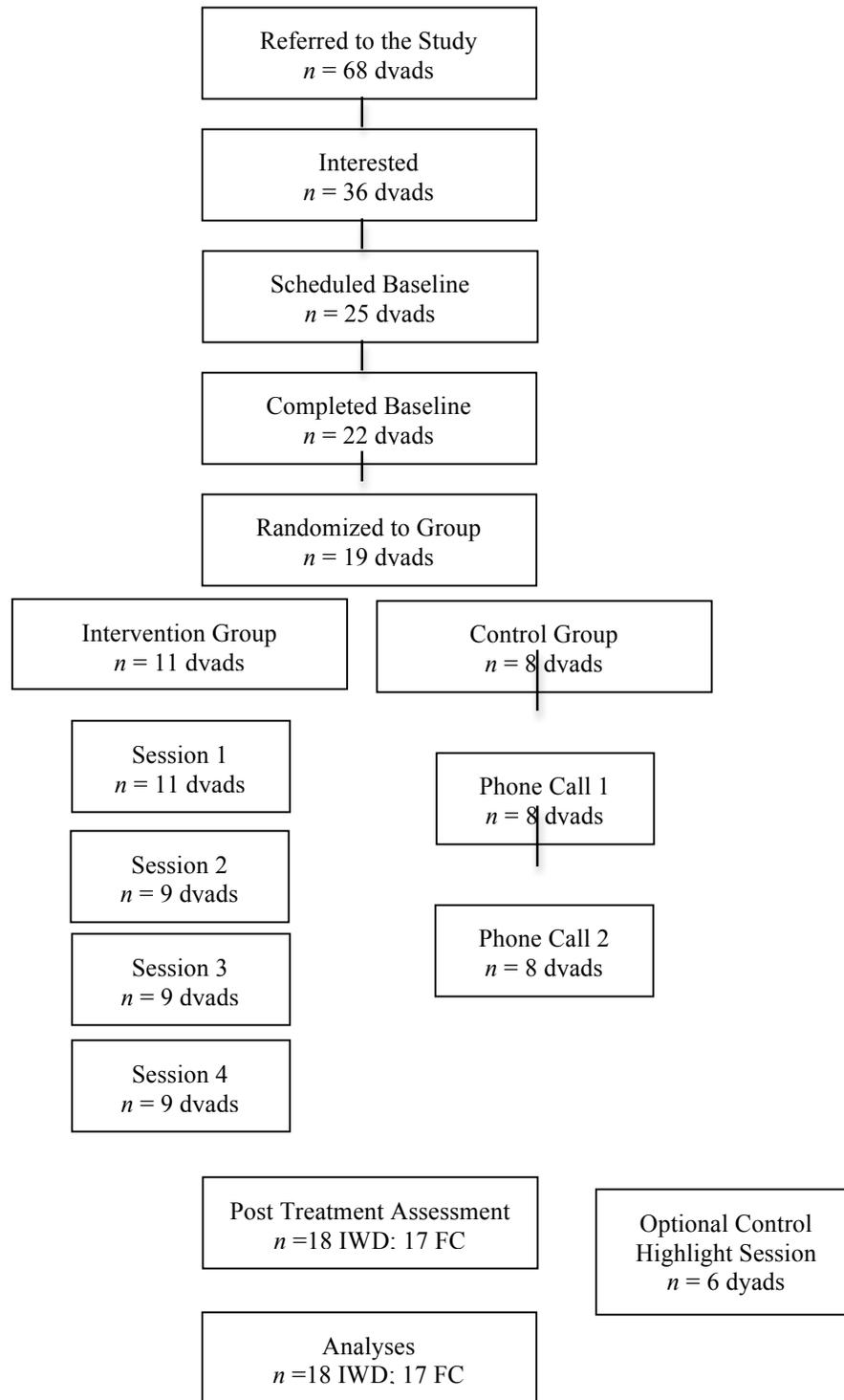
While obtaining proxy consent from a legally authorized representative such as a court appointed guardian would have been preferred, the percentage of individuals who have executed such legal documents is exceeding low. In a recent study exploring legal aspects of Alzheimer's disease among individuals with dementia and their family caregivers, only 11% of individuals with dementia had a legally authorized representative (Ruggieri & Piccoli, 2003). For this reason general practice guidelines permit next of kin to provide consent (e.g., The University of Alabama's Elder Law Clinic; The Legacy Project, Rebecca Allen, PI; etc.), particularly when risks are minimal as in the current study. Furthermore, one target of the current intervention was to increase advance care plans such as the appointment of a legal decision maker (see Session 3

of the PIPAC intervention). Since a close family contact such as a spouse or adult child was required to participate in order to be eligible for the study, the proxies were readily available in the event that a participant failed to meet capacity to consent independently.

Participant Characteristics

Recruitment and attrition. Initial communication with community partners began in February 2008 with recruitment of participants being completed from July 2008 through April 2010. During the course of the study a total of 68 potential dyads were referred to the study (i.e., expressed initial interest or willingness to hear more about the study to a community liaison; see Figure 4). Of these potential dyads, 18 (26.5%) were referred from nursing homes, 14 (20.6%) from assisted living facilities, 22 (32.3%) were referred by a local geriatrician, eight (11.7%) from an independent living community, one from a local senior group, and five (7.4%) were referred from another study (e.g., Dr. Allen's LIFE project). A portion of referred individuals were determined to be ineligible by research staff during the pre-baseline screen for eligibility; specifically, seven individuals were determined to be too impaired based on clinical observation, one individual had a traumatic brain injury rather than a dementia diagnosis, one individual was advanced in age but did not have a dementia diagnosis, and two did not have an identifiable family member or friend contact that was interested in participating. In addition, three individuals could not be reached for screening into the study. Thirty-two of the individuals reached by phone or approached in person were no longer interested in participating after hearing the details of the study (47% of referrals). The primary reasons given for not participating by patients and their family contacts were concerns about time involvement, feeling "too busy," and individuals with dementia diagnoses who felt as though they did not have any memory problems and were not interested in a study that focused on memory ($n = 3$).

Figure 4. Study design and summary of sample size.



Note. IWD = Individual with dementia; FC = Family contacts.

Twenty-five dyads were enrolled in the study (i.e., eligible after the initial screening and scheduled baseline assessments); however, three dyads did not complete baseline after being enrolled (12%). Reasons for not completing baseline included: (a) family concern regarding increased behavioral problems (e.g., agitation, aggression, etc.) in the individual with dementia, (b) a family medical emergency (i.e., participant's husband was admitted to hospice), and (c) cancellation of the baseline followed by an inability to reach them after the initial encounter. Of the 22 dyads that completed baseline assessments, three (13.6%) were determined to be ineligible after baseline based on clinical dementia ratings in the moderate ($n = 2$) or not impaired ($n = 1$) range. The remaining 19 dyads were randomly assigned to the experimental ($n = 11$) or control conditions ($n = 8$). Randomization procedures were compromised for one dyad to assure that they were assigned to the same group as their best friend who was participating at the same time. These two women spent everyday together because they had rooms next to one another in an assisted living facility and concerns about cross contamination of condition appeared to trump randomization to group in this particular case.

One of the individuals with dementia died during participation in the study. His wife was also medically frail (i.e., bed-bound with Parkinson's Disease) and post-treatment data was not pursued; however, a follow-up supportive bereavement visit was completed. A second family decided to discontinue participation at the request of the individual with dementia after the initial intervention session (which took place across two home visits). The individual with dementia reported that she was primarily interested in getting help with organization (e.g., bills, etc.) and was no longer interested in doing the study. This dyad did complete post-treatment assessment and therefore were included in the preliminary data analyses described in the current study. Overall, two out of 19 dyads discontinued participation during the study (i.e., one due to death

and one who changed her mind after starting the project) for an attrition rate of 10.5%. Final analyses were as inclusive as possible given the small n and feasibility design; therefore, analyses reflect all 18 dyads with available post-treatment data (10 = intervention, 55%; 8 = control, 44%).

Recruitment rates for the PIPAC intervention were comparable to the original Legacy Project (see Table 1). This speaks to aspects of demand and feasibility since the PIPAC intervention did not have the same level of resources as the Legacy Project (i.e., a full time research assistant, paid graduate research assistants, and a paid community recruiter).

Table 1. Comparing rate of recruitment across studies.

Study	First Baseline Assmt.	Last Post-Treatment Assmt.	Protocol Length	Months of Data Collection	Final Sample	Dyads / month
<u>Legacy</u>	10/15/2003	01/18/2006	5 weeks	27 months	31 dyads	1.15
<u>PIPAC</u>	02/25/2009	04/30/2010	6 weeks	14 months	18 dyads	1.29

Individuals with dementia were between the ages of 75 and 96 ($M = 82.8$, $SD = 6.46$) years old with 6 to 22 years of education ($M = 15.37$, $SD = 3.55$). Six (31.6%) were men and 13 were women (68.4%). The sample was predominantly White/Caucasian ($n = 18$, 94.7%) with one Black/African American (5.3%) individual with dementia. Roughly half of the individuals in the study ($n = 10$, 52.6%) reported taking medications for their memory or their mood and one intervention participant reported a relevant change in medication in the three months prior to the study (i.e., adding a new antidepressant to several other existing psychotropic medications). See Table 2. Sample characteristics by group. Demographic data is also presented by living arrangement for community dwelling participants and those in long-term care (see Table 3).

Table 2. Demographic characteristics of dyads that completed post-intervention assessment.

Sample Characteristics	Experimental Condition	
	Control Group (<i>n</i> = 8)	Intervention Group (<i>n</i> = 10)
Patients	<i>M</i> (<i>SD</i>) or % (<i>n</i>)	<i>M</i> (<i>SD</i>) or % (<i>n</i>)
Gender (% Female)	75% (6)	70% (7)
Race (% African American)	0% (0)	10% (1)
Age	84.25 (7.99)	80.80 (4.47)
Education in years	16.75 (3.24)	13.90 (3.38)
Self-reported health	-	-
Poor	0% (0)	20% (2)
Fair	25% (2)	30% (3)
Good	50% (4)	40% (4)
Excellent	25% (2)	0% (0)
Income Adequacy	-	-
Not very difficult	25% (2)	40% (4)
Not at all difficult	75% (6)	60% (6)
DRS Total Raw Score	110.00 (20.02)	119.10 (14.12)
DRS Total AEMSS	3 (3.16)	5.11 (3.33)
CDR Score	-	-
Very Mild (0.5)	0% (0)	40% (4)
Mild (1)	100% (8)	60% (6)
Memory-Related Diagnosis ¹	-	-
Alzheimer's disease	25 % (2)	20% (2)
Dementia (Unsure of Etiology)	25 % (2)	60% (6)
Vascular Disease	25 % (2)	20% (2)
Other (PD, Advanced Age)	25 % (2)	0% (0)
Family Contacts	<i>n</i> = 7	<i>n</i> = 10
Gender (% Female)	71.40% (5)	60% (6)
Race (% African American)	14.30% (1)	10% (1)
Age	68.57 (11.70)	66.20 (11.32)
Education in years	16.29 (1.80)	15.80 (1.75)
Income Adequacy	-	-
Difficult	0% (0)	30% (3)
Not very difficult	42.90% (3)	20% (2)
Not at all difficult	57.10% (4)	50% (5)
# ADL Tasks that Require Assistance	3.57 (1.62)	2.60 (1.71)
# IADL Tasks that Require Assistance	6.29 (2.50)	5.60 (2.36)
IWD Taking Meds for Mood/Mem	100% (7)	80% (8)
Change in Meds in Last 3 Months	0% (0)	10% (1)

Note. ¹ = Memory related diagnoses were based on the family contact's report; ADL = Activity of daily living; IADL = Instrumental activity of daily living; CDR = Clinical Dementia Rating; DRS = Dementia Rating Scale

Family contacts were between the ages of 52 and 90 ($M = 70.14$, $SD = 12.16$) with 12 to 20 years of education ($M = 15.48$, $SD = 2.04$). The majority of family contacts were either spouses ($n = 9$, 47.4%) or adult children ($n = 8$, 42.1%), but one was a niece to the individual with dementia (5.3%) and one (5.3%) was a paid companion that had known the individual with

dementia for more than 15 years. Family contacts were 84.2% White/Caucasian ($n = 16$) and 12.5% Black/African American ($n = 2$). See Table 2 for additional demographic data at baseline.

Research Staff

A total of eleven different research staff were involved in at least one aspect of implementing the PIPAC intervention as assessors ($n = 8$), interventionists ($n = 5$), or control callers ($n = 5$; note that numbers do not represent discrete groups). One of these individuals possessed a Ph.D. in Clinical Psychology, six were current doctoral students in Clinical Psychology or Social Work, 3 were undergraduate research assistants, and two were full-time research staff at the Center for Mental Health & Aging. Research staff represented good gender diversity; three men and two women served as interventionists and two men and six women served as assessors. Racial diversity of research staff was more limited; one individual (9%) was Indian American and the remaining 10 were White/Caucasian. Research staff volunteered time associated with the project as all funding support for this study (\$4,000) was designated for research materials (i.e., purchase of the DRS) and participant incentives.

Table 3. *Demographic characteristics by living arrangement for dyads that completed study.*

Sample Characteristics	Community Dwelling (n = 8)	Long-Term Care (n = 10)
Patients	M (SD) or % (n)	M (SD) or % (n)
Gender (% Female)	62.5% (5)	80% (8)
Race (% African American)	12.5% (1)	0% (0)
Age	82.12 (6.98)	82.50 (6.13)
Education in years	15.00 (5.04)	15.30 (1.20)
Experimental Group		
Intervention	50% (4)	60% (6)
Control	50% (4)	40% (4)
Income Adequacy		
Not very difficult	25% (2)	40% (4)
Not at all difficult	75% (6)	60% (6)
DRS Total Raw Score	109.88 (20.11)	119.20 (13.95)
Relationship to Patient		
Spouse	50% (4)	40% (4)
Child	25% (2)	60% (6)
Niece/Nephew	12.5% (1)	-
Paid Companion	12.5% (1)	-
CDR Score		
Very Mild (0.5)	12.5% (1)	30% (3)
Mild (1)	87.5% (7)	70% (7)
Living Arrangement Details		
Living alone independently	25% (2)	-
Lives in community with others	75% (6)	-
Assisted Living	-	40% (4)
Nursing Home	-	60% (6)
Family Contact Reported Characteristics		
# ADL Tasks that Require Assistance	2.75 (1.91)	3.22 (1.56)
# IADL Tasks that Require Assistance	5.25 (3.24)	6.44 (1.12)
Hours Per Day Providing Care	7.75 (4.92)	3.33 (3.49)
EQ-5D Subjective Health	68.75 (14.58)	52.78 (16.98)
Mobility		
No problems walking	62.5% (5)	22.2% (2)
Problems walking	12.5% (1)	66.7% (6)
Confined to bed	-	11.1% (1)
Self-Care		
No problems	50% (4)	44.4% (4)
Some problems washing/dress	25% (2)	22.2% (2)
Unable	-	33.3% (3)
Usual Activities		
No problems	12.5% (1)	44.4% (4)
Some problems	62.5% (5)	22.2% (2)
Unable	-	33.3% (3)
Pain/Discomfort		
None	25% (2)	22.2% (2)
Moderate	37.5% (3)	55.6% (5)
Extreme	12.5% (1)	22.2% (2)

Note. ADL = Activity of daily living; IADL = Instrumental activity of daily living; CDR = Clinical Dementia Rating; DRS = Dementia Rating Scale; EQ-5D = EuroQol- 5 Domain Quality of Life Measure

Measures

Background characteristics and objective indicators of stress.

Demographics. Socio-demographic information included: sex, age, primary racial or ethnic group, education level, living arrangement, time since diagnosis, and income adequacy. Income adequacy was assessed with a single item that asked about difficulty paying for the basics, response options ranged from 1 = *very difficult* to 5 = *not very difficult*. Additionally, because some medications can impact mood and quality of life, individuals were also asked if they were taking any antidepressants, anxiolytics, or memory enhancers (e.g., acetylcholinesterase inhibitors) and whether there had been any changes in these medications in the last 3 months (see Appendix).

Subjective health. Health status was measured using the sum of three subjective health questions (Levy-Cushman & Abeles, 1998; see Appendix). Scores ranged from 3-10 with higher scores indicating better perceived health. A Cronbach's alpha of .77 was obtained in the current sample.

Cognitive functioning in dementia. The Dementia Rating Scale (DRS-2; Mattis, 2005), is a 36-task screening tool used to assess level of cognitive functioning for individuals with dementia or other cognitive disorders. The DRS-2 was used to assess performance across six domains: (a) Attention, (b) Initiation-Perseveration, (c) Construction, (d) Conceptualization, (e) Memory, and (f) Total. The DRS-2 is preferred over the original DRS because of percentile data based on a wider age range and increased sensitivity to changes in cognitive status. The DRS-2 has good test-retest reliability correlation coefficients (i.e., .97) with subscales ranging from .61 to .94. Test-retest data is not available for the current sample, because participants only completed cognitive functioning indicators at the baseline assessment.

Dementia severity. The Clinical Dementia Rating (CDR; Washington University ADRC, 1999) was developed for the evaluation of severity/staging of dementia of the Alzheimer's type, but has been used in other populations as well. The CDR is a five-point scale, where 0 indicates *no cognitive impairment*, 0.5 indicates *very mild dementia*, 1 indicates *mild dementia*, 2 indicates *moderate dementia*, and 3 indicates *severe dementia*. Six domains (i.e., memory, orientation, judgment and problem-solving, community affairs, home and hobbies, and personal care) are rated independently to calculate the overall CDR rating. Ratings in each domain are based on cognitive functioning alone, not impairments resulting from physical frailty. Eligibility criteria for the current study required an overall rating of .5 (very mild or questionable dementia) or 1 (mild dementia). All assessors making judgments about the CDR completed the online training course and were Certified CDR Raters.

Functional status. Independence in daily care needs was assessed using the Physical Self-Maintenance and Instrumental Activities of Daily Living (IADL) Scale (Lawton & Brody, 1969) across six physical care domains (i.e., activities of daily living, ADL) and eight IADL domains; higher scores indicate greater dependence. This scale has satisfactory inter-rater reliability and construct validity (Lawton & Brody). The IADL and ADL scales obtained Cronbach's alphas of .75 and .72, respectively, in the current sample.

Appraisal & coping.

Awareness. Individual awareness of deficits in memory was assessed using the 13-item Memory Awareness Ratings Scale (MARS; Clare, Wilson, Carter, Roth, & Hodges, 2002). Participants and their family contacts reported on the frequency that the individual with dementia would have difficulty performing an everyday task (0 = *never* to 4 = *always*). Sample items include assessing ability to remember a name, recognize a face, and deliver a message (see

Appendix). Total scores for the individual with dementia and the family contact are summed; scores range from 0-52 with higher scores indicating greater difficulty performing memory tasks. Participants' self-report obtained a Cronbach's alpha of .85, while family contacts' report reached .95. Discrepancy scores were calculated comparing participant self-report and family contact report of abilities across a number of tasks, with family contact report of abilities used as the "gold standard." A Cronbach's alpha of .92 was obtained for discrepancy scores in the current sample. The performance-based portion of the awareness measure was omitted to reduce participant burden and fatigue.

Coping with early dementia. The patient's coping strategies for managing memory problems was assessed using the Index for Managing Memory Loss (IMML; Keady & Nolan, 1995). The IMML is a 42-item measure describing frequently used coping strategies described by individuals with dementia that was originally designed for use in clinical practice rather than quantitative research. Psychometric properties have not been reported in the literature; however, a Cronbach's alpha of .733 was obtained in the current sample by obtaining a count of endorsed coping strategies at baseline.

Emotional & health-related outcomes.

Depression and anxiety. Symptoms of depression were assessed using the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young, & Shamoian, 1988), which combines an interview with the individual and the family contact. Based on responses to the two interviews, nineteen items are rated on a three-point scale (*absent, mild or intermittent, and severe*) for: (a) mood and related signs, (b) behavioral disturbance, (c) cyclic function and ideational disturbance, and (d) physical signs. Higher scores represent more depressive symptomatology, with nine points or more indicating significant depressive symptoms. The

CSDD has been recommended above other measures in this population (e.g., Mayer et al., 2006) for its sensitivity and reliability. Furthermore, Gibbons, Teri, Logsdon, and McCurry (2006) have suggested that the three anxiety items on the CSDD are comparable to other measures of anxiety in individuals with dementia. Because of staffing constraints the individual with dementia was interviewed by the research assistant and the family contact completed the structured interview questions using paper and pencil. Clinician ratings of self-reported depression data obtained a Cronbach's alpha of .87 in this sample, while the family contact responses obtained a Cronbach's alpha of .77.

Quality of life. Quality of life was assessed using two measures to ensure adequate sensitivity to detect change in such a global construct. First, summed scores on the Quality of Life in Alzheimer's Disease scale (QOL-AD; Logsdon, Gibbons, McCurry, & Teri, 1999; Logsdon, Gibbons, McCurry, & Teri, 2002) were calculated. Patients and family contacts each rated thirteen domains: physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole using a Likert-type scale (0 = *poor* to 4 = *excellent*). Good construct validity, internal reliability (Cronbach's alpha = .84), and test-retest reliability ($r = .76$) have been demonstrated (Logsdon et al., 2002). Self-rated scores obtained a Cronbach's alpha of .87 while family contact data obtained a Cronbach's alpha of .82.

Second, the Bath Assessment of Subjective Quality of Life (BASQID; Trigg, Skevington, & Jones, 2007) is a recently developed self-report measure that is recommended as a supplement to more traditional or observable indicators of quality of life (e.g., proxy report). The BASQID uses self-report ratings for individuals with mild to moderate dementia with a focus on positive life experiences rather than issues of loss or negative outcomes. Fourteen items are rated on a five point Likert-type scale with values ranging from 0 to 4, with lower scores indicating a more

poor assessment of quality of life. A sample item on the BASQID is “How satisfied are you with your ability to talk to other people?” The BASQID has good construct validity and internal consistency (Cronbach’s alpha of .89) for the total score (see Trigg et al., 2007 for details). The current sample obtained a Cronbach’s alpha of .87.

Meaning. Multidimensional conceptualization of meaning in life was assessed across four domains: (a) values, (b) purpose, (c) goals, and (d) reflections on the past using the 14-item Meaning in Life Scale created by Krause (2004; see Appendix). A well-validated measure of meaning for individuals with dementia is not readily available; however, a Cronbach’s alpha of .92 was obtained in this sample suggesting that Krause’s Meaning in Life Scale has good internal reliability statistics based on our small sample.

Social engagement. Social engagement and withdrawal were assessed using items modified (Mor et al., 1995) from the Minimum Data Set questionnaire. This six-item measure includes the ability to take advantage of social interactions and to initiate meaningful social contacts. Individuals and their family contact rate: (a) ease interacting with others, (b) ease doing planned or structured activities, (c) ease doing self-initiated activities, (d) establishment of own goals, (e) involvement in community social activities [modified from “pursues involvement in the life of the facility”], and (f) acceptance of invitations into group activities. Patient ratings obtained a Cronbach’s alpha of .77 and family contact ratings obtained an alpha of .79.

Emotional support and connectedness. Emotional support and connectedness were rated using Krause’s (2004) emotional support and anticipated support scales. This measure is one of the few that has not directly been applied to individuals with dementia; however, both scales obtained satisfactory internal consistency as indicated by a Cronbach’s alpha of .84 for the Emotional Support subscale and .75 for the Anticipated Support subscale. The two subscales

combined into a single scale ranging from 7-28 with a Cronbach's alpha of .87. Higher scores indicate higher levels of self-reported support and connectedness.

Autonomy and dependence. The Euro-QoL-5 (EQ-5D; Euro QoL, 1990) was used to assess autonomy and health-related quality of life across five domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression (see Appendix). Self-report and family contact report were completed, as has been done in previous studies, with individuals with mild to moderate dementia (i.e., Vogul, Mortensen, Hasselbalch, Andersen, & Waldemar, 2006). Scores on each domain range from 1 to 3 with higher scores indicating greater dependence in that domain. The EQ-5D has obtained satisfactory reliability and validity data in individuals with dementia (Coucill, Bryan, Bentham, Buckley, & Laight, 2001) and obtained a Cronbach's alpha of .73 in the current sample of individuals with dementia and a .67 in their family contacts.

Decisional conflict scale (DCS; O'Connor, 1993). Participants' perceptions of uncertainty in choosing options and factors contributing to uncertainty such as lack of information, lack of clarity regarding personal values, and lack of support in decision making was assessed using the DCS. A three category response set (i.e., *yes, no, undecided*) has been recommended for those with low literacy levels and offers a simpler response set for cognitively impaired individuals. Test-retest reliability has been documented at 0.81 and internal consistency has ranged from 0.78 to 0.92 (O'Connor, 1995). The 10-item scale obtained a Cronbach's alpha of .86 in the current sample.

Family contact stress or strain. The brief (12-item) version of the Caregiver Burden Interview (Zarit, Orr, & Zarit, 1985; Bedard et al., 2001) measured relationship stress that could impact the family contact's report of variables related to the individual with dementia (e.g., their quality of life, social engagement, etc.). Caregiver (CG) burden was also added as an

exploratory aim, to determine what effect, if any, the patient-centered intervention has on this commonly used outcome measure. Family contacts were asked to rate items such as “Do you feel that because of the time you spend with (IWD) that you don’t have enough time for yourself?” and “Do you feel angry when you are around (IWD)?” on a five point scale from 0 (Never) through 4 (Nearly always), yielding a possible range of 0 to 48. Higher values indicated greater levels of CG burden. Factor analyses have supported a two-factor structure (“personal strain” and “role strain”); however a total scale score was used for these exploratory analyses. A Cronbach’s alpha of .84 was achieved in the current sample at baseline.

Project Evaluation

Treatment fidelity and implementation. Careful tracking of treatment implementation was documented on a Treatment Fidelity Checklist to aid in the evaluation of feasibility. Kolanowski, Buettner, and Moeller (2006) noted challenges in the assessment of treatment fidelity in interventions targeting individuals with dementia. Specifically, they argue that treatment delivery (i.e., training interventionists and monitoring delivery of the intervention) and enactment are the most important components of treatment implementation when working with cognitively-impaired individuals in which measures of knowledge (i.e., receipt) may be less meaningful. In line with these recommendations, Treatment implementation strategies were conceptualized along three categories: *delivery*, *receipt*, and *enactment* with varying degrees of emphasis in the current study.

Treatment delivery. Researchers were trained through independent reading, didactic instruction, and role-play to ensure accurate delivery of treatment. Specific attention was paid to select interventionists with previous experience working with cognitively impaired populations as well as racially diverse groups. Participant Notebooks, which served as intervention manuals,

could be taken into the home and were reviewed by interventionists in advance. Interventionists without previous experience on the Legacy Project completed a “mock Session 1” as part of their training. Treatment delivery was monitored using a delivery checklist (see Appendix) immediately following sessions to ensure that all treatment components were delivered/addressed during each session (i.e., review of advance care planning and end of life treatment options, choice of one Legacy activity, etc.). Furthermore the PI (Hilgeman) and her research mentor, Dr. Rebecca Allen, were available for ongoing consultation and support of interventionists throughout their work with families in the study. Research assistants who completed Supportive Control Calls were provided with a script and documented each call’s duration and content on a Contact Log developed for this purpose.

Treatment receipt. The degree to which intervention individuals received intervention components was assessed by documenting the length of all intervention sessions, as has been done in previous studies (Allen, Hilgeman, et al., 2008). Knowledge questionnaires and other measures of receipt were omitted based on recommendations by Kolanowski and colleagues (2006).

Treatment enactment. For intervention individuals, *treatment enactment* was assessed by rating each member of the project who attended the session (e.g., family contact, individual with dementia, interventionist) on their effort, talkativeness, or percentage of the work completed: (a) during the session and (b) since the last session. In addition, family contact presence or absence at each session was documented separately. For example, if all three members were at the session and participated equally, each individual would receive a percentage score of 33%. See Appendix for a copy of the checklist.

Project Satisfaction & Acceptability

A project evaluation instrument was developed to solicit feedback regarding participants' experiences in the PIPAC Project. The measure was adapted from a project evaluation form that was used in the Legacy Project (Allen, Hilgeman, et al., 2008) with some questions targeting all individuals who participated in the study and some designed specifically for participants in the intervention condition. Before completing the measure at the completion of post-treatment, primary participants and their family contacts were introduced to the form with the following instructions:

“Your feedback is one of the best ways we have of developing future services and projects for older adults living with memory problems and their families. We want your honest feedback about your experiences, your feelings, and your opinions about the PIPAC Project. None of your responses will affect your relationship with the PIPAC Project in any way. Do you have any questions before we begin?”

The measure was completed separately by the patient and the family contact. It consists of 22 items that assess satisfaction with the project through multiple choice and open-ended formats. Items were analyzed descriptively rather than calculating a summary score. See the full measure in the Appendix.

Focus Group

The last component of measuring project feasibility was a focus group conducted with research staff volunteers who served as the interventionists. A senior researcher, who was not otherwise involved in the project (i.e., Dr. Patricia Parmelee), facilitated the 90-minute focus group to collect feedback about the intervention design. The focus group was guided by a semi-structured interview using an exploratory approach. Sample questions used to guide the focus

group targeted areas of feasibility consistent with Aim 1 (See Appendix, for the full list of Sample Questions). A note-taker who was not a participant in the group documented the content of the focus group session, which served as the primary data for the purposes of this study. The group was also digitally audio-recorded for future transcription. All interventionists (n = 5) who were involved in the study were able to attend. Research staff volunteers were not compensated for any part of their participation in the PIPAC study.

Procedure

Intervention and control group protocols.

PIPAC Intervention Group (see Appendix for details) individuals received 4 in-home sessions over four to six weeks from trained interventionists. Since the intervention was patient-centered, the family contact was welcome but not required to attend intervention sessions. Family member involvement (i.e., attendance and engagement with the project) was documented using treatment implementation documenting procedures. *Session 1*: focused on an introduction to the intervention components and the initial portion of the self-maintaining component, which was modified from the self-identity interview designed by Cohen-Mansfield and colleagues (2006) and the Legacy intervention (Allen, Hilgeman, et al., 2008; see Figure 3). *Session 2*: continued the self-maintaining component by assisting the individual with dementia in the implementation of the Legacy activity as a means of recording identity salient roles (e.g., through video, scrapbook, or family tree). *Session 3*: followed-up on the Legacy identity self-maintenance module and introduced the advance care planning module. The advance care planning module combines the patient-centered advance care planning interview (Briggs et al., 2004) and the enhanced information intervention (Allen, Allen, et al., 2008) to begin communication about advance care planning needs. A focus on *Living Well* questions makes the

transition from self-maintaining to self-adjusting components more natural (see Appendix). The final session, *Session 4*: discussed the previous two components as well as future implementation and maintenance of the two types of coping in the early stages of the disease. Any additional information regarding completion of previous components was discussed at the last session and verbal consent was obtained to share materials with family members who were not present, as indicated.

Minimal support model control group. (see Appendix) When working with frail populations, it is critical to determine the effects of the intervention from providing attention alone. Developing a face-valid attentional control can be quite challenging. Therefore, we modeled our attentional control after the emotional support intervention presented in McMillan et al. (2006). However, our emotional support control was administered via telephone contact for most participants, as in the Legacy project (Allen, Hilgeman, et al., 2008). Some individuals with dementia in the current study either did not have access to a phone or were uncomfortable using the phone, for these individuals ($n = 3$) face-to-face non-specific support was provided. All phone contact was with the person with dementia; family contacts did not receive supportive calls. Two phone contacts were scheduled to last at least 10 minutes but no more than 30. In the Legacy project, phone contact with the dyad lasted on average 16 minutes for the first phone call, the second averaged 13 minutes, and the third averaged 14 minutes in length. The current study was similar with the first control call lasting $M = 17.5$ ($SD = 11.2$) minutes and the second call lasting $M = 14.63$ ($SD = 6.78$).

Research staff engaged in supportive conversations with participants, using empathic listening and reflection. No information was provided regarding self-maintenance through life-review activities or education about advance care planning. At the end of the post-treatment

assessment, interested control group dyads were scheduled for an optional in-home PIPAC workshop to receive the participant notebook and an abbreviated life-review component or the advance care planning component depending on their interest.

Procedural Protocols

Adverse events protocol. In order to ensure participant safety and welfare in all aspects of the project, the following adverse events protocol was developed. Although no adverse events were anticipated as a result of the PIPAC intervention, it is acknowledged that some unforeseen circumstances that may adversely affect participants could occur. In the case of an adverse event, the PI (MH) and her direct supervisor (a licensed clinical psychologist, RSA) were to be immediately contacted by research staff. For example, one of the intervention group individuals with dementia (91 years old) was admitted to the hospital and ultimately died of pneumonia after the first intervention session. His death was discussed in the team meeting and a plan of action was developed (i.e., sympathy visit to the family contact who was also in the nursing home, etc.).

All interventionists were trained and closely supervised by a licensed clinical psychologist, and all adverse events during the course of the project were discussed in project team meetings. Team problem-solving resulted in a specific adverse event protocol for each situation. None of the participants in the study expressed thoughts of suicide, concerning levels of depression, or persistent negative reactions to the intervention. If such adverse events had occurred, the intervention would have been discontinued and the dyad would have been contacted by the PI for clinical assessment and, potentially, referral for clinical services. Over the past ten years of research in our lab, an average of one to two individuals per project have expressed clinically significant concerns and have been referred to services outside of the project.

Adverse effects were documented on contact sheets provided to each member of the research team for use with every home visit. One file was established in which all information regarding adverse events was collected so that the PI could monitor all hazards in the project to detect any patterns that may exist. The contact sheets and files for adverse events were stored in a secure location with the data. No significant adverse events or patterns of negative reactions developed as a result of the study.

Data Management and Analysis

Data entry. Data was entered using TELEform software (Cardiff, 1999) available at the Center for Mental Health and Aging (CMHA). The principle investigator (MH) reviewed all data for accuracy. Descriptive analyses of all assessment data was conducted in order to examine distributional properties and to ensure that assumptions of statistical tests were not grossly violated in this small sample. Cronbach's alpha statistics were also calculated from baseline data to ensure good internal consistency before use in statistical tests. This was particularly important for measures that had not been validated in populations with mild cognitive impairment and early dementia.

Treatment of missing values. Missing values are unavoidable in applied clinical intervention research. Where possible, variables to index the number and reasons for missing values were documented. Based on the distribution of missing values some participants were eliminated from analyses ("list-wise deletion"). Mean-imputation was used on scales where no more than 25% of data was missing, as has been done in other clinical outcomes research (Belle, et al., 2006). No evidence emerged that missing values were related to treatment group or outcome measures, therefore it was not necessary to control for missing values statistically (Cohen & Cohen, 1983). One participant's data is missing entirely from the study (i.e., the

family contact for the last family that was enrolled) due to some miscommunication among project staff; however, attempts to obtain his data, which he wanted to send through the mail continue to be made. His mother, the individual with dementia is included in all analyses (see Figure 4, which reflects his omitted data). Intervention individuals who completed at least one intervention session (i.e., 2 visits) were included in final analyses. True intention to treat methodologies were determined to be too conservative for this small feasibility study, so the dyad that dropped out after the individual with dementia died is not included in the final analyses.

Chapter 3. Results

Aim 1: Evaluating Feasibility of the PIPAC Intervention

Project satisfaction data. One of the primary areas of feasibility evaluated in this study was the extent to which individuals were satisfied with the project and felt that it was acceptable. The project satisfaction measure was added after 3 dyads had completed the study. The remaining 15 dyads are represented in the following descriptive statistics, including the dyad that chose to discontinue their participation.

When asked about their *overall experience* in the project, 92.9% of individuals with dementia felt like the study was clearly explained, 100% felt that they had been treated with respect during the study and that the research staff were friendly and professional. Among their family contacts, similar satisfaction was indicated such that 100% reported that: (a) the study was clearly explained, (b) they felt treated with respect, and (c) staff were friendly and professional. Among individuals with dementia in the intervention group, 50% reported benefiting *some* from the study while an additional 42.9% reported benefiting *a great deal*. Similarly among intervention group family contacts, 44.4% reported benefiting *some* and an additional 44.4% reported benefiting *a great deal* from the overall study despite the patient-centered focus of the intervention. Overall, 87.5% of individuals with dementia would recommend the project to others in a similar position. The only individual that reported that he would not recommend the project, indicated “I don’t like to recommend projects to other people. I don’t like to get into other people’s lives.” In addition to general feedback about the study, satisfaction with the specific intervention components or activities was also assessed using the project evaluation measure.

A final indicator of satisfaction or demand was demonstrated by the elective participation in an extra home-visit for individuals in the control group. Specifically, 6 of 8 dyads (75%) requested

that the research staff return to their homes to deliver the intervention package in an abbreviated format after the post-treatment assessment. The interventionist who delivered the “PIPAC Highlights Session” or booster-type session, would encourage the dyad to choose either the life review component or the advance care planning component as a focus for the roughly 90 minute session. One of the dyads was more interested in the advance care planning module, while the remaining five wanted to focus on life review. Control families received their own copy of the Participant Notebook to use independently; some elements were omitted (i.e., mention of compensation for purchasing materials, etc.) to tailor it for family use.

Self-maintenance: Remembering the past. When individuals with dementia were asked about the life review component of the project, 62.5% reported *a positive experience- I enjoyed it*, 25% reported finding it *interesting or important, but not really enjoyable*, and 12.5% reported *a neutral experience*. None of the individuals with dementia reported a negative experience with life review. Among intervention family contacts who attended the sessions and completed the project evaluation ($n = 4$), one individual (25%) reported that their loved ones’ life review was a *positive experience*, two (50%) reported a *neutral experience*, and one (25%) reported a *negative experience*. One family contact who did not answer the multiple choice questions and therefore is not included in the aggregate data reported above, wrote down the side of the survey, “My mother enjoyed talking and writing about her life and I think she will continue this when the project is over.” Seven of the intervention group individuals with dementia (87.5%) reported that they would continue working on the project after the research staff were no longer involved, and the same number reported being either *satisfied* or *very satisfied* with the progress they had made on their Legacy project. Finally, 87.5% of individuals with dementia indicated that they felt that the Legacy component had helped them communicate with their loved one (the remaining 12.5% were *unsure*).

Self-adjusting: Focusing on the future. Regarding the advance care planning component of the intervention, individuals with dementia were evenly split (33%) between rating the experience as: (a) *a positive experience- I enjoyed it*, (b) *interesting or important, but not enjoyable*, and (c) *a neutral experience- neither negative or positive*. None of the individuals with dementia reported a negative experience with the advance care planning component. For family contacts, the advance care planning component was rated similarly as the life review component such that one individual (25%) reported that the advance care planning component was a *positive experience*, two (50%) reported a *neutral experience*, and one (25%) reported a *negative experience*. Among individuals with dementia, 100% reported that the advance care planning component had helped them communicate their wishes with loved ones. Regarding satisfaction with the advance care planning component, 50% of individuals with dementia reported that they were *neither satisfied nor dissatisfied*, 37.5% reported feeling *satisfied*, and 12.5% reported feeling *very satisfied*. In addition, 37.5% reported that they were considering changes to their future plans after completion of the advance care planning component.

In addition to the multiple choice questions, open-ended questions gave participants a chance to expand on their answers. Table 4 displays quotes taken from the open-ended responses.

Table 4. Selected quotes from the Project Evaluation completed at post-treatment assessment.

Q: What do you think was the most useful part of this project?	
Intervention IWD:	<i>"The whole design was wonderful, being able to discuss these things and share things with my family."</i>
Intervention IWD:	<i>"Just recording history."</i>
Control IWD:	<i>"It was useful. You said things that helped me think twice and all that."</i>
Control IWD:	<i>"Awareness."</i>
Intervention FC:	<i>"Having mother involved in doing something on a regular schedule and making an actual book that she can hold or see as something she did"</i>
Intervention FC:	<i>"For us the advance directive and legal aspect. We have been needing to do this and was spurred on to get it done."</i>
Intervention FC:	<i>"My husband's legacy scrapbook was very mind-stimulating and enjoyable."</i>
Q: What was the least useful part of this project?	
Intervention IWD:	<i>"It takes a lot of time, but I hope it will be positive for me in the long run."</i>
Intervention FC:	<i>"Medical decisions- But that is because she already had that in place so we didn't have to do anything- Everyone should have such plans."</i>
Intervention FC:	<i>"Life legacy. When someone has had 3 families, children who have died, and become a widower, remembering can bring on adverse feelings sometimes."</i>
Control FC:	<i>"I think he enjoyed the visits in the home, but the phone calls weren't as stimulating."</i>
Q: Would you recommend this project to others in similar situations?	
Intervention FC:	<i>"This is a very positive project in my opinion. It brings someone from the project to your home to talk with. It forces you to think very seriously about your situation and lets you know to get your affairs in order and do it now."</i>
Q: What was your reaction to answering questions like the ones completed today? (post-treatment assmt.)	
Control FC:	<i>"Makes you think of many areas of health and caregiving- and to always be positive with partners."</i>
Control IWD:	<i>"It made me understand aging better."</i>
Intervention IWD:	<i>"It gives more of an overview of your present situation and helps you relate a little more some of the things you should consider and accomplish presently."</i>
Q: What would you change about this project to make it better?	
Intervention FC:	<i>"Consider a group sharing activity if several residents were involved in the project."</i>
Control FC:	<i>"I'm looking for answers and how to respond to everyday life- I'm feeling my way in coping with this disease."</i>

Note. IWD = Individual with dementia; FC = Family Contact

Treatment Implementation

Treatment implementation was recorded across three domains using the Treatment Fidelity Checklist (see Appendix). As shown in Table 5, one element of the dyads engagement or enactment with the intervention was measured by family contact attendance at each session.

Family contacts were represented at 56.8% of the intervention sessions across the duration of the project with highest attendance at the first session (i.e., 72.7%) and lowest attendance at the fourth session (45.5%).

Table 5. Treatment implementation data for intervention families.

	Intervention Sessions				Across Sessions 1-4
	Session 1	Session 2	Session 3	Session 4	
<u>Treatment Enactment</u>					
FC Attended; <i>n</i> (%)	8 (72.7)	6 (54.5)	6 (54.5)	5 (45.5)	6.25 (56.8)
% Effort <i>M</i> (<i>SD</i>)*					
IWD Effort During	35.9 (16.1)	43.7 (14.0)	43.2 (15.9)	47.2 (19.7)	43.8 (13.2)
FC Effort During	17.7 (16.2)	17.6 (14.7)	24.8 (19.1)	19.4 (20.6)	20.4 (15.3)
Interv. Effort During	46.4 (19.5)	38.7 (16.0)	39.8 (15.9)	33.3 (14.4)	37.6 (12.2)
IWD Effort Between	N/A	36.3 (26.2)	41.4 (33.8)	52.2 (31.8)	47.2 (25.7)
FC Effort Between	N/A	56.9 (24.3)	28.1 (17.1)	27.8 (30.1)	22.5 (31.5)
Interv. Effort Between	N/A	17.2 (32.9)	30.3 (40.0)	20.0 (34.2)	39.9 (16.7)
<u>Treatment Delivery</u>					
% Adherence <i>M</i> (<i>SD</i>)	85.9 (14.1)	88.9 (12.5)	92.6 (6.3)	97.0 (3.5)	92.2 (5.0)
Completed in 1 visit; <i>n</i> (%)	10 (90.1)	11 (100)	11 (100)	11 (100)	10.8 (97.5)
<u>Treatment Receipt</u>					
Min. Time in Min	35	45	30	30	35
Max. Time in Min	120	120	120	115	102.5
Mean Time in min. <i>M</i> (<i>SD</i>)	73.5 (23.5)	86.7 (20.9)	83.3 (28.3)	71.7 (26.0)	74.3 (22.0)

Note. FC = Family Contact; IWD = Individual with dementia; * indicates the percentage of “work” done in the session by those who were there; values for effort during the session and values indicating effort between the sessions should add up to 100%.

A second indicator of treatment enactment was the percentage of the work, talking, or overall contribution made by each individual at the session as indicated by a percentage adding up to 100%. Looking across sessions, individuals with dementia contributed significantly during sessions accounting for 35.9 to 47.2 percent of the effort in the sessions. Notably, individuals with dementia accounted for the majority of the contribution or engagement in all sessions except the first one, which was lead more by the interventionist as may be expected. In comparison, family contacts accounted for approximately 20.4% of the discussion or work in the sessions.

A third indicator of enactment was contribution between sessions (i.e., “homework”). Unsurprisingly, family contacts were more active after the first session when materials for the Legacy project are gathered, accounting for 56.9% of effort between the first and second sessions and 39.9% of work between all of the sessions. Of note, individuals with dementia were very engaged with the project even between sessions completing between 36.3 and 52.2% of the work done outside of formal visits (e.g., working on the Legacy, initiating conversations about future plans, etc.). One indicator of practicality and implementation was the amount of effort and preparation required by interventionists between sessions. Although interventionist burden is addressed more fully with the focus group data, the Treatment Fidelity Checklist reflected that on average interventionists were only completing about 22.5% of the work between sessions.

Treatment delivery was indicated by complete, partial, or absent discussion of intervention components during the session. Accurate delivery of the intervention ranged from 85.9% to 97% delivery adherence of intervention elements. Across session treatment delivery achieved an adherence rating of 92.2%, which is comparable to the 91.6% treatment delivery score of the original Legacy Project. The two most common elements that were not completely addressed were discussing “pros and cons” of Legacy project options during the first session and “assigning homework to discuss advance care planning with family” during the third session. With the exception of one session that was discontinued prematurely due to unexpected visitors, all intervention sessions were completed in a single visit (i.e., material could be covered in the allotted time).

Treatment receipt was measured by tracking length of intervention sessions as has been done in previous studies (e.g., Allen, Hilgeman, et al., 2008). Sessions ranged from 30 to 120 minutes, with an average of 74.3 across sessions. The second session, which is used to work on

the Legacy project was the longest session at just under an hour and a half. However, it was not unusual for sessions to last up to two hours.

Focus Group with Interventionists

Five interventionists worked with the 11 families who were randomized to the intervention condition. All interventionists were able to attend the focus group, which was held at a mutually convenient location on The University of Alabama's campus. Two of the interventionists worked with only one family, while the remaining three interventionists worked with between 2 and 4 families. One of the interventionists was a licensed clinical psychologist, three were doctoral students in clinical psychology and one was a doctoral student in social work. Three of the focus group participants also served as interventionists on the original Legacy Project (Allen, Hilgeman, et al., 2008) and all had previous experience working with individuals with dementia.

Experience as an interventionist. The focus group opened by inviting general feedback about the experience of serving as an interventionist on the PIPAC project. Most of the interventionists reported that they enjoyed working on the project and found it to be "rewarding." In addition, they reported that the intervention was "fun" and "easy to learn." Interventionists also commented that the cognitive status of the individual impacted the "nature" or course of the intervention, such that more impaired individuals had more difficulty with complex and open-ended tasks. Furthermore, some individuals in the project had already completed advance care planning documents, which one interventionist felt impacted the advance care planning discussion significantly.

The facilitator then asked about the most challenging and rewarding aspects of the project. Two interventionists reported difficulty scheduling as the primary challenge, noting

complications in their own schedules as well as the need to reschedule around “good days and bad days” (i.e., fluctuations in participant’s cognitive status or general functioning). One interventionist, who worked with the family that discontinued, reported difficulty with “buy in” and the challenge of assessing interest to engage in the study over time with an individual who is having difficulty with organization and memory. Two different interventionists noted the challenge of “continuity” when the individual with dementia would not remember the project from one week to the next, a challenge that was complicated when family contacts were not involved. The last challenge that was discussed resulted from a negative reaction by one participant to the advance care planning component. Specifically, one interventionist found it difficult to switch to the advance care planning component after the Legacy task because the individual with dementia focused on his losses and referred to himself as a “monkey.” This required the interventionist to change focus to the Legacy component to “get him back on track.”

Despite these challenges, interventionists also described rewarding aspects of the study, which centered around enjoyment felt during completion of the life review component. The interventionists focused on sharing in the life review process and feeling good as a result of promoting reminiscence in the individuals or dyad. For example, interventionists described individuals with dementia “lighting up” while talking about work as a young adult, enjoyment felt while “watching the love that they [the couple] shared” and feeling good about appreciation expressed by participants and their families.

Feasibility of the intervention. The focus group participants were also asked about how well different aspects of the project worked and what could be improved. Generally, the interventionists felt that the study had been successful. All reported feeling well trained to provide the intervention (e.g., “It was easy to pick up, the packet lays it out”). Furthermore, they

found the Participant Notebook easy to use (i.e., “it has good flow;” and “it’s laid out well”). Regarding the intervention design, all of the interventionists agreed that four sessions “felt right;” however, one interventionist indicated that if it were to change he believed that it could benefit from another session “depending on the family.” Interventionists also reported that the burden between sessions was “small and doable;” they elaborated that it may vary some by family, but none of the interventionists spent significant time outside of sessions working on the projects. Focus group participants also reported that they did not encounter any problems conducting the intervention in the homes of the participants.

Much discussion was focused on the advance care planning component of the PIPAC package as this was not included in the original Legacy Project (Allen, Hilgeman, et al. 2008). Interventionists described significant variability among participants’ reactions to the advance care planning session. Some interventionists felt that it was important to know whether the family had advance care planning documents in place and felt a need to “pitch it differently” for these families. In line with this recommendation, one interventionist suggested a decision-tree or flow-chart to know “whether to push it or not.” Several of the focus group participants discussed the placement of the advance care planning session in the four-session sequence. Specifically, one interventionist reported that it felt separate from the Legacy component, while another emphasized that it “needs to tie in more to living well in the future.” All of the interventionists agreed that the advance care planning session was a “useful” component and for a couple of families a primary interest. However, all agreed that the sequence of sessions deserved reconsideration as the advance care planning component “may fit better elsewhere” (e.g., first or last). One interventionist suggested more of a focus on a discussion about “values” rather than decision-making, an idea that was popular among the focus group participants.

When asked about the adaptation of the Legacy component for individuals with dementia, interventionists unanimously believed that it had translated to the new population “really well.” They also emphasized the importance of flexibility and redirection when working with families. Finally, focus group participants were asked about any advice or other comments about their experiences as an interventionist. On a practical note, many of the interventionists agreed that calling before the appointment was an essential element of their success. In fact, one interventionist suggested that calling the participant on the day of the intervention should be incorporated into the study protocol. Another noted that “patience is a virtue” when working with individuals with dementia and it was mentioned that it may be more difficult for interventionists who have not been trained as clinicians. Family dynamics between the individual with dementia and their family member (i.e., resentment, guilt, etc.) can also affect the success of a session, one interventionist noted. As the focus group ended, one interventionist reported that he felt a sense of “generativity” serving as an interventionist and another noted that working on the project had been “loads of fun.” All focus group participants would recommend being an interventionist to others; collectively the group felt that it increased their ties to the community, was helpful personally, individuals felt “moved by the human connection,” and one interventionist reported that it “doesn’t feel like an intervention, its fun.”

Aim 2: Estimates of Treatment Effects

The second aim of the current study was to conduct limited-efficacy testing of the PIPAC intervention on emotional and health-related outcomes in order to determine appropriate targets of the PIPAC intervention in the future. A series of one-way between subjects analyses of covariance (ANCOVAs) were used to examine the main effect of “group” on post-treatment variables of interest while controlling for values at baseline. ANCOVA was chosen for these

analyses because it offers increased sensitivity over simple one-way ANOVAs by accounting for more of the error variance in the dependent variables (i.e., values at post-treatment). ANCOVA is also useful in small n designs like the current study when randomization is either not possible or fails to successfully equate groups at pre-treatment (see Table 6 depicting raw means). As a result, ANCOVA was used to statistically correct for differences between groups at pre-treatment so that the estimated marginal means could be used to calculate effect sizes as depicted in Table 7.

Partial eta squared statistics of effect (Cohen, 1973) were used as the primary indicator of likely treatment effects in this small sample. Partial eta squared statistics were chosen for two primary reasons: (a) because they are more commonly used with ANCOVA than other types of effect sizes (e.g., Cohen, 1973; Kennedy, 1970), and, (b) to facilitate comparability to the original Legacy study (Allen, Hilgeman, et al., 2008) in line with the goal of assessing elements of feasibility such as adaptation. A large effect is indicated by a partial eta squared (η_p^2) greater than or equal to 0.14, a medium effect is determined by a value greater than or equal to 0.06, and small effects are determined by values greater than or equal to 0.01. For the purposes of the current study, effect sizes greater than or equal to .06 (a medium effect) will be interpreted as potentially clinically meaningful in the discussion of results below. Medium to large effects are more likely to be replicated in a later study and are more likely to remain following a more robust comparison group than the one used in the current study. Cohen's d statistics were also calculated for the purposes of the current feasibility study because they are one of the most common methods of estimating effect sizes and are more easily interpreted than the partial eta squared effects. In order to calculate Cohen's d statistics, standard error terms were converted into standard deviations and used with the estimated marginal means from the post-treatment

ANCOVAs. Both types of effect sizes are presented in Table 7 since estimating the magnitude of treatment effects is one of the primary goals of the current study. Furthermore, in an examination of commonly used effect sizes, Levine and Hullett (2002) recommend that partial eta squared effects be reported alongside of another estimate of effect when possible (Levine & Hullett, 2002). When the partial eta squared and Cohen's *d* statistics are estimated at different magnitudes, the partial eta squared statistics will be interpreted as the primary indicator of effect as they are a slightly better match for estimated effects in ANCOVA.

Self-reported emotional outcomes. In line with our hypotheses, intervention individuals with dementia reported less depressive symptomatology at post-treatment assessment than individuals in the control group, $F(1,15) = 5.51, p = 0.03, \eta_p^2 = 0.27$ (see Table 7). They also reported increased quality of life on the BASQID at post-treatment assessment, $F(1,15) = 1.13, p = 0.31, \eta_p^2 = 0.07$. Contrary to our expectations, other indicators of self-reported emotional outcomes did not appear to be affected by the PIPAC intervention. Specifically, anxiety, meaning, social engagement, emotional and anticipated support, and quality of life as measured by the QOL-AD did not demonstrate meaningful differences at post-treatment assessment. Descriptive means at baseline and post-treatment assessment by group are displayed in Table 6, while results of the ANCOVAs examining differences between groups at post-treatment assessment are displayed in Table 7.

Table 6. Raw means for patients and family contacts that completed PIPAC.

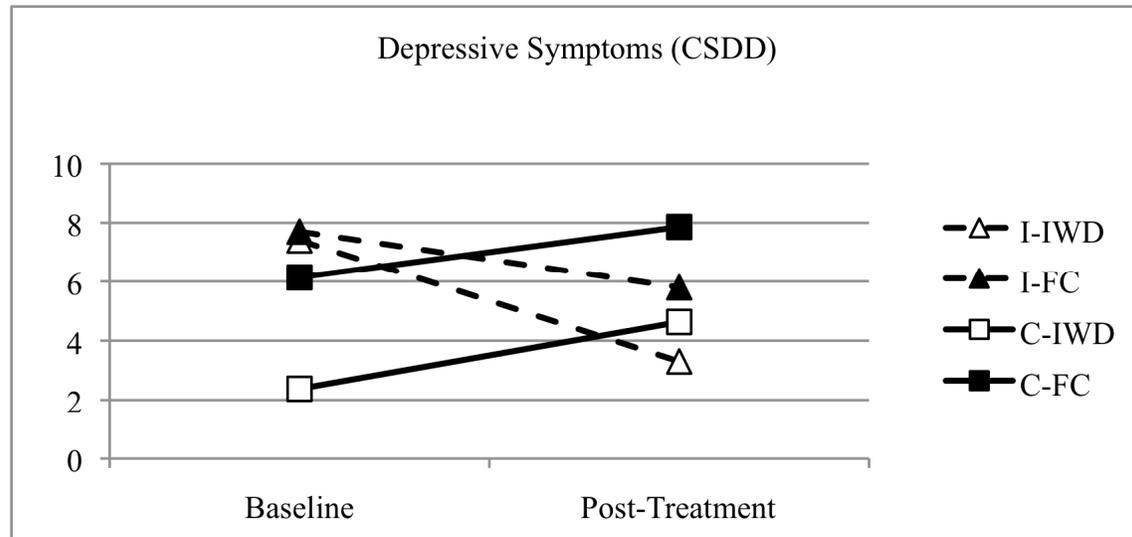
Participant Characteristics	Experimental Condition			
	Intervention Group (n = 10 dyads)		Control Group (n = 8 dyads)	
	Baseline	Post	Baseline	Post
<u>Individual with Dementia</u>				
CSDD- Depression	7.40 (6.67)	3.30 (2.98)	2.38 (1.85)	4.63 (4.03)
CSDD- Anxiety	0.60 (0.70)	0.20 (0.42)	0.38 (0.52)	0.25 (0.46)
Meaning	47.30 (6.62)	46.30 (7.76)	46.87 (8.37)	44.23 (9.61)
Social Engagement	4.50 (1.90)	4.90 (1.97)	5.00 (0.92)	5.13 (0.83)
BASQID	50.60 (11.33)	53.40 (11.04)	59.75 (12.34)	55.75 (14.48)
QOL-AD	36.30 (5.87)	38.09 (4.85)	40.88 (5.00)	39.43 (3.96)
Emotional & Ant. Support	21.10 (4.63)	21.80 (4.02)	23.63 (3.58)	24.29 (3.73)
Health-Related QOL (EQ-5D)	-	-	-	-
Mobility	1.60 (0.70)	1.40 (0.52)	1.25 (0.46)	1.50 (0.53)
Self-Care	1.30 (0.68)	1.20 (0.42)	1.38 (0.52)	1.25 (0.46)
Usual Activities	1.30 (0.48)	1.30 (0.48)	1.25 (0.46)	1.13 (0.35)
Pain/Discomfort	1.80 (0.79)	1.70 (0.68)	1.50 (0.54)	1.38 (0.52)
Anxiety/Depression	1.60 (0.52)	1.50 (0.53)	1.25 (0.46)	1.25 (0.46)
EQVAS	77.00 (15.67)	77.50 (14.19)	73.12 (11.00)	75.00 (21.21)
Decisional Conflict (DCS)	29.44 (26.98)	13.50 (13.75)	22.50 (19.09)	17.50 (21.04)
Uncertainty	41.67 (33.07)	20.00 (22.97)	37.50 (42.26)	15.63 (22.90)
Informed	25.93 (25.15)	15.00 (19.95)	20.83 (23.14)	29.17 (31.81)
Values & Clarity	22.22 (34.11)	17.50 (26.48)	28.13 (41.05)	12.50 (35.36)
Support	29.63 (30.93)	5.00 (8.05)	10.42 (15.27)	10.42 (15.27)
IMML Coping	25.80 (6.62)	26.60 (4.86)	46.88 (8.37)	22.88 (4.55)
MARS Awareness	35.10 (6.03)	34.80 (7.47)	31.50 (7.86)	34.50 (7.37)
<u>Family Contact</u>				
CSDD- Depression	7.70 (4.40)	5.80 (4.54)	6.14 (5.08)	7.86 (4.56)
CSDD- Anxiety	1.00 (0.47)	0.90 (0.74)	1.00 (0.82)	1.00 (0.82)
Social Engagement	4.20 (1.99)	4.28 (1.49)	3.14 (1.95)	3.57 (1.90)
QOL-AD	15.10 (3.80)	18.20 (3.04)	16.95 (4.69)	15.63 (5.07)
Health-Related QOL (EQ-5D)	-	-	-	-
Mobility	1.89 (0.60)	1.60 (0.52)	1.71 (0.49)	1.60 (0.89)
Self-Care	1.89 (0.60)	1.60 (0.70)	1.71 (0.49)	1.80 (1.10)
Usual Activities	2.00 (0.54)	1.70 (0.68)	2.43 (0.54)	2.20 (0.84)
Pain/Discomfort	2.00 (0.71)	2.00 (0.67)	1.86 (0.69)	1.80 (0.84)
Anxiety/Depression	1.78 (0.44)	1.70 (0.48)	1.71 (0.49)	2.00 (0.71)
EQVAS	55.00 (19.20)	58.50 (17.80)	60.67 (20.11)	62.86 (17.99)
MARS Awareness	20.89 (9.58)	22.47 (9.89)	22.00 (13.52)	14.50 (8.33)
MARS Discrepancy Score	15.11 (6.66)	12.33 (11.33)	8.71 (17.80)	19.79 (11.01)
CG Stress	18.78 (7.43)	18.78 (7.12)	15.71 (7.39)	13.29 (7.36)

Note. CSDD = Cornell Scale for Depression in Dementia; BASQID = Bath Assessment of Subjective Quality of Life in Dementia; QOL-AD = Quality of Life in Alzheimer's disease; EQ-5D = EuroQoL- 5; IMML = Index for Managing Memory Loss; MARS = Memory Awareness Rating Scale; EQVAS = EuroQoL Visual Analog Scale of Subjective Health; CG = Caregiver

Self-reported health-related outcomes. We also hypothesized that intervention individuals with dementia would report greater health-related quality of life at post-treatment assessment as measured by the Euro-QoL and less decisional conflict than control individuals after completion of the PIPAC intervention. Self-rated dependence in mobility at post-treatment assessment was less for intervention group individuals with dementia than for those in the control group, $F(1,15) = 2.72, p = 0.12, \eta_p^2 = 0.15$. However, other indicators of autonomy/health-related quality of life (i.e., self-care, usual activities, pain & discomfort, anxiety & depression, and a visual analog scale of self-rated health) were not different between groups at post-treatment (see Table 7). A main effect of group was indicated for decisional conflict, $F(1,14) = 3.74, p = 0.07, \eta_p^2 = 0.21$, such that intervention group individuals reported less overall conflict or discomfort with advance care planning at post-treatment than individuals in the control condition. Medium partial eta squared effects were also observed for two of the subscales. Intervention group individuals reported feeling less unsupported in their decisions ($F(1,14) = 0.95, p = 0.35, \eta_p^2 = 0.06$) as well as less distressed about lack of information regarding decision making ($F(1,14) = 1.50, p = 0.24, \eta_p^2 = 0.10$). The uncertainty subscale and the values clarity subscale were not markedly different between groups at post-treatment.

Family contact reported emotional outcomes. Family contact ratings of individuals with dementia revealed differences by group at post intervention for depressive symptomatology, such that intervention individuals were rated as less depressed than control individuals, $F(1,14) = 1.72, p = 0.21, \eta_p^2 = 0.11$. They were also rated as having higher quality of life at post-treatment on the QOL-AD, $F(1,14) = 5.41, p = .04, \eta_p^2 = 0.28$ (see Table 7). Differences by group were not reported on a measure of social engagement or items assessing anxiety.

Figure 5. Raw scores of depressive symptomatology at baseline and post-treatment assessment by group.



Note. I = Intervention, C = Control; IWD = Individual with dementia, FC = Family Contact; CSDD = Cornell Scale for Depression in Dementia.

Family contact reported health-related outcomes. Family contact ratings of health-related indicators of well-being revealed differences between groups on the Euro-QoL-5 domains of: self-care ($F(1,11) = 1.44, p = 0.26, \eta_p^2 = 0.12$), usual activities ($F(1,10) = 2.52, p = 0.16, \eta_p^2 = 0.18$), and anxiety/depression ($F(1,11) = 2.03, p = 0.18, \eta_p^2 = 0.16$). Mobility, pain and discomfort, and the family contact rating of the individual with dementia's health status on a visual analog scale were not notably different between groups at post-treatment assessment.

Secondary Aim: Exploring Treatment Effects on Coping, Awareness, and Caregiver Stress

An exploratory aim was to examine the impact of PIPAC on coping strategies and awareness in the early stages of dementia, which may serve as moderators of intervention effects or targets of future interventions (see SPM-ED, Figure 1). We were also interested in determining whether the patient-centered PIPAC intervention, which makes family contact participation optional, could have an effect on caregiver stress. As predicted, intervention

individuals reported more coping strategies at post-treatment assessment than control group individuals, $F(1,16) = 3.35, p = 0.09, \eta_p^2 = 0.17$. No hypotheses were offered about the impact of the intervention on awareness; however, both individuals' ratings of their memory abilities [$F(1,15) = .91, p = 0.36, \eta_p^2 = 0.06$] and family contact ratings of memory abilities [$F(1,13) = 2.41, p = 0.15, \eta_p^2 = 0.16$] showed an effect of treatment, such that intervention individuals and their family contacts rated memory functioning as better at post-treatment assessment than those in the control group. Furthermore, discrepancy scores between the individual with dementia and their family contact were decreased for individuals in the intervention group at post-treatment assessment [$F(1,13) = 2.25, p = 0.16, \eta_p^2 = 0.15$] compared to those in the control group. In other words, intervention dyads were more in synch in their ratings of memory abilities at post-treatment assessment than control group dyads. Finally, there was an also an effect of treatment group on family contact ratings of stress at post-treatment assessment [$F(1,13) = 1.64, p = 0.223, \eta_p^2 = 0.11$], such that family contacts in the intervention group reported higher levels of stress than those in the control group (see Tables 6 and 7).

Table 7. Estimated treatment effects at post-treatment assessment.

	Experimental Condition		ANCOVA			
	Interv. (<i>n</i> = 9) <i>EMM</i> (<i>Std. Error</i>)	Control (<i>n</i> = 8) <i>EMM</i> (<i>Std. Error</i>)	<i>F</i>	<i>P</i>	η_p^2	Cohen's <i>d</i>
<u>Individual with Dementia</u>						
CSDD- Depression	2.23 (0.93)	5.82 (1.05)	5.50	0.03	0.27**	1.25**
CSDD- Anxiety	0.17 (0.13)	0.29 (0.14)	0.40	0.54	0.03	0.31
Meaning	47.05 (2.49)	45.60 (2.80)	0.15	0.71	0.01	0.19
Social Engagement	5.01 (0.45)	4.98 (0.50)	0.00	0.97	0.00	0.02
BASQID	56.60 (2.92)	51.75 (3.30)	1.13	0.31	0.07*	0.54*
QOL-AD	39.33 (1.01)	37.87 (1.14)	0.85	0.31	0.05	0.47
Emotional & Ant. Support	22.14 (1.28)	23.81 (1.56)	0.63	0.44	0.04	- 0.40
Health-Related QOL (EQ-5D)	-	-	-	-	-	-
Mobility Dependence	1.31 (0.12)	1.62 (0.14)	2.72	0.12	0.15**	0.82**
Self-Care Dependence	1.22 (0.11)	1.23 (0.13)	0.01	0.92	0.00	0.03
Usual Activities Limited	1.29 (0.12)	1.14 (0.13)	0.73	0.41	0.05	- 0.41
Pain/Discomfort	1.65 (0.18)	1.44 (0.20)	0.58	0.46	0.04	- 0.38
Anxiety/Depression	1.36 (0.08)	1.43 (0.09)	0.28	0.61	0.02	0.28
EQVAS	76.51 (5.16)	76.23 (5.79)	0.00	0.97	0.00	0.02
Decisional Conflict (DCS)	13.89 (5.40)	18.75 (5.73)	3.74	0.07	0.21**	0.30
Uncertainty	21.69 (7.15)	16.22 (7.59)	0.28	0.61	0.02	- 0.26
Informed	15.57 (8.27)	30.40 (8.78)	1.50	0.24	0.10*	0.60*
Values & Clarity	20.87 (8.56)	10.90 (9.08)	0.64	0.44	0.04	- 0.39
Support	4.87 (4.28)	11.19 (4.56)	0.95	0.35	0.06*	0.49
IMML Coping	26.81 (1.46)	22.79 (1.64)	3.35	0.09	0.17**	0.89**
MARS Awareness	33.56 (1.71)	36.01 (1.92)	0.91	0.36	0.06*	0.46
<u>Family Contact</u>						
CSDD- Depression	5.51 (1.33)	8.26 (1.60)	1.72	0.21	0.11*	0.64*
CSDD- Anxiety	0.90 (0.21)	1.00 (0.25)	0.09	0.77	0.01	0.15
Social Engagement	4.02 (0.39)	3.95 (0.47)	0.01	0.91	0.00	0.06
QOL-AD	18.67 (1.01)	14.96 (1.21)	5.41	0.04	0.28**	1.15**
Health-Related QOL (EQ-5D)	-	-	-	-	-	-
Mobility	1.59 (0.18)	1.73 (0.25)	0.19	0.67	0.02	0.22
Self-Care	1.56 (0.21)	1.99 (0.29)	1.44	0.26	0.12*	0.59*
Usual Activities	1.61 (0.25)	2.23 (0.32)	2.25	0.16	0.18**	0.75*
Pain/Discomfort	2.00 (0.20)	1.80 (0.27)	0.34	0.57	0.03	- 0.29
Anxiety/Depression	1.68 (1.31)	1.99 (0.18)	2.03	0.18	0.16**	0.11
EQVAS	58.23 (4.27)	58.48 (5.24)	0.00	0.97	0.00	- 0.02
MARS Awareness	21.09 (2.88)	14.34 (3.26)	2.41	0.15	0.16**	0.76*
MARS Discrepancy Score	13.40 (3.30)	21.04 (3.76)	2.25	0.16	0.15**	0.74*
CG Stress	17.78 (1.64)	14.56 (1.87)	1.64	0.22	0.11*	- 0.63*

Note. CSDD = Cornell Scale for Depression in Dementia; BASQID = Bath Assessment of Subjective Quality of Life in Dementia; QOL-AD = Quality of Life in Alzheimer's Disease; EQ-5D = EuroQoL- 5; IMML = Index for Managing Memory Loss; MARS = Memory Awareness Rating Scale; EQVAS = EuroQoL Visual Analog Scale of Subjective Health; CG = Caregiver; ** = indicates a large effect size; * = indicates a medium effect size.

Chapter 4. Discussion

The results of this study generally support the clinical utility and feasibility of the PIPAC intervention package. The overall purpose of this study was to examine the viability, practicality, and likelihood of clinically meaningful effects of PIPAC to determine whether a larger scale, randomized efficacy trial is warranted in the future. Conclusions about the results are organized by Aim and collapsed across collection methodologies (i.e., the focus group, treatment implementation and tracking data, and quantitative findings).

Aim 1. Conclusions about feasibility

Support for the feasibility of the study is best summarized across areas of focus as outlined in Aim 1; specifically, conclusions are drawn about the (a) acceptability, (b) implementation, (c) practicality, and (d) adaptation of the PIPAC study based on the feedback of the interventionists, family contacts, and individuals with dementia. Acceptability was assessed through satisfaction, actual use of the intervention (i.e., enactment during and between the sessions), expressed interest in the intervention material, and participants' intentions to continue using the skills/materials after the conclusion of the study. Acceptability was demonstrated across indicators with few exceptions. Specifically, nearly all individuals who participated in the study regardless of group (92.9-100%) felt that the project was well explained, that they were treated with respect and that interactions with project staff were friendly and professional. Intervention dyads overwhelmingly felt that the project had benefited them at least somewhat (FC = 88.8% and IWD = 92.9%) with most individuals believing that they had benefitted a great deal from the study. This finding speaks to the face validity of the intervention as a meaningful

and beneficial activity. Change on clinical indicators (e.g., such as depression and anxiety) is important, but a willingness to engage in the activity because it feels beneficial may increase the longevity of effects after the researchers are no longer in the home. In fact, over one third of dyads in the study planned to make changes to their advance care plans or documents after the study ended. In addition, almost 90% of individuals with dementia believed that they would continue working on their Legacy after the project ended. The desire to continue working on aspects of the life review component after the end of the study was also endorsed by 57% of intervention family contacts.

Another indicator of the acceptability of the project was the level of engagement of the individuals and their families between and during the home sessions. Despite dementia diagnoses, individuals in the study contributed significantly to the sessions and the completion of both components (see Table 5). This high level of engagement suggests that the intervention components appropriately targeted the cognitive level of individuals in the study. It is unlikely that participants with dementia would have accounted for almost 44% of the work in the sessions and 47% of the work between sessions if it was overwhelming, too challenging, or overly simplistic. Signs of disengagement such as the interventionist doing all of the work between sessions or having to schedule extra intervention sessions because of lack of progress by the family (e.g., not gathering materials for the Legacy component, etc.) were not reported by interventionists during the study. In fact, during the focus group the interventionists focused on how rewarding it was for them to engage the individuals with dementia and their families in such positive activities.

Notably, two of the individuals with dementia had somewhat negative reactions to one of the components (i.e., one became upset by the advance care planning component and one refused

to initiate the Legacy component). Both of these individuals enjoyed the intervention as a whole and reported high satisfaction with the other aspects of the intervention. Perhaps as suggested by the interventionists in the focus group, “flexibility” and “patience” when working with individuals with limited cognitive resources is essential. This view would be consistent with classic models of person-environment fit for individuals with dementia (e.g., Competence Press Model, Lawton, & Nahemow 1973; Nahemow, 2000). Specifically, as dementia progresses, individuals have fewer cognitive/internal resources to cope with stress in their environment (e.g., in this case an unpleasant or challenging activity), which increases the importance of flexibility in the environment or in any intervention activity in order to restore balance between environmental press and the individual’s ability to manage environmental demands. For these two individuals, reductions in cognitive flexibility, increased perseverative thinking, or other cognitive changes may have made it difficult to navigate a task that prompted negative feelings about the past or current functioning. For these reasons, it is unlikely that any intervention that is designed to engage individuals with dementia socially and emotionally would be universally positive for all individuals all of the time. Therefore, these negative reactions are not weighed more heavily in determining the overall acceptability of the intervention than the positive feedback received across other aspects of the project. However, they are considered further in the future directions section below.

The second area of focus for assessing feasibility (Aim 1, continued) was implementation. Implementation for the purposes of this study includes the extent that the intervention was administered successfully (i.e., treatment delivery) and the extent that the intervention can be carried out in the field the way that it was designed (Bowen et al., 2009). Treatment delivery data from the PIPAC intervention revealed that the intervention content was administered at

approximately 92% adherence across sessions as indicated by the presentation and completion of certain elements during each session. Any time the interventionist rated an element as not fully completed or “not applicable” (see the Treatment Fidelity Checklist in the Appendix), points were deducted from their delivery score. Despite challenges to administering the intervention in a strict, predefined way (e.g., as described above) interventionists were largely successful in the implementation of the intervention according to the manual and 10/11 dyads completed the intervention sessions without interruption or addition of an extra session (see Table 5). One aspect that contributed to the success of implementation was the ease with which research staff could learn the intervention package. Two of the interventionists had not been involved with previous versions of the intervention package (i.e., the Legacy Project, Allen, Hilgeman, et al., 2008), but were able to learn it and deliver it without much effort. During the focus group, one of these individuals described the intervention as “easy to learn” and added that the Participant Notebook, which serves as an in-session workbook, was “laid out well.” By having a common workbook for the dyad and interventionist to use, a few things are accomplished. The intervention elements are more likely to: (a) be remembered by the interventionist, (b) be presented in a consistent order/manner across interventionists, and (c) are available for the family to look over between sessions as desired. Each of these benefits likely increases the feasibility of implementing the intervention again in the future.

A third measure of feasibility that was a focus of the current study was practicality. Specifically, we addressed practicality by answering the question: can this intervention be done in a way that makes sense given the resources that are available? Although a formal cost analysis was not conducted for this project, the intervention was carried out with a limited budget and limited staff (i.e., only three months of full-time effort by the PI, reliance on volunteers, and on a

budget of \$4,000.00). Although the limited resources available for the current study contributed to the limited scope of the project, it also demonstrated the low level of resources necessary to deliver an intervention that was enjoyed by the participants, well received by those delivering the intervention package, and produced clinically meaningful changes in indicators of well-being (i.e., depression, quality of life, etc.). Also the fact that the intervention is only four sessions and can be completed either with or without family contacts present increased the usability of the intervention package. Some individuals with dementia never had their family member present, while others had a family member at all intervention sessions. Finally, although the target population was somewhat narrow in scope (i.e., individuals in the very early-mild stages of dementia), it was delivered across a variety of settings without complication (i.e., within an individual's room at the nursing home to private homes in the community). Each of these properties of the intervention package facilitate its practical use in the community in the future and support further testing of the PIPAC intervention.

The next area of focus in terms of feasibility was the *adaptation* of the original Legacy Project and the Patient-Centered Advance Care Planning Interview for use in individuals in the early stages of dementia (Allen, Hilgeman, et al., 2008; Briggs, 2004). The purpose of evaluating adaptation is to determine whether previously tested interventions can be successfully applied in a new population, in this case early dementia. Perhaps the best way to determine adaptation is to examine whether similar outcomes are observed across studies or populations. Although this will be discussed in greater detail below, briefly, the primary findings for the original Legacy Project included increased social engagement, reduction in physical illness burden, increased meaning, and decreased caregiver distress. For patients in the current study, some outcome variables indicated similar results although they were measured in slightly different ways. Specifically,

aspects of illness burden such as self-care dependence, mobility, and awareness of memory deficits were impacted by the intervention. However, meaning did not change in this population and caregiver distress actually appeared to decrease for those in the control group (see raw means Table 6), which will be discussed in more detail below. PIPAC also demonstrated some treatment effects that were hypothesized for the original Legacy study, but not supported in that population (i.e., increased well-being or quality of life). So in summary, although treatment effects were observed at similar points in the stress process model across the two populations, (for example, Legacy’s impact on meaning in chronic illness could be compared to PIPAC’s impact on coping in early dementia), the exact findings were not replicated across studies. The implementation of the intervention as measured by treatment enactment, receipt, and delivery were comparable.

Finally, system-level or organizational aspects of the intervention’s feasibility (i.e., demand, integration, and expansion) were not a direct target of this study, but can be discussed briefly based on data that was collected. For example, during the focus group with interventionists “buy in” and marketing of the intervention were discussed in terms of targeting a population that is not necessarily in distress. More specifically, although improvements in depression and illness burden were observed, the intervention is largely focused on improving positive affect and coping (i.e., quality of life, communication of wishes, etc.). Therefore a couple of the interventionists posed questions about demand for such an intervention. For participants who enrolled in the study, one indicator of interest or demand was the number of control families (i.e., 75%) that elected to receive a “Highlights Session” after post-treatment assessment. Additionally, community recruitment sites and liaisons were very receptive to the idea of the project as demonstrated by global interest in the project across 19 community

partners. In fact, 94.7% (18/19) of all organizations that were approached granted access to the older adults they served. The single exception, the Tuscaloosa VA, was interested but not a feasible recruitment site given increased restrictions for conducting research with veteran populations. One organization, an assisted living facility for individuals with dementia, was particularly eager to partner with the PIPAC research team; however, due to limitations in resources (i.e., staff, time, and reimbursement for travel for volunteers) this resource in Birmingham, AL was under utilized relative to demand.

Aim 2. Conclusions about the Clinical Utility of the PIPAC Intervention

Results addressing the second aim of the current study revealed several areas of clinically meaningful effects for the individuals with dementia. Clinically meaningful effects were determined by medium to large effect sizes for differences between groups at post-treatment beyond the effects of any differences that existed at baseline (i.e., ANCOVA's controlling for baseline values), as was described at the beginning of the results section. Effects of this magnitude are more likely to be replicated in a second study and in the presence of a more robust control condition (e.g., attentional support control conditions, etc.), which would likely be appropriate in the next level of efficacy testing. Relatively large effects of the treatment were observed across domains for individuals with dementia. Specifically, at post-treatment assessment intervention individuals with dementia reported significantly lower ($p = .03$) depressive symptomatology than those in the control group beyond the effects of baseline values of depression (raw means are depicted in Figure 5). This finding was further supported by the medium-sized effect of intervention family contacts' report of lower depression post-treatment (see Table 7) and the less sensitive estimate of anxiety and depression on the EuroQol-5 (i.e., none, some, a lot of depression/anxiety). This suggests that the PIPAC intervention accounted for

clinically meaningful differences in depressive symptoms, which was one of the primary variables of interest in the development of this study. This finding partially replicates change on the Cornell Depression Scale (Cohen's $d = 1.2$ in their sample and 1.25 in the current study) that was found by Romero & Wenz (2001) in their more broadly defined mild to severe dementia, inpatient, single-group design. Medium to large effect sizes were also observed for quality of life at post-treatment assessment, such that self-report on the BASQID reflected a medium effect ($\eta_p^2 = .07$ and a Cohen's $d = 0.54$) and family contact report of the individual with dementia's quality of life reflected a large effect of treatment (i.e., $\eta_p^2 = .28$ and a Cohen's $d = 1.15$). These combined findings speak to the clearly promising effects of PIPAC on emotional indicators of well-being. Notably, care recipient depression and well-being were not impacted in the original Legacy study (Allen, Hilgeman, et al., 2008), which may indicate that the patient-centered PIPAC intervention is a particularly good fit for these outcomes in individuals with early stages of dementia.

Intervention effects were also observed for health-related indicators of quality of life. Specifically, individuals with dementia and their family contacts noted changes in illness burden or health-related quality of life as measured by the Euro-Qol-5. Self-reported mobility demonstrated a large treatment effect (see Table 7), while medium to large effects were obtained on three of five of the family contact rated domains (i.e., self-care, usual activities, and anxiety/depression). In addition, small effects ($d = .2$ to $.3$) were observed for pain/discomfort and mobility as rated by family contacts. Although some of these effects are small and may not be stable over time, this collection of findings suggests that the PIPAC intervention has an impact on the functioning of individuals with dementia in domains related to health. Interestingly, these effects do not seem to be related to an increase in social engagement, which

did not appear to be affected by experimental group at post-treatment assessment. Perhaps as individuals are engaged in self-maintenance and self-adjusting activities, increased desire for independence in mobility, self-care, and usual activities are renewed. Alternatively, actual behaviors across these domains may remain stable, but perception of independence or autonomy may become more salient in the context of the PIPAC intervention. For example, perhaps family contacts provide individuals with dementia more opportunities for independence after being reminded of previous aspects of the individual's identity that may have changed with disease progression. Or perhaps family contacts and individuals themselves see the same behaviors as more indicative of strengths that are maintained rather than in terms of perceived losses. Based on this small sample the exact nature of the effects are difficult to determine; however, in a larger sample more control variables can be included to better explain moderating effects and alternative explanations for these early findings.

Finally, changes in decisional conflict or unease about future care decisions was also in the predicted directions such that individuals with dementia reported less overall discomfort with advance care plans at post-treatment compared to those in the control group. Variability on this measure was quite large across domains and for the total score, which likely accounts for different estimates of effect size across indicators (i.e., a large partial eta squared effect and a small Cohen's *d* effect, see Table 7). On subscales of this measure, intervention individuals reported less conflict about information related to advance care plans as well as decreased concern about the support they would receive around such decisions (both medium sized effects, see Table 7). Interestingly other subscales did not demonstrate such benefits of the PIPAC intervention. Although not clinically meaningful as defined in the current study, estimated marginal means for those in the control group appear to reflect less distress around values and

clarity as they relate to advance care plans (see Table 7). More research is needed on the relation between general feelings of uncertainty about the future in the context of progressive dementia as it relates to future care planning for medical treatments and across other domains. Some aspects of illness burden seem to be improved by the intervention as does overall decisional conflict about future medical care decisions; however, the exact mechanisms for these changes is undeterminable from the current data. It is possible that either one of the components (self-maintaining or self-adjusting) could be accounting for these effects, but perhaps just as likely, the combined impact of the two components may make individuals feel more prepared for the future or less burdened by their illness in the present.

Findings that did not display meaningful treatment effects included: social engagement (self and proxy report), meaning, and emotional and anticipated support. Absence of clinically relevant effects could be due to factors related to measurement of these constructs, how malleable they are by a brief intervention, and/or simply a poor fit of the intervention package to these outcomes, among other explanations. To our knowledge, none of these measures have been used previously as outcomes for interventions targeting individuals in the early stages of dementia. Although Cronbach's alphas were acceptable (.77 for social engagement) to excellent (.87 and .92, for social support and meaning, respectively) in the current sample, perhaps these self-report measures were not sensitive to change in this population. For example, a significant portion of the individuals in the study had difficulty remembering the study as well as other recent events from week to week. Unlike symptoms of depression or quality of life that are focused on the present (i.e., "how am I doing right now?"), perhaps constructs like meaning or social support are more stable or retrieved from older memories in individuals with memory impairments (i.e., "do I believe that I have a purpose in life?"; "if I were sick would someone be

there with me?"; etc.). This potential explanation would not account for family contact ratings of these constructs, which theoretically would be based on current observations. Notably, caregivers in the Legacy study reported increased social engagement at post-treatment, a finding that was not replicated by PIPAC. Perhaps differences in measurement (i.e., assessing talkativeness vs. more global social behavior, such as willingness to join in group activities) best explains this finding. Meaning was also measured differently across studies, introducing additional measurement variance across the Legacy Study (Allen et al., 2008) and PIPAC designs. More research is needed on the impact of interventions such as PIPAC on symptoms such as social withdrawal or social anxiety in individuals in the early stages of dementia. Interestingly, one of the family members suggested the addition of a group activity for individuals who may live in residential settings (see quotes in Table 4). Self-maintenance and self-adjusting discussions consistent with the content of the PIPAC intervention could easily be modified for a group setting as has been done in other long-term care interventions (see the Life Review Group Program by Chiang, Lu, Chu, Chaing, & Chou, 2007, as an example). Modifying the intervention to include groups may be a more powerful treatment manipulation targeting social engagement than working one-on-one or as a dyad with the interventionist. Finally, more research is needed on "meaning" in individuals with early stage dementia. In this small sample, individuals with dementia decreased in meaning (i.e., "my life is driven by a greater purpose," etc.) across groups while improving in other areas. If interventions targeting self-maintenance and self-adjustment impact coping but not meaning, re-examination of the use of meaning and purpose for the sake of coping is likely warranted (Folkman, 1997) for these individuals.

Secondary Aim. Conclusions about Coping, Awareness, and Caregiver Burden

Finally, examination of the secondary or exploratory aim was conducted in much the same way as the primary outcomes (i.e., ANCOVAs predicting values at post-treatment from group assignment while controlling for baseline values on that measure). However, because we examined coping quantitatively in individuals with early dementia and looked at the effects of the intervention on awareness of memory deficits, both of which are novel to this study, a priori hypotheses were not developed. Interestingly, individuals with dementia increased the number of coping strategies that they reported at post-treatment compared to control group individuals. The measure of coping was developed as a clinical tool rather than for the purposes of research (i.e., Keady & Nolan, 1995) and prior to this study no psychometric properties were available. The IMML obtained a satisfactory Cronbach's alpha of .73; however, the 42-item format contributed significantly to the assessment burden of the current study and has notable overlap in items that could be reduced. Additional research with this measure is clearly needed to develop a more user-friendly, yet equally sensitive measure of coping for individuals with dementia. It is exciting that the PIPAC intervention, which targeted coping, was able to demonstrate a large effect of treatment on this important variable in the Stress Process Model- Early Dementia (see Figure 1). Perhaps the current study can foster future scale development and additional research on the impact of coping in the model, which ultimately may affect outcomes of psychological distress and well-being.

With regard to effects of treatment on awareness, several note-worthy findings emerged. Perhaps most important is a large effect of the intervention on awareness as defined by the discrepancy between IWD's ratings and the ratings of their family contacts at post-treatment. Specifically, discrepancy scores were less for intervention dyads indicating greater agreement

about cognitive abilities compared to families that did not receive the PIPAC intervention. Upon closer inspection, a large treatment effect was also observed for family contacts' ratings of their loved one's performance on cognitive tasks post-treatment, such that they reported better cognitive functioning in their family member than those in the control group. Notably, individuals with dementia also showed effects of treatment as indicated by a medium effect; however, individuals with dementia in the intervention group actually reported themselves lower in cognitive abilities (indicating increased awareness of deficits) than those in the control group at post-treatment. Although it is impossible to know from the current study, perhaps increased self-adjustment coping promoted movement toward a more accurate reflection of cognitive abilities in the intervention group individuals. Although this may seem like a negative finding, in that individuals believe they are more impaired, Clare (2004) and others would suggest that increased awareness or in most cases *increased accuracy* of self-evaluation offers an opportunity for communication about needs. Like the findings related to coping, additional research about awareness as a modifiable construct and an element in the stress process model is needed to best serve this population. Based on the SPM-ED (see Figure 1), it is feasible that increased coping may not be possible without some increased awareness.

Finally, the only counterintuitive finding as a result of treatment occurred for family contacts on the measure of caregiver burden or distress. A medium effect size (see Table 7) emerged for differences in estimated marginal means at post-treatment. In combination with examination of the raw means (see Table 6), results revealed that family contacts in the control group decreased in caregiver burden from baseline to post-treatment while those in the intervention condition remained stable across time. It is possible that the minimally intrusive supportive phone calls targeting individuals with dementia or the assessment visits themselves

gave family contacts in the control group the opportunity to feel validated by the research staff. Perhaps family contacts in the intervention group did not receive the same benefit due to the increased burden of having someone in the home more frequently or perhaps elements of the intervention promoted maintained caregiver burden by increasing feelings of ambiguous loss or anticipatory grief (Boss, 2006, 2007). It is understandable that reflecting on past memories and discussing future care in the context of a progressive illness like dementia could be difficult for family members. Perhaps caregivers who attended all four sessions differed in their acceptance of the disease process or their comfort in engaging in such topics despite loved ones' cognitive limitations. Future studies may want to more fully assess caregiver needs, perceptions, and beliefs about loss and identity in the context of dementia.

In conclusion, intervention individuals with dementia showed better outcomes at post-treatment than control individuals across self-report and family contact report measures for depression, quality of life, health-related indicators of well-being or illness burden (i.e., mobility, self-care, usual activities, etc.), and increased awareness. Intervention group individuals also reported more coping strategies at post-treatment than individuals in the control group. The present results show that the PIPAC intervention is a promising psychosocial intervention for people with early to mild dementia that focuses on outcomes beyond cognitive skills training and orientation, which are frequently targeted outcomes early in the disease (e.g., Van Mierlo, Van der Roest, Meiland, & Droes, 2010).

Recent reviews of the literature have demonstrated that relatively few interventions, (e.g., reality orientation, procedural memory stimulation, and brief counselling) have obtained similar effects in individuals in the early stages of dementia (e.g., Bates, Boote, & Beverley, 2004; Van Mierlo et al., 2010). Bates et al. (2004) focused on four studies that met criteria for review (i.e.,

prospective study designs with a control group and an intervention group targeting psychosocial outcomes in individuals in the mild stages of dementia) out of a possible 208 considered. Of these studies ($n = 19-28$), only one demonstrated improvement on depressive symptoms and none improved quality of life. Furthermore, none of these studies attempted to target coping or awareness. In another recent review, Van Mierlo, Van der Roest, Meiland, and Droes (2010), reviewed studies published from 1990 to 2008 to identify effective interventions for individuals with dementia across a range of outcomes (i.e., cognitive functioning, agitation, restlessness, insomnia, quality of life, repetitive behaviors, speech problems, physical health, etc.). The authors' primary conclusion after reviewing the 71 studies was the importance of targeting interventions to specific characteristics of individuals with dementia. Specifically, these authors argued that the type of intervention (e.g., light therapy, progressive muscle relaxation, patient-centered bathing, caregiver support/training, etc.) has to be targeted toward specific characteristics of individuals in order to be most effective (i.e., stage of the disease, institutional placement, etc.). Although these two reviews are not particularly surprising in their findings, relatively few studies utilized reminiscence or life review techniques (i.e., $n = 8$ across all stages of dementia) and none explicitly mentioned decreasing uncertainty about the future by planning for advance care. Therefore, even small pilot or feasibility studies like the current test of the PIPAC intervention are able to contribute to the existing literature.

Limitations

The current study is not without limitations. First, the modest sample size of this feasibility study is a primary limitation for making any conclusions about efficacy; in other words, power was too low to test the effects of the intervention. Second, while this group of participants was more diverse in some ways (i.e., participants were referred from over 15

different community partners) than similar studies, participants were primarily White/Caucasian with high educational achievement and high SES (see self-reported income adequacy Table 2 and Table 3). Only three of the 36 interested dyads were Black/African American and two were determined to be ineligible before baseline was scheduled (i.e., one individual had severe dementia and the other had been diagnosed with a TBI rather than dementia). The lack of racial diversity in the current sample is in stark contrast to the original Legacy project (Allen, Hilgeman, et al., 2008), which was predominantly Black/African American (69.4% compared to PIPAC's 5.3% of IWDs and 12.5% of FCs). This discrepancy can perhaps be explained by involvement of an African American paid recruiter that worked for the original Legacy Project and more successfully tapped the Black/African American community during that study. Future efficacy trials of the PIPAC intervention will need to more actively recruit minority and lower SES samples to better reflect national racial and economic characteristics of this population.

A third limitation of the current study is the lack of a delayed follow-up assessment (e.g., 3 months after treatment) to demonstrate more lasting effects of the intervention. Certainly longitudinal designs including a maintenance phase of the intervention or booster sessions to promote continued self-maintenance and self-adjustment over time would be ideal. With this in mind a first step could be to measure continued use of the intervention materials without further intervention (i.e., Do they look at the Legacy materials over time? Or do advance care planning discussions and plans continue after research staff are no longer involved?).

Another potential limitation of the current study is that family contact participation was made optional during intervention sessions. This was done primarily for feasibility reasons and introduced variability across participants' intervention sessions. However, one could argue that it may also have presented a more ecologically valid picture of how individuals in the early to mild

stages of dementia spend their time and cope in their daily lives. Some participants in the study were quite independent, for example living alone, without children or spouses in their daily lives, while others were never left alone (see Table 3). In some ways it seems artificial to design interventions that only target one of these clinical pictures or requires the more independent individual to complete a project with another person when that is outside the normal experience of their daily life. Whether family involvement is allowed to vary in future testing of PIPAC efficacy trials will be considered carefully; however, if resources permit additional measurement of this factor could enrich future psychosocial interventions targeting individuals in the early stages of dementia.

Finally, a few methodological improvements could be made in future studies to increase the scientific rigor of efficacy testing. Specifically, blinding assessors and participants to condition was not possible in the current study; families knew whether they were in the intervention or control group based on the sequence of events that occurred after baseline. A different control condition in the future might make this more possible. Furthermore, due to the staffing and resources of the current study we were limited to assuring that the post-intervention assessor was not involved with the family as an interventionist or control caller. However, at times this meant that the family was interacting with three different staff members across visits, and measures that were based on clinical impression such as the CSDD may have been completed by one assessor at baseline and a different assessor at post-treatment (introducing additional error variance).

Despite these limitations, the current study offers methodological improvements over previously published single-group designs that have utilized self-maintenance strategies for therapeutic effects in dementia (e.g., Romero & Wenz, 2001). For example, PIPAC narrows the

scope to individuals in the early to mild stages of the disease. In contrast, Romero and Wenz's (2001) Self-Maintenance Therapy included individuals with Mini-Mental Status Examination (MMSE; Folstein, Folstein, & McHugh, 1975) scores of 1 to 30. Although we considered including lower functioning individuals in this feasibility study, we felt that different modifications of the intervention package would be more appropriate for those who were more impaired. For example, presentation of the advance care planning component may need to be even more delicate or concrete for someone in the later stages of the disease. In the current sample, the individual that became the most upset during that component was in the lowest quartile cognitively, based on the DRS (i.e., total score = 95). Consistent with our patient-centered focus, this study was limited to individuals in the very mild to early stages of dementia before expanding to more heterogeneous groups.

Conclusions and Future Directions

Overall, the current study was a successful demonstration of feasibility and limited efficacy testing of the PIPAC intervention. Looking forward, data from the current study will be used to make several specific modifications to the intervention package before a larger clinical trial is conducted. The primary change will be to the self-adjusting coping module. Specifically, the content of that session will be broadened to focus on acceptance in the context of a progressive illness and increased communication of wishes for the future. During the focus group with interventionists, all research staff reported that the advance care planning session was a useful element; however, some felt that the flow of the two components was disjointed. Furthermore, interventionists expressed concerns that the session was less applicable for families that already had future care planning documents in place. To address these concerns, the sequence will be changed so that the self-adjusting component will be moved to the first session

rather than beginning with the self-maintenance (life review) component. This will accomplish two goals: (a) interventionists' concerns about disrupting the life review sessions with the second component will be addressed as the self-adjusting component is not intended to carry across more than one session; and, (b) a more broad discussion about values can be integrated into ideas about future care from the beginning of the sequence. Specific questions about planning documents, which was intended to be a small focus in the current Participant Notebook, will more explicitly be described as a secondary goal of this session. An over emphasis on completing specific documents (i.e., durable power of attorney, health care power of attorney, etc.) can easily be interpreted as a legal task that needs to be completed but feels emotionally removed from promoting care that is consistent with an individual's identity, beliefs, and values. Focus instead will be on broader ideas about enhancing communication to promote dignity and values-consistent decision-making in the disease process.

In line with these goals, Song and colleagues (2009) recently published their modification of Briggs (2004) patient-centered advance care planning intervention. The Sharing Patients' Illness Representations to Increase Trust (SPIRIT) intervention focuses on increased communication of values about treatment wishes, acceptable and unacceptable outcomes, and the dying process in African American families. The resulting conversation is designed to better prepare families in the event that surrogate decisions need to be made in the future. Perhaps following Song and colleagues' model would be more appropriate for individuals in the early stages of dementia. Interestingly, their approach is markedly similar to elements of Chochinov's Dignity Therapy (Chochinov et al., 2004). A return to elements central to Chochinov's work with individuals at the end of life would realign the self-adjusting component of PIPAC with the

goals of maintaining pride and hope, discussing the impact of burden on families, and thinking about future care planning in terms of generativity.

After the self-adjusting component has been modified with these goals in mind, it may be determined in the future that a more tailored intervention package is appropriate. Within the caregiving literature it has been acknowledged that interventions with multiple components allow for emphasis to be placed on different elements of the intervention based on assessment of needs (i.e., Burgio et al., 2009; Gallagher-Thompson et al., 2000). Taking a more targeted approach based on the individual or family would have worked well for several of the dyads in the current study and should be considered as the PIPAC intervention develops further.

Finally, the heterogeneous nature of the current sample in terms of living situation (see Table 3), introduced the possible expansion of PIPAC in two different settings: (a) skilled nursing facilities or other long-term care communities such as assisted living facilities, and (b) individuals living at home with family caregivers. In part, interventionists' globally positive reactions to the delivery of the PIPAC intervention and relative ease of learning the materials suggests the option of training staff in an assisted living facility or nursing home to deliver the intervention in the future. Although individuals with dementia were generally similar across settings in the current sample (see Table 3), those in long-term care were generally more dependent in ADL/IADL care needs. Additional attention to performance-based tasks that may be included in the intervention could need additional monitoring by trained interventionists to more closely promote appropriate engagement with materials (e.g., cutting and pasting in a scrap book, etc.). Like other interventions that are focused on the identity of the individual receiving care, it is anticipated that the PIPAC intervention could have positive effects for individuals with dementia as well as the nursing staff involved in the project. Studies in long-term care facilities

have repeatedly demonstrated that the relationship between nursing staff and residents is enhanced when a greater understanding of the individual's life is appreciated by those providing care (e.g., Anderson, Taha, & Hosier, 2009).

Alternatively, application of the PIPAC intervention for individuals with mild dementia who are living in the community also deserves closer inspection. Family contacts in the intervention group did not report benefits through the reduction of caregiver burden. This is not particularly surprising given the patient-centered focus of the current PIPAC intervention. However, increasing involvement of the family contact without losing the patient-centered focus could be achieved through other self-maintaining activities targeting the dyad. For example, encouraging shared pleasant events that are consistent with salient roles (e.g., going fishing, working on a quilting project together, cooking favorite recipes from childhood, etc.) could be a meaningful way of supporting identity-maintenance. Facilitation of adjustment-related coping could also be part of these shared activities as family contacts learn to support individuals in different ways given cognitive losses (e.g., having someone else prepare a fishing line; encouraging the individual with dementia to pick out patterns for a quilt, but not do the sewing; or encouraging the IWD to mix ingredients, but not control the gas stove). Coaching dyads in the community through the planning of these shared events would be consistent with other strengths-based activities for individuals with dementia (e.g., Montessori-based interventions, Orsulic-Jeras, Schneider, & Camp, 2000). Assessment of positive aspects of caregiving (Tarlow et al., 2004) could be added to determine whether family contacts benefitted with increased positive affect as was observed in individuals with dementia in the current study. Many of these potential future modifications are not necessarily novel approaches to care. However, in combination with the successful aspects of the current study, the PIPAC intervention package could be used to

promote patient-centered coping focused on the specific needs of individuals in the early stages of the disease.

Although numerous interventions targeting individuals with dementia have been developed, the number that specifically target individuals in the early stages of the disease are more limited. The PIPAC intervention was developed with this gap in the literature in mind. The current study successfully demonstrated both the feasibility of the intervention as well as the potential for clinically meaningful effects on depressive symptoms, quality of life, indicators of illness burden, concerns about health-care decision-making, coping and awareness. The breadth of psychosocial outcomes that may be modifiable through this brief, four-session intervention warrant further investigation. It is our hope that researchers will continue to develop the current intervention package to promote the values, dignity, and coping strategies of individuals with dementia in ways that are consistent with the lives they have lived and their hopes for the future.

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APPENDICES

Appendix Table of Contents:

- A. Intervention Session Protocol and Summary
- B. Control Condition Protocol and Summary
- C. PIPAC Participant Notebook
- D. UA IRB Checklist for Capacity
- E. UA IRB Approved Recruitment Materials
- F. Focus Group Sample Questions
- G. Cash Receipt Tracking Documents
- H. UA IRB Letter of Approval and Face Sheet
- I. Treatment Fidelity Measure
- J. TELEformed Measures
 - a. Dyad Tracking Form
 - b. Demographics Data- Patient Form
 - c. Bath Assessment of Subjective Quality of Life (BASQID)
 - d. Subjective Health
 - e. MARS Awareness (Participant Versions)
 - f. Index for Managing Memory Loss (IMMEL) Coping
 - g. Quality of Life in Alzheimer's Disease Scale (QOL-AD)
 - h. Meaning in Life Scale
 - i. Social Engagement
 - j. Emotional Support and Anticipated Support
 - k. Decisional Conflict Scale and Satisfaction
 - l. Euro-QoL- 5D: Health-Related Quality of Life (mobility, self-care, etc.)
 - m. Dementia Rating Scale (DRS-2)
 - n. Clinical Dementia Rating Scale

- o. Cornell Scale for Depression in Dementia (CSDD): Including anxiety subscale
- p. PIPAC Project Evaluation and Satisfaction
- q. Demographics Data- Family Contact
- r. Quality of Life- Family Contact Report
- s. MARS Awareness (Family Contact Versions)
- t. Social Engagement- Family Contact Version
- u. Caregiver Burden Inventory
- v. ADL/IADL Dependence Measures
- w. Euro-QoL- 5D: Health-Related Quality of Life Family Report
- x. Project Evaluation / Satisfaction

APPENDIX A: Intervention Sessions

Session One: Introduction and Initiation of the Self-Maintaining Legacy Component

The goals of the first session are (a) to promote rapport between the interventionist and participant, (b) to introduce the intervention components and begin a conversation about the participant's personal experience with dementia, and (c) initiate the self-maintaining component. An overview of the self-maintaining and self-adjusting model of coping with memory loss was presented and components of the intervention were explained in these terms. The participant was encouraged to provide examples of each type of coping from their own experience to promote investment in the intervention.

After arriving at the participant's home at the established time, the interventionist engaged in casual conversation for three to five minutes before introducing the participant notebook. The interventionist then used the participant notebook to introduce the outline for the coming sessions and provided a general overview of the material for the coming weeks. The interventionist answered any questions that the participant had about the training or its components.

The interventionist then initiated the Self-Maintenance Legacy Component via the Legacy Project portion of the participant notebook. The participant was guided through the self-maintenance interview modeled after Cohen-Mansfield's work with individuals in the later stages of the disease. Four primary domains were the focus of this interactive interview: (a) Professional Roles, (b) Family Roles, (c) Leisure Activities, and (d) Personal Attributes. The interventionist explained each of the different roles and used questions to assess each aspect of the individual's identity while noting that often the most important roles are those that are maintained across time. For example, the interventionist explained, "Some 'roles' that people serve in are social roles, or based on our relationships with the other people in our lives, while others are more like traits or attributes of who you are. When you think about what makes you unique, what roles come to mind?" After discussing important values, beliefs, and activities through use of the participant notebook, participants were encouraged to narrow their focus to one domain to emphasize in their Legacy Project.

The interventionist then lead the participant through a brainstorming activity designed to come up with ideas for recording or telling their life story. For example, a scrap book, recipe book, video tape, written letters, or recorded audiotapes were all possible options. Once the participant decided on a primary role or aspect of their past or present identity that they wanted to record as well as the means to create their concrete Legacy, a plan for the coming week was developed. At the end of the first session, participants received \$20 to help with any costs associated with materials for the project.

The participants were assigned homework to discuss the roles they identified with a family member or close friend. In addition, they also were instructed to begin gathering materials necessary for the execution of their Legacy, which was the focus of the next session.

In order to close the session, interventionists provided a summary of completed material. The date of the next session was set at this time. Interventionists reinforced material covered during the initial session and encouraged participants to complete homework assigned earlier in the session.

Session Two: Self-Maintaining Legacy Project Continued

The goals of the second session were to (a) discuss the homework from the previous session, (b) discuss progress made collecting materials for the Legacy project, and (c) use session time to work on the Legacy with the participant.

After arriving at the participant's home at the prearranged time, the interventionist engaged in casual conversation with the participant for three to five minutes before beginning the content for the second session. The interventionist then began the second session by addressing general questions about the program up to this point. The interventionist then facilitated discussion about the homework with the participants focusing on their experience sharing aspects of the first session with a family member or friend. This helped foster discussion regarding progress made toward collecting materials for the Legacy project and shaped the content of the second session. If the participant had gathered materials, the interventionist coached, reinforced, and problem-solved the participant's attempts to create one tangible and lasting personal Legacy. Depending on the individual participant, the second session could involve the interventionist guiding the participant in the completion of the Legacy. For example, if desired, the second session can be transcribed or a copy of the tape can be provided to the participant to include in their project. Discussion questions drawn from the "Guide for Telling Your Life Story" were included in the Appendix of the Participant Notebook to guide this session, if the participant did not gather materials or did not have the cognitive capacity to complete a more independent project. For some more impaired individuals, transcripts or audiotapes of the second session could be the primary tangible output of the Legacy component.

Near the end of the second session, the interventionist again encouraged the participant to share their Legacy with other family members and friends. A section of the participant notebook served as a visual cue/prompt for guiding this sharing between sessions. In addition, the participant was assigned homework to continue working on their Legacy.

Before leaving the participant's home, the interventionist scheduled the third session for the following week.

Session c: Legacy Check-In and Transition to Patient-Centered Advance Care Planning Interview

The goals of the third session are to (a) discuss continued progress on the Legacy project, (b) transition into the introduction of the advance care planning component of the intervention, and (c) complete the patient-centered advance care planning interview (Steps 1-5) as a means of discussing future care plans.

After arriving at the participant's home at the prearranged time, the interventionist and the participant reviewed the first two sessions and the goals of the intervention to this point. The interventionist then began discussing the next component of the intervention, the patient-centered advance care planning interview. The interventionist began the discussion by using the participant notebook to discuss the "Living Well" questions, which helped transition from the Legacy component to the future planning component. Living well questions include: (a) "What present or future experiences are most important for you to live well at this time in your life?" Add if needed: "In what way do you feel you could make this time especially meaningful to you?" (b) "What fears or worries do you have about your illness or medical care?" Add if needed: "For example, do you feel that there are needs or services that you need to discuss?" (c) "Who or what sustains you when you face serious challenges in life?" (d) "Do you have any religious or spiritual beliefs that help you deal with difficult times?" The interventionist was trained to be sensitive to the participant's emotional reaction to these questions, and efforts were made to take each of these as slowly and delicately as was deemed clinically appropriate.

When ready, the interventionist moved on to questions designed to focus the participant on their current health and the impact of their memory on their need for future plans or future care. The Patient-Centered Advance Care Planning Interview discussed this as the first step during which the individual was encouraged to describe their illness representations along five domains (i.e., identity, cause, timeline, consequences, and cure/control). For example: (a) "Tell me what your current illness/symptoms feel like to you?" (b) "What do you think is the cause of these symptoms?" (c) "What are possible complications that may occur because of your memory loss?" (4) "How have these symptoms (and your memory loss) affected your life?" (5) "What do you expect of your current plan of care? What do you hope for?"

Once the interventionist discussed the individual's understanding and perceptions of their memory loss and other health concerns, the next point of discussion was to explore their

current thoughts about care. One question was used to introduce this topic: “In general, which of the following approaches to your medical treatment would you prefer? (a) Treatment that focuses on extending life as much as possible, even if this means you might have more pain or discomfort, or (b) Treatment that focuses on relieving pain and discomfort as much as possible, even if this means you might not live as long” (Casarett et al., 2005).

More detailed follow-up questions and prompts followed: “What have you discussed with your family about what you might choose for your future medical care, including care at the end-of-life? Do you think you have had enough discussion and has it been specific enough?” or: “Why do you think you have not yet thought about planning for your future medical care, including care you would prefer to have at the end of your life?” If needed, the interventionist can also guide the participant through discussion of their own experiences, for example: “What experiences have you had in dealing with family/friends who have died or been seriously ill? What did you learn from those experiences? Did they help you form any ideas about your choices for future medical care?”

At this point, the interventionist may take a more psychoeducational approach and choose to review common reactions that some individuals have to discussing advance care directives (taken from Brechlin & Schneider, 1993). For example, some individuals express (a) “I didn't know that people had choices in these matters. Mustn't doctors always do everything that can be done to sustain life?” (b) "Our doctor knows best. Shouldn't she/he make these decisions for me when the time comes?" (c) "Frankly, I don't know anything about such issues. I have never considered making decisions like this and I wouldn't know where to begin." Similarly, family members and close loved ones may share the following common reactions to this material: (a) "But I am the closest relative (spouse, daughter, etc.). Surely I have the right to make these decisions for my loved one if he can't make them for himself." (b) "I find it too upsetting to think about my relative's decline. I can't even contemplate his future deterioration."

The interventionist then presented information to replace any current misconceptions including information on illness and any self-identified gaps in the individual's knowledge about future care. The Medical Information Stimuli sheets (Allen, Allen, Hilgeman, & DeCoster, 2008) were available in the appendix of the Participant Notebook for reference. The interventionist provided information on benefits/burdens of life-sustaining treatment related to patient's medical/surgical condition before moving on to specific decisions related to their future care. Specifically, the interventionist then led the individuals in a discussion of the selection of an appropriate surrogate decision-maker. This discussion reviewed with the patient the characteristics of an ideal decision-maker: (a) one that is willing and that the patient trusts to follow his/her wishes; (b) one that the

patient has talked to about life-sustaining preferences and (c) one that can make decisions under sometimes stressful situations. This included discussion of the range of authority in making decisions that would be expected from the surrogate decision-maker. Finally, the interventionist discussed the importance of completing a plan, e.g. Statement of Preferences (and Power of Attorney for Healthcare document if applicable).

This session concluded with a summary of the material that has been covered and encouragement to discuss this material with a loved one or close family friend for homework before the final session. The interventionist could say:

I know that this is a lot of information to take in. I want to support you in whatever way I can. While these decisions may be difficult to make, and difficult to talk about, you are giving a gift of love to those close to you who may have to make decisions for you if you become unable. By knowing your wishes, they will have the comfort of knowing what you would want them to decide for you.

The session then ended with reinforcement/praise for discussing these tough issues and setting the final intervention session for the following week.

Session 4: Wrap-Up and Closing Session

Goals for the final session were to (a) review homework related to the patient-centered advance care planning component, (b) check-in with the participant regarding the Legacy project, (c) offer the individual a chance to share their project and future plans with the interventionist, and (d) discuss future plans to continue progress made on Legacy and ACP.

After arriving at the prearranged time, any questions from the following week were addressed and the homework was discussed. The final intervention session consisted of sharing the Legacy project with the interventionist and evaluating the intervention procedures. Specific questions provided in the PIPAC Participant Notebook were discussed by the interventionist and participant to evaluating the experience of constructing a personal Legacy and completing the ACP interview. The interventionist coached and reinforced the individual's efforts to use the Legacy materials in their daily lives. The participant was then encouraged to construct other Legacies and share their Legacy work with other family members and friends. Thus, the interventionist gave the individual the continuing homework assignment to build on the current project by constructing other Legacies or documenting other important roles. Where appropriate, the interventionist obtained consent from the individual with dementia to share aspects of the intervention with the family contact.

The final intervention session concluded by thanking the individual for participating in the intervention and scheduling the post-intervention assessment a week after the last intervention session.

APPENDIX B: Control Condition Protocol

The emotional support contact control was administered individually via telephone with the persons with dementia and was designed to provide minimal, non-specific support. Phone contacts provided a minimal support contact but not full attentional control. Each control call lasted between 10 and 30 minutes. Control callers asked participants about how they were doing and feeling in general and spontaneous activities of social engagement that they enjoy with their family contacts. When not possible to conduct control calls by phone, in person visits were provided for a few participants.

Control Call One

The research assistant (RA) contacted the participants at prearranged preferred times. The research assistant ensured that it was a convenient time and engaged in supportive conversation on a topic of the person with dementia's choosing. Phone contacts were aimed to last between 5 and 10 minutes. Potential topics could include: how the person with dementia was feeling, any stories they would like to discuss, and their experience with general health issues. If necessary, research assistants could reschedule the phone call and terminate this session. RAs were trained to talk with the participants following an active listening model. They were encouraged to be cooperative and helpful to the participants while being careful not to provide any information included in the intervention components. The research assistant emphasized the participant's importance to the project to promote retention. After answering any relevant questions the participants may have, RAs thanked the participant for their time and scheduled the next telephone call.

Control Call Two

The second control call followed a similar format to the first. Again, research assistants contacted the participant at the prearranged time indicated during the previous telephone call. The RA ensured that it was a convenient time for the participant and if necessary arranged another time for the telephone call. The RA then spoke with the participants for a time of no less than five minutes but no more than twenty minutes. The conversation followed an active listening model. The researchers continued to be cooperative and supportive while being careful not to provide any treatment components from the intervention. The importance of their continued involvement in the project was emphasized in order to maintain their interest in the project. At the end of the conversation, the RAs scheduled the post-intervention assessment and reminded the participants of the option for a one-time PIPAC workshop to introduce them to the intervention materials after the completion of the second assessment.

APPENDIX C: Participant Notebook

The PIPAC Project

**Preserving Identity and Planning for Advance Care
(PIPAC) Project**

Funded by the
Center for Mental Health and Aging

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TABLE OF CONTENTS

Introduction to the PIPAC Project
Overview of Visits 2, 3, 4 and 5 to Your Home
Introduction of Coping Strategies

Session 1: Deciding on a Personal Legacy

Session 2: Constructing Your Personal Legacy

Session 3: Advance Care Planning Interview

Session 4: Wrapping Up

APPENDIX

Narrowing the Focus

Family History

Growing Up

Adult Life

Growing Older

Medical Information Sheets

INTRODUCTION TO PIPAC

The Preserving Identity and Planning for Future Care Project, called PIPAC for short, is designed to help individuals like you reflect on experiences in your life from the past, present, and in the future that are most important for you to live well. The current project will be guiding you through questions and activities to help you think about the things in your life that sustain you when you face certain challenges. This is referred to as coping.

One thing that we will be focusing on is your personal experience with memory loss or changes in your ability to do things that were once easy for you. Some people with memory loss have described their ideas about dealing with their memory loss as “not a big deal” or “just an expected part of aging” while other people have described sadness or “uncertainty about the future.”

There is no right way to deal with challenges that you face as a result of your memory. But there are ways to increase positive or good experiences that can help you deal with some challenges.

1. One way to deal with memory loss is to hold on to things from the past and present that are important to you. In a way, maintaining the things that make you who you are.

What types of activities are you doing now that help you hold onto the past and the things that make you special?

2. Another way is to try to plan for changes related to memory loss and acknowledge that things are changing. This can be a way adapting to new challenges.

What types of things do you do now to help you adapt to changes in your memory?

What we will do in this project...

As part of this project we will be doing two main activities to help you think about the things or values that have been important to you in the past and those that will be important in your future. By doing this we are trying to increase positive or good ways of thinking about the past as well as good ways to think about and plan for the future.

1. The first activity we will be doing is documenting a part of your life story or creating a personal Legacy.

For this activity we will be focusing on things that make you unique or pieces of your identity that are especially important to you. The Legacy you create will be a valuable gift you can give your loved ones. What may be a surprise to you is how valuable this process can be for you.

In order to do this we are going to focus on the roles in your life that have been most important to you. We will then create a project together that you can use to remind you of the important things in your life now and in the future. Looking back and sharing special memories can be both entertaining and rewarding.

It can help you appreciate the richness of your life, the people that have been important to you, and the experiences that have influenced you. You will be creating something tangible and uniquely yours- the story of your life, the way you want to tell it. Whether you would like to express this story of your life through pictures, recipes, a scrapbook, audiotapes, or through other means is one of the first choices you and the PIPAC staff member will make.

Our purpose, as part of the PIPAC project team, is to help you and your loved one decide on a Legacy project that is unique to you and helps tell your life story as you want it to be told. To help you decide on one project, we will use some questions to guide us.

2. The second activity we will be doing is discussing and writing down your ideas about what it means to live well in the future.

Specifically, we will be discussing your experience with memory loss and the types of care you would want should you become sicker than you are today. It can be upsetting at times to think about becoming sick or needing medical care, but doing so can help you plan and communicate your wishes to your family and loved ones. By telling them what you would want in order to be comfortable or live well, you are giving a gift to them in the future.

The PIPAC team will guide you through questions that you may not have considered before. For example, we will discuss:

- What fears or worries do you have about your illness or medical care?
 - For example, do you feel that there are needs or services that you need to discuss?
- Who or what sustains you when you face serious challenges in life?
 - Do you have any religious or spiritual beliefs that help you deal with difficult times?
- Who do you want to make decisions about your medical care if you cannot do so yourself?

By thinking about these topics now, you can turn any uncertainty or fears about future care into plans for action. That way, who you are today can impact the choices that may be made for you in the future.

Before we begin, let's discuss what we will be doing over the next couple of visits to your home.

Overview of Visits 2, 3, and 4 to Your Home

- **Session 1** (Visit 2):

At this time, the PIPAC staff member who will be working with you throughout the project activities (Visits 2-4) will help you develop a more in depth plan for the project. You will discuss important family or social roles, occupational roles or jobs, values and traits, and even things you have enjoyed doing in your free time. You will then pick the role that is most important and will decide on a Legacy activity to record this role in a way that fits you and your family.

- **Session 2** (Visit 3):

During this visit, you will begin working on the Legacy activity if you have not done so already. The project staff can help you in any way you need to create a project that you are proud of and that reflects the things in your life that are most important. All materials needed for the project should have been gathered after the last Session (for example: pictures, recipes, stories from other family members), and some progress should be made on the activity if possible.

- **Session 3** (Visit 4):

In this visit, the project staff member will begin the second part of the project. Questions designed to focus on your current health and the impact of your memory on the need for future plans or future care. Your wishes will be documented in this notebook and can be shared with your family, and potentially turned into legal documents to secure your wishes in the future.

- **Session 4** (Visit 5):

This is the last visit with the research staff member who has been helping you with the Legacy activity and Future Planning. During this visit you will be encouraged to show off your Personal Legacy, finish any questions you have about future care, and to discuss your feelings about the process. This visit will conclude by evaluating the success of the project and discussing what you have learned as well as how you might continue to use this project in the future. This will

also be an opportunity for you to tell us, how you felt about the project.

SESSION 1: Deciding on a Personal Legacy

Goal 1. Using Reflection Questions to narrowing the focus of this activity to reflect one important role in your life.

Goal 2. Making a plan for how you want to tell your story (what you want to create).

Step 1: Identifying a role or piece of my personal life story that I want to focus on.

In order to help you focus your attention on what areas you would like to approach or discuss in your Legacy project, we will discuss some roles that may be important in your life now or in the past.

Some 'roles' that people serve in are social roles, or based on our relationships with the other people in our lives, while others are more like traits or attributes of who you are.

When you think about what makes you unique, what roles come to mind?

What type of family roles have you been in? For example, a spouse, a parent, a child?

The types of jobs, activities, or occupation you held in the past is another type of role that is important to many people. What things did you do either professionally or in the home? How big of a part of your life was this activity? How long did you do it?

What types of leisure activities did you enjoy in the past? Are there any that you continued to enjoy over a long period of your life?

What traits, accomplishments, or group memberships have been most proud of?

What things would you want people to remember about you?

Finally, are there any additional things not mentioned above that you valued or cared about in your life?

Session 1 Supplement:

If a family member or friend is present they can be involved too.

When you and your loved one are trying to decide on a Legacy activity you can give your input as well. Tell your loved one which things you would most like to have from them, in the form of a Legacy. Which roles come to mind when you think about your loved one?

My favorite memories of times with my loved one are...

The things I most want to remember about my loved one are...

The lessons/values I have learned or most associate with my loved one are...

Step 2. Narrowing the Focus of your Legacy

Hopefully, after discussing the reflection questions aloud with the research staff you are beginning to get some ideas as to what is important to you.

You may already have in mind exactly which area of life you want to focus on for your Legacy project. But if you have not narrowed your choices down yet, there are some more specific options for you to consider in the Appendix, located in the back of this notebook.

It may be helpful to put marks, or highlight specific questions or points you want to include.

Before we move on, use any notes that you made above and any comments discussed with the research staff and pick one role or area of your life that you want to focus on. Roles that were important and that lasted for a long period of your life may be good ones to consider.

If you would like, we can jot down any ideas or specifics in the space below.

Congratulations!

You are getting closer to picking your Personal Legacy Project.

Now that you know the specific role that you want to include in your Legacy, it is time to pick an activity to help tell your story.

Step 3. Discussing Possible Solutions

At this time, let's focus on the best way to capture the main points of what you thought about above. You may already have in mind the type of project you would like to use for your Legacy. There is no right way to tell your story. Work with these memories and roles in any way that feels good and creative to you. You know best how to tell your own story.

BRAINSTORMING:

Lets take five minutes and each come up with some ideas for a Legacy Activity focused on _____.
(The role identified above.)

The point here is to generate ideas, not to choose one or say whether each idea is good or bad. That will come later. During these five minutes, we will throw out activity ideas. When we are finished, we will go through each of our ideas as well as tips for specifics projects and talk about the Pro's (positive things) and Con's (negative things) of each activity.

TIPS for Legacy Activities:

Below are several ideas (and tips for using these ideas) for you to consider. The PIPAC team member will help you create your project, but you can get help from family members and friends as well.

Ideas to consider:

- **WRITING OR RECORDING STORIES ON PAPER**

1. Writing your story may be easier with the help of another person. Since you have already chosen a member of your family to participate in this project with you, they may be able to write the stories as you tell them.
2. If you chose to have your loved one write for you, it will be very important to talk slow enough for them to record your memories accurately. You will need to ask them to read back what you have said at several different points, to make sure they are getting it the way you want it stated.
3. The PIPAC staff member can also help record your stories.
4. If you decide to write them yourself, first organize your thoughts in a notebook before you begin writing them down. Once you start writing concentrate on what you want to say, not grammar or spelling.

- **RECORDING ON A DIGITAL AUDIO CASSETTE RECORDER**

1. Using audiotapes can be a rewarding choice for a Legacy activity because not only do you have the stories and memories themselves, but you also have the voice that goes with them.

2. When recording, it is important to label each tape with information such as who was present, the subjects discussed, and the date they were recorded.
3. Don't forget to turn the tape recorder on. **Just check to make sure the tape is recording.** Remember to turn the tape over when the tape stops.
4. Don't worry about editing the tape. But if there is something you want to erase from the tape, make sure you know how to record over that section without erasing other valuable material on the tape.
5. Stay in a quiet location and keep the microphone close to both the person helping you and yourself so that you can be sure you are recording what is being said.

- **SCRAPBOOK OR PHOTO ALBUM**

1. Select a Photo Album or Scrapbook that matches your personal style.
2. Decide on a theme for your scrapbook/album. Do you want this to be of a certain event or time frame in your life or do you want it to be a selection of pictures, etc. from a longer time range? Do you want to include names, dates, poems, or songs (Scrapbook) or do you want this to be an album of pictures only?
3. Gather all of the photos, ticket stubs, and anything else you want to include in your scrapbook/photo album before beginning the project.
4. Decide on an order. Do you want things to be chronological? Do you want there to be different sections for different members of

your family? Do you want to tell a story with your pictures and scraps?

5. Try to locate names and dates of individuals in the photos, (if you choose to include them) so that there can be as much detail as possible.

6. Think about any materials you will need and gather them ahead of time. For example, Construction paper, markers, pens, tape, etc. The Legacy project staff will help you with these materials.

- **VIDEO TAPE RECORDING**

1. Use a quality video tape and make sure you know how to use the recording equipment before starting.

2. Try to use a microphone that can be clipped to your shirt or blouse so that the sound is picked up by the camera. But don't worry if this is not available, most video cameras do a pretty good job of picking up sounds in a quiet room.

3. Put the camcorder on a tripod or any stable surface.

4. Set up the view so that it only includes what you want to be included (you, possibly your family member as well, etc.).

5. Find a spot where the light is bright enough and there are few or no shadows.

- **FAMILY COOKBOOK**

1. Begin brainstorming on some of the recipes you would like to include in your cookbook.

2. Will you limit this cookbook to your recipes or include recipes from extended family and favorite cookbooks as well?
3. Decide on a format. Do you want these to be hand-written, typed, a collection of already written cards, etc?
4. Do some research. If you need to call relatives or friends in order to get them to send you recipes you would like to include, begin contacting them now.
5. Collect any materials you will need before beginning the project. For example: a recipe book, pens, tape, yarn, anything you will need to collect these recipes, etc.
6. Think of stories or other sensory information that comes to mind when thinking of a certain recipe. For example if your recipe for homemade oatmeal cookies makes you think of you own mother and the smell of cinnamon and the way she looked standing in the kitchen in the mornings; include these stories in your cookbook. You could also include a picture of your mother if one is available.
7. Use this cookbook to tell a story- personalize it in anyway that you like.

- **OTHER IDEAS**

1. Don't limit yourself to the ideas above; if you are very good at knitting, quilting, or cross-stitching consider making your Legacy project involve these activities.
2. You could put together a booklet of tips, collect patterns that mean a lot to you, or begin a quilt with the members of your family picking the different fabrics to be included.
3. You could write and collect letters to your family members for them to open at future events/ceremonies. For example, letters to your grandkids could be written with your words of wisdom and

wishes for their graduation from high school or college, their marriage, or the birth of their first child or grandchild.

The possibilities for your Legacy project are endless. Spend some time discussing with your ideas with the PIPAC staff member. Think about the kind of Legacy that best represents you and is something you can be proud of.

Look through the list of ideas you came up with during the Brainstorming activity and eliminate any ideas that are unacceptable.

Step 4. Pro's and Con's of Legacy Activities

*** If you have already decided... move on to the next session.*

By now you have generated a list of potential Legacy activities and eliminated any that are unacceptable to you. Now let's use the space below to list Pro's and Con's for the ideas you are still considering.

IDEA #1:

PRO'S:

CON'S:

IDEA #2:

PRO'S:

CON'S:

IDEA #3:

PRO'S:

CON'S:

Step 5. Choosing a Legacy Project

Now all you have left to do is to choose one project from the ideas discussed above. Using the list of Pro's and Con's that you came up with, talk about each idea, and choose the project that feels best for you.

The idea I have decided on for my Legacy Project is:

The PIPAC Project will provide \$20.00 to help with the costs of completing your project. This money should be used for purchasing materials or towards other expenses that will help with completing your project. All you have to do is sign this receipt saying you got the money.

Step 6. Discuss with your family before the next session.

For “homework” discuss the role you identified with a family member or close friend. Use this notebook to guide your discussions. In addition, get your family member or close friend to assist in gathering materials necessary for the completion of your Legacy, which will be the focus of the next session.

Our Plan and Goals for next week:

The time for the next home visit (session) will be:

_____.

If I need to cancel, I should call _____.

SESSION 2: Constructing Your Personal Legacy

- Goal 1. Have all materials necessary for constructing your Personal Legacy.
- Goal 2. If you have not already done so, begin working on your Legacy activity.

Last week, we began by talking about the fact that there is no right way to deal with challenges that you face as a result of your memory. But there are ways to increase positive or good experiences that can help you deal with some challenges. One way to deal with memory loss is to hold on to things from the past and present that are important to you. In a way, maintaining the things that make you who you are.

The Legacy Project is one way of doing this. Today, we will be continuing where we left off last week.

But before we do, did you talk to your family about the roles and project we discussed last week? Although the focus of this part of the PIPAC project is for you to tell your story, one rewarding and meaningful aspect can be to share it with others.

Step 7. Working on the Legacy Activity you chose.

The majority of this week's home visit will be spent putting together the Legacy project.

Are all materials ready?

Did you have any trouble obtaining these materials?

Are there things that you did not understand or that did not feel right about last week's session?

If you are ready to work on the project we decided on last week lets get started!

If not...

Why don't we review the Steps in the workbook this week and see if we can decide on a Legacy activity that will be a better fit for you.

Let's get started!

Step 8. Discuss with your family before the next session.

For "homework" discuss the progress you have made on your Legacy. You should continue to work on your Legacy before the next session (either with your family or by yourself), if you feel comfortable doing so.

Plan and Goals for next week:

The time for the next home visit (session) will be: _____.
If I need to cancel, I should call _____.

SESSION 3: Living Well Through Future Planning

- Goal 1. Discuss progress on Legacy project.
- Goal 2. Introduce the next activity: Future Planning.
- Goal 3. Complete reflection questions as a means of discussing future care plans.

When we first began, I told you we would be doing two types of activities. The first one, the Legacy project is designed to help you hold on to and maintain important parts of your past and present.

The second activity, the focus of our meeting today, is to discuss and write down your ideas about what it means to live well in the future. Specifically, we will be discussing your experience with memory loss and the types of care you would want should you become sicker than you are today. It can be upsetting at times to think about becoming sick or needing medical care, but doing so can help you plan and communicate your wishes to your family and loved ones. By telling them what you would want in order to be comfortable or live well, you are giving a gift to them in the future.

Step 1. We will start today by talking about what it means to live well.

What present or future experiences are most important for you to live well at this time in your life? In what way do you feel you could make this time especially meaningful to you?

What fears or worries do you have about your illness or medical care? For example, do you feel that there are needs or services that you need to discuss?

Who or what sustains you when you face serious challenges in life?

Do you have any religious or spiritual beliefs that help you deal with difficult times? If so, tell me about them.

Step 2. Focusing on your current health and memory.

Tell me what your current illness/symptoms feel like to you?

What do you think is the cause of these symptoms?

What are possible complications that may occur because of your memory loss?

How have these symptoms (and your memory loss) affected your life?

What do you expect of your current plan of care? What do you hope for?"

Step 3. Focusing on your thoughts about future care.

In general, which of the following approaches to your medical treatment would you prefer?

A) Treatment that focuses on extending life as much as possible, even if this means you might have more pain or discomfort, or

B) Treatment that focuses on relieving pain and discomfort as much as possible, even if this means you might not live as long.

What have you discussed with your family about what you might choose for your future medical care, including care at the end-of-life?

Do you think you have had enough discussion and has it been specific enough?

(If applicable...) Why do you think you have not yet thought about planning for your future medical care, including care you would prefer to have at the end of your life?

What experiences have you had in dealing with family/friends who have died or been seriously ill? What did you learn from those experiences? Did they help you form any ideas about your choices for future medical care?"

Step 4. Common reactions to discussing future medical care.

How does it feel to talk about your future medical care?

Some people say:

- "I didn't know that people had choices in these matters. Mustn't doctors always do everything that can be done to sustain life?"
- "Our doctor knows best. Shouldn't she/he make these decisions for me when the time comes?"
- "Frankly, I don't know anything about such issues. I have never considered making decisions like this and I wouldn't know where to begin."

Some people's families might say:

- "But I am the closest relative (spouse, daughter, etc.). Surely I have the right to make these decisions for my loved one if he can't make them for himself."

- "I find it too upsetting to think about my relative's decline. I can't even contemplate his future deterioration."

Do any of these common reactions sound like you or your family? If so, explain.

There is specific information about some of the types of health care treatments that you might want to consider in the back of this notebook. It is called the Medical Information Sheet. Discuss these with your family and friends as you make specific choices about your health care. If we have time, we can come back to these during this session.

Step 5. Choosing a surrogate (or alternate) decision maker.

One of the most important decisions you can make about your future medical care is: who you would want to make medical decisions for you if you were not able to do so yourself.

An ideal decision maker is:

- Someone that is willing to make decisions for you.
- Someone that you trust to follow your wishes.
- Someone that you have talked to about life-sustaining preferences, and
- Someone that can make decisions under sometimes stressful situations.

Have you thought about who you might want to make decisions for you? If so, who?

If they are unable to make decisions for you, is there another person who you would trust?

What types of decisions would you want this person to make?

Step 6. Making a plan after today.

Talking about these issues is important, and the topics we discussed today are a good place to start. But, in order for these discussions to be of value to you and your family, you will need to share your answers to these questions with the important people in your family.

You and your family may want to consider making legal documents (for example:

Durable Power of Attorney, Living Will, and a Healthcare Power of Attorney documents) to secure these wishes.

I know that this is a lot of information to take in. The PIPAC staff wants to support you in whatever way we can. While these decisions may be difficult to make, and difficult to talk about, you are giving a

gift of love to those close to you who may have to make decisions for you if you become unable. By knowing your wishes, they will have the comfort of knowing what you would want them to decide for you. To decide in ways that are in line with who you are, your identity.

Step 6. Discuss with your family before the next session.

For “homework” discuss the topics we covered today with your loved ones and continue working on your Legacy project before our final session next week.

Plan and Goals for next week:

The time for the next home visit (session) will be: _____.
If I need to cancel, I should call _____.

Session 4. Evaluating the Success of Your Legacy and Future Planning

- Goal 1. Show any work/progress (or the completed Legacy if it is ready) made over the last several weeks.
- Goal 2. Discuss your experiences during the whole project with the PIPAC staff.

Step 1. Evaluate the Success of your Legacy Activity and Future Planning

There are many different ways to measure success on a project like this because there is no right or wrong way to approach and produce a Personal Legacy or make plans for future care. Below are some questions to guide discussion.

1. How satisfied are you with the progress you have made on your Legacy Activity?

2. How did recalling these memories make you feel?

3. Will you and your family continue working on your Personal Legacy after the Research staff is no longer involved?

4. How satisfied are you with the plans for future care we discussed?

5. What did you like about this project overall?

6. What did you dislike about this project overall?

7. How could we, the PIPAC research Staff, improve to better help families produce Legacies?

8. Do you feel like this Legacy activity helped you communicate?

9. Do you feel like the future planning activity helped you communicate?

10. What specific areas of this process worked well for you?

11. What specific areas of this process did not work as well?

Step 2. Using what you have learned to cope in the future.

Your experience during this project is as unique as the Legacy Activity you have been working on. Discuss with your family member and the research staff anything that you have learned during this process and how you could use this information in the future. Will you make other Personal Legacies? Will you reflect on your Legacy when your memory troubles you? Will you tell other members of your family about these types of projects?

With your permission, we can share these activities with your family member or discuss further any of the topics we have discussed in the past.

Thank you for your hard work on this project!

PIPAC Participant Notebook
APPENDIX

Additional Questions to help you narrow your focus and to consider including in you personal Legacy.

FAMILY HISTORY:

- What do you know about your family coming to the United States?
 - What are the stories about who came, why they came, where they lived, etc.?
- When and where were you born?
 - For whom were you named? A relative? A famous person, etc.?
 - Where did your family live when you were born?
 - Who was in your immediate family then?
 - What else do you know about your beginnings
- Did you know any of your great-grandparents/grandparents?
 - What do you remember about them?
 - Describe some memories you have of them, their home, where they lived, etc?
 - How did they influence your life?
- Where did your parents grow up?
 - Where were they born?
 - How did they meet?
 - Do you know any stories about their courtship/marriage?
 - How did your mother and father influence you?
 - What do you remember most about them?
- Did you have brothers and sister?
 - Were you the oldest, youngest, middle child?
 - What are some of your favorite stories about your siblings?

- **GROWING UP:**
- Where did you live?
 - How frequently did you move as a child?
 - Did you have any pets?
 - Did any relatives, other people, live in the same house?
- What school did you attend?
 - How did you get to school?
 - Were the educational expectations different for boys and girls at this time?
 - What do you remember about teachers?
- Were you a healthy child?
- What kinds of celebrations did you and your family have?
- Who were your closest relatives?
- Describe your neighbors.
- Who were your closest friends?
- Did you have any hobbies or play any sports?
- Do you remember the influence science, technology, or industry had on your life?
 - Remember any new inventions (cars, refrigerators, air conditioning, television, etc?)
- What was the financial situation like in your family?
 - Did your mother work? Her profession?
 - How did your family handle hard times?
- Were you interested in politics, etc?

- **ADULT LIFE:**
- When did you first consider yourself an adult?
- Did you marry?
 - How did you meet your spouse?
 - Describe your spouse when you first met.
 - Did you have a significant song?
 - What was your wedding/honeymoon like?
 - What were some of the happiest times/hardest times with your spouse?
- Describe your first home.
- If there was a separation by divorce or death, how did you feel about it?
 - How did it change your life?
- Did you marry again?
 - Tell this story.
- Did you have children?
 - When was your first child born?
 - How did you feel about being a parent?
 - What was your role in childcare? Your spouse's role?
 - What were some of your favorite memories of your children as they were growing up?
 - How did your relationship with your children change as they became adults?
- Did you have grandchildren?
- How was your health as an adult?
- What was your community/church life like?
- What were your vacations like? Favorites?
- How did you and your spouse earn a living?
 - Were there hard times? How were they handled?
- What were your views on politics, religion, world events, etc?

- **GROWING OLDER:**
- How old are you?
 - What is it like for you at this age?
 - Do you like being this age? Why?
- Did you look forward to retirement, if you are retired?
 - What were your plans for this time?
 - Do you miss work?
 - What have you done since you and your spouse retired?
- Where do you live now and how long have you lived here?
- How did you feel about moving into the place you live now?
- Describe your family at this time?
 - What is your relationship with them like at the present time?
- Are you a grandparent?
 - What has it meant to you to be a grandparent?
- Who are your friends now?
 - What do you share in common with them?
 - How are they important to you?
- What are some of your memories about special anniversaries or celebrations?
- How would you describe your current health condition?
 - What kind of help are you receiving?
 - Have you been a caregiver for any member of your family or friends? What were your feelings?
 - How does it feel now, if you are receiving care?
- Have you lost a spouse? A child? A dear friend or relative?
 - How has this loss affected you?
- Did you get any new hobbies after retirement?
- What are your favorite books, authors, and fictional characters?
 - Why is that?
- Do you enjoy the work of any particular artists?
- Is there anything you wish you still had time to learn?
- Is technology helping you to have a better quality of life?
- Have your opinions about politics, religion, or worldly affairs changed in recent years?
- How has religion influenced the way you deal with death and illness?
- What is most important to you at this time in your life?

ADVANCE CARE PLANNING- SUPPLEMENTARY INFORMATION

TREATMENT OPTION – ARTIFICIAL NUTRITION AND HYDRADTION

Artificial nutrition and hydration, also called tube feeding, is used when you have problems swallowing or can no longer eat or drink on your own. A PEG tube can be used to give your body nourishment, and therefore replaces ordinary eating and drinking.

THE PROCEDURE

A PEG tube requires surgery and a short stay in the hospital. A cut is made in your abdominal wall and the tube is placed directly into the stomach. You will be given an anesthetic to help you sleep during surgery. After the PEG tube is inserted, proteins and liquids can be pumped directly into your stomach. After you are released from the hospital, a nurse or your caregiver will need to regularly check the PEG tube to make sure that it is working properly.

BENEFITS

1. Nutrients and fluids provided though the PEG tube prevents choking and reduces pain due to constipation.
2. Your family may feel better knowing that you are being fed by the PEG tube. Providing nourishment is often a symbol of their care and love.

RISKS

1. Nutrients provided through the PEG tube may increase feelings of nausea and vomiting.
2. The area where the PEG tube is inserted may become infected and cause pain or the tube may come out of the stomach.

ALTERNATIVES

Your family may provide juices or soft foods such as jell-o, pudding, and ice cream. If you are unable to take in these things, small ice chips can be used to wet your lips and reduce dry mouth. However, this option is less likely than the PEG tube to help you live longer.

TREATMENT OPTION – CPR (CARDIOPULMONARY RESUSCITATION)

If you stop breathing or your heart stops beating, doctors can perform CPR.

PROCEDURE

In CPR, doctors press up and down on your chest to keep your heart beating. They also help you continue breathing by blowing air into your mouth. If you do not begin to breathe on your own, you can be placed on a machine that breathes for you.

BENEFITS

1. CPR may help you live longer if it is successful.
2. CPR is a fairly simple procedure, and it may help your family feel that everything possible is being done to treat your health problems.

RISKS

1. CPR may result in pain from broken ribs and discomfort from being on a breathing machine (mechanical ventilator).
2. CPR may help you live longer in a more debilitated (sick or ill) state, resulting in sadness and fatigue, and perhaps a desire for death.

ALTERNATIVES

If you do not want CPR or to be placed on a breathing machine, you need a DNR. DNR means "Do Not Resuscitate." It is a written statement which says that you do not want doctors to perform life sustaining procedures.

If you are not interested in aggressively treating any newly developing condition in a hospital, you may need a DNH or "Do Not Hospitalize" Order. A DNH order may be appropriate if you are near the end of life with an end-stage illness such as Alzheimer's Disease or cancer and prefer to focus on remaining comfortable in your home or in a nursing facility.

TREATMENT OPTION - MECHANICAL VENTILATION

Mechanical ventilation (MV) can be used to assist you to breathe when you can no longer breathe on your own. MV can provide your brain with needed oxygen so that you can maintain your thinking skills and quality of life.

THE PROCEDURE

This procedure requires surgery called tracheotomy and a varying period of time in the hospital. A tracheotomy provides surgical access to the trachea to allow oxygen to flow into your lungs. You may have to have a tracheotomy in order to be able to use a mechanical ventilator for weeks, months, years, or even the rest of your life.

BENEFITS

1. MV can either assist you to breathe or they can take over breathing for you completely and keep you alive.
2. Your family may feel better knowing that you knowing that your breathing is being assisted or controlled by MV.

RISKS

1. Some types of tubes inserted may cause coughing and pain.
2. Infections (pneumonia, for example) may occur as a result of MV for patients who use MV for an extended period of time.

ALTERNATIVES

If you do not choose to have a MV, you may not be able to breathe on your own. Lack of oxygen to your brain will cause brain damage that will harm your thinking skills and make your quality of life worse. Eventually, if you do not begin to breathe on your own, you will die.

APPENDIX D: Capacity Checklist for Consent

Capacity to Consent Checklist

Complete this checklist as you review the informed consent with the potential participant. Explain to the participant that:

“We are going to go over a form called the ‘Informed Consent,’ which will explain everything you are being asked to do as part of the study. Feel free to stop me at any time to ask questions. I have a copy that I will read out loud, and here is a copy for you to look at. We are going to go slow and review parts of the document as we go to make sure you understand all the pieces of the project. Are you ready? OK...”

1.) Does the participant understand the nature of the research and of his/her participation?

_____ Check #1: After reviewing “What is this study about?” on page 1 of the consent form, say to the participant, *In your own words tell me what this study is about.*

If the participant has difficulty, provide simple prompts such as:

- *This study is for people with memory problems, can you tell me more about it?*
- *This study will guide you through two activities can you tell me about some of the things we will be doing?*

_____ Check #2: After reviewing the section, “What will I be asked to do in this study?” on page 2, say to the participant, *In your own words, tell me some of the things you will be asked to do as part of this study.*

If the participant has difficulty, provide simple prompts such as:

- *As part of participation you will be assigned to one of two groups, can you tell me the difference in the “intervention group” and the “no intervention group”?*
- *You and your family member will also be asked some questions as part of the study. What type of questions might you be asked?*

Record any notes here:

2) Does the participant appreciate the consequences of the participation, including personal consequences?

_____ Check #1: After reviewing the section “What are the benefits or good things that might happen as a result of being in the study” say: *In your own words, tell me some of the good things that might come from being in the study?*

_____ Check #2: After reviewing the section on risks of being in the study on page 3 say, *Now tell me some of the bad things that may come from being in the study?*

- If the participant is unable to spontaneously provide positive or negative consequences, make note of any prompts that are used or sections that are repeated.

Record any notes here:

3) Does the participant show the ability to understand alternatives, including the option not to participate?

_____ Check #1: After reviewing the section “What are my rights as a participant” say: *Do you understand that your participation is voluntary, it is your decision?*

_____ Check #2: Also ask, *Is anyone pressuring you to take part in this study?*

_____ Check #3: And “*If you change your mind about being in the study, what can you do?*”

Record any notes here:

4) Does the participant show the ability to make a reasoned and consistent choice?

_____ Check #1: After reviewing the entire consent form, say: *Do you have any final questions about the study? Does this sound like something you want to take part in?*

_____ Check #2: Make note throughout the informed consent process and the initial assessment (Baseline) regarding the consistency of their choice to take part in the study.

Record any notes here:

APPENDIX E: Recruitment Materials

INITIAL PHONE CONTACT SCRIPT

“Hello my name is _____, from The University of Alabama. I received your name and contact information from _____ at _____ (insert referral agency here), who mentioned that you might be interested in learning more about a new study we are doing.

If you have time, may I tell you more about the project we’re doing and see if you’re interested in participating?”

- If no then the researcher or recruiter will say, “Thank you and have a wonderful day.”
- If yes, then the researcher or recruiter will say specifically:

“Great. Well, we are doing a study to help us better understand the everyday experiences of people who have been diagnosed with a memory-related problem like dementia or Alzheimer’s disease.”

“Have you or someone you know been diagnosed with a memory problem?”

- If no, then explore why they are interested in learning more about the study.
- If yes, then listen to whether they are the potential participant with dementia or whether they are the potential family member/family contact and modify accordingly as you proceed.

“The title of the study is Preserving Identity and Planning for Advance Care. Like the title suggests, this study has two parts.

1. The first part is designed to help an individual like you (or your loved one) create a personal legacy or activity to honor one important aspect of their life story. The whole family can help work on a legacy, but our team would work primarily with you (or your loved one). In the past, some families have made scrapbooks, cookbooks, photo albums, and tapes of the older adult’s life story. Our staff would help you (or your loved one) design a project that best fits you (or your loved one).
2. The second part of the study is designed to help individuals like yourself (or your loved one) start planning for future care needs, such as the kinds of medical decisions you might face in the future. By thinking about these decisions now, you can be more involved in your future care.

“Do you have any questions about what the study is about?”

- Answer questions. Use additional information on this script if needed.

“The project will take about an hour of your time for a period of several weeks. In exchange for your help you and close family member will receive a small thank you at the end of the project.”

“The whole study from start to finish will take around a month to complete. Is this something you would be willing to consider participating in?”

- If no, then the recruiter or researcher will say, “Thank you for your time and have a wonderful day.”
- If potential participant answers yes to interest in the study, then specifically the recruiter or researcher will say:

“Wonderful. At this time I would like to ask you a few questions to see if the study is appropriate for you:

ASK these questions if you are speaking with the potential participant with dementia.

*** If you are speaking with the family contact proceed to page 4:*

- Are you 55 years of age or older?
 - **YES** no
- Are you able to read and speak English?
 - **YES** no
- Have you ever been diagnosed with a memory-related problem like dementia?
 - **YES** no
- Do you have a family member (like a spouse or adult child) that might be able to attend two of the appointments with you?
 - **YES** no

ELIGIBLE: If the potential participant answers YES to all of the study criteria then ask:

“So far it sounds like you are eligible to be in the study. Would it be OK if I spoke with your family member to tell them about the study and to see if they would be willing to help out?”

If yes, gather contact information and call family member or try to speak with them on the phone when you are done with this potential participant.

If no, then ask if they want to tell their loved one about the study and get back with us. We can either follow up in a couple of days or they can call us back after they have talked to their family member.

NOT ELIGIBLE: If the participant is not eligible, say: “Based on your responses, you are not eligible for this study. We need people who are _____. Thanks again for your interest in our project. Do you have any questions before we get off the phone today? OK, have a great day. Goodbye. ”

Continued from above:

When you have gathered all necessary information from the potential participant, say:

“Thank you so much for taking the time to talk with me today and for your interest in the study. After I have spoken with your family member I will call you back to schedule our first meeting. Have a great day! Bye.”

** Eligibility criteria for family contact:

- Do you have at least weekly contact with your loved one with dementia or other memory problem?
 - **YES** no
- Are you able to read and speak English?
 - **YES** no
- Are you generally available by phone?
 - **YES** no
- Do you live close enough to your loved one’s home or another convenient place so that you could participate in two interviews with your loved one?
 - **YES** no

ELIGIBLE: If the potential participant answers YES to all of the study criteria then ask:

“Great, it sounds like you are eligible to be in the study. Would it be OK if I spoke with your family member to tell them about the study and to see if they are also interested in participating?”

If yes, gather contact information and call family member or try to speak with them on the phone when you are done with this potential participant.

If no, then ask if they want to tell their loved one about the study and get back with us. We can either follow up in a couple of days or they can call us back after they have talked to their family member.

NOT ELIGIBLE: If the participant is not eligible, say: “Based on your responses, you are not eligible for this study. We need people who are _____. Thanks again for your interest in our project. Do you have any questions before we get off the phone today? OK, have a great day. Goodbye. ”

Continued from above:

When you have gathered all necessary information from the potential participant, say:

“Thank you so much for taking the time to talk with me today and for your interest in the study. (After I have spoken with your family member I will call you back to schedule our first meeting.) Have a great day! Bye.”

*** Once both family members have agreed to be in the study schedule the Baseline assessment with both members of the family. Let them know that informed consent (their official agreement to be in the study) will occur first thing at the Baseline assessment.*

DRAFT Content for Recruitment Flyer:

Have you or someone you know been diagnosed with dementia, Alzheimer's disease, or other memory problem?

WHAT:

You may be eligible for a free study interested in understanding your everyday experience of living with memory problems. Some participants will complete tasks to document aspects of their life story and plan for future medical needs. All participants will receive a small monetary incentive as a "thank you" for their time.

WHERE:

All meetings can take place in your home or wherever you are most comfortable.

HOW:

If you would like to learn more about this study provide your name and contact information on this form and we will give you a call:

Name: _____

Phone Number: _____

OR You can Contact Us At:

Michelle Hilgeman, M.A. (205) 348-0266

Rebecca Allen, Ph.D. (205) 348-7518

APPENDIX F: Focus Group Sample Questions

Sample questions for focus group.

The one time optional focus group will be semi-structured. The following questions will guide the Focus Group Facilitator, but they are not intended as a script.

Questions about your experience as an interventionist on the project:

- To open, what general feedback do you have to offer about your experience as an interventionist in the PIPAC Project?
- What was the most rewarding part of your work as an interventionist?
- What was the most challenging aspect of your role as an interventionist?
- How did you feel about going into peoples' homes to conduct a project like this?
- What advice, if any, would you offer to future interventionists working with this population (dyads in the early stages of dementia)?
- Did you feel adequately trained for your role in the project?
 - What additional training would have been helpful?
- How did you feel about the life story/reminiscence aspect of the project? What about the advance care planning aspect?
 - What recommendations do you have for improving these components?
- Would you recommend being a PIPAC interventionist to other research volunteers? Why or why not?

Questions about the Intervention and Participant Population:

- How do you feel about the amount of time that you needed to spend with families during each session? Was it too much? Not enough? Please explain...
- How much time did you spend working on the project between sessions? Is this realistic to expect of research volunteers?
- We aimed to complete the four intervention sessions in 4-8 weeks. After taking into consideration that things come up that may interfere with scheduling both for the patient/caregiver and volunteer, is this amount of time adequate?
- How did you feel about the Participant Notebook?
 - Did you have the Participant Notebook out during all of the Sessions?
 - Did you or the family write in the Participant Notebook?
- How do you feel about the timing/sequence of the intervention sessions?
- Were there too many or too few intervention sessions?
- Was the length of the session too long or too brief?
- Is there anything else that you would like to add or change if you had designed the study?

Appendix G: Cash Receipt Tracking Documents

PIPAC PROJECT

Michelle M. Hilgeman, M.A. & Rebecca S. Allen, Ph.D.
Center for Mental Health and Aging
The University of Alabama

Cash Distribution:

The signatures and initials below indicate the receipt of reimbursement for participation in the Preserving Identity and Planning for Advance Care (PIPAC) Project.

I received \$20.00 _____ (Primary Participant initials)

I received \$10.00 _____ (Family Member Participant initials)

1. Primary Participant Receiving:

Print name Social Security #

Signature Date

2. Family Member Participant Receiving:

Print name Social Security #

Signature Date

3. Staff Giving Cash:

Print name

Signature Date

Reason for Cash: (please check one)

- Receipt at completion of Assessment Visit #1 (Baseline)
- Receipt at completion of Assessment Visit #2 (Post-Interv.)

April 5, 2010

Office for Research

Institutional Review Board for the
Protection of Human Subjects

THE UNIVERSITY OF
ALABAMA
R E S E A R C H

Michelle Hilgeman
Department of CMHA
College of Arts and Sciences
Box 870315

Re: IRB Application 08-008-R1 (Revision 2), Preserving Identity and Planning for Advance Care (PIPAC): An Intervention to Increase Coping in the Early Stages of Dementia”

Dear Ms. Hilgeman:

The University of Alabama Non-Medical Institutional Review Board has recently reviewed the revision request for your protocol. The board has approved the change in your protocol.

Please remember that your approval period expires one year from the date of your original approval, 5/15/2009, not the date of this revision approval.

Should you need to submit any further correspondence regarding this proposal, please include the assigned IRB application number.

Good luck with your research.

Sincerely,



Stuart Usdan, PhD
Chair, Non- Medical Institutional Review Board
The University of Alabama



152 Rose Administration Building
Box 870117
Tuscaloosa, Alabama 35487-0117
(205) 348-5152
FAX (205) 348-8882

UNIVERSITY OF ALABAMA INSTITUTIONAL REVIEW BOARD FOR THE PROTECTION OF HUMAN SUBJECTS

REQUEST FOR APPROVAL OF RESEARCH INVOLVING HUMAN SUBJECTS

I. Identifying information

Table with 4 columns: Investigator Type, Name, Department, College, University, Address, Telephone, FAX, E-mail. Rows for Principal Investigator (Michelle M. Hilgeman, M.A.), Second Investigator (Rebecca S. Allen, Ph.D.), and Third Investigator.

Title of Research Project: Preserving Identity and Planning for Advance Care (PIPAC): An Intervention to Increase Coping in the Early Stages of Dementia

Date Printed: Funding Source: Center for Mental Health & Aging Student Research Award (\$2,000)

Type of Proposal: [] New [X] Revision [] Renewal [] Completed [] Exempt. Includes instructions: Attach a renewal application, Attach a continuing review of studies form, Please enter the original IRB # at the top of the page.

UA faculty or staff member signature: _____

II. NOTIFICATION OF IRB ACTION (to be completed by IRB):

Type of Review: [X] Full board [] Expedited

IRB Action:

- [] Rejected Date: _____
[] Tabled Pending Revisions Date: _____
[] Approved Pending Revisions Date: _____

[X] Approved—this proposal complies with University and federal regulations for the protection of human subjects

Approval is effective until the following date: 5/14/2010

- Items approved: [] Research protocol: dated
[] Informed consent: dated
[] Recruitment materials: dated
[X] Other: study staff dated

Approval signature _____ Date 4-5-10

Primary Participant ID <input style="width: 100%; height: 20px;" type="text"/>	Date of Session 1 <input style="width: 15%; height: 20px;" type="text"/> / <input style="width: 15%; height: 20px;" type="text"/> / <input style="width: 20%; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 100%; height: 20px;" type="text"/>
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This checklist measures aspects of the Interventionist's interactions with the primary participant and their family contact and/or other members of the family.

The checklist is broken down by session, such that each intervention visit is covered in a unique section and should be completed as soon as possible after the corresponding intervention visit is completed.

INTERVENTION SESSION 1

Treatment Receipt:

1. How long was the session (in minutes)?

Treatment Delivery:

Delivery Scale

- | | | | | |
|--|----------------------------------|---------------------------------|----------------------------------|---------------------------|
| 1. Introduction: There are different ways to cope with changes in memory (p.3-4) | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |
| 2. What we will do in this project: 2 activities we will be doing (p.4-6) | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |
| 3. Overview of Visits: can review quickly if already covered (p.7) | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |
| 4. Step 1-2: Identify a role or piece of life story as a focus (p.8-11) | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |
| 5. Step 3-4. Discussing possible solutions, pros and cons, and reviewing the tips (if applicable). (p.12-17) | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |
| 6. Step 5-6. Review or solidify the idea for the project and outline specific tasks for the participant to do before next week. (p.18) | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |

Treatment Delivery Notes and/or comments:

41451

Primary Participant ID <input style="width: 100%; height: 20px;" type="text"/>	Date of Session 1 <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 40px; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 100%; height: 20px;" type="text"/>
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INTERVENTION SESSION 1

Treatment Enactment:

1. Was the family contact at the session?

Yes No

2. Were others present at the session?

Yes No

3. Using a percentage (like a pie chart) that must add up to 100%...

a) How much of the work/talking **during the session** did the primary participant engage in or do:

%

b) How much of the work/talking **during the session** did you the interventionist do:

%

c) How much of the work/talking **during the session** did others (family/friends) do:

+ %

*** if no others were present then record a "0" for their part*

100 %

Treatment Enactment Notes and/or comments:

Primary Participant ID [][][][]	Date of Session 2 [][] / [][] / [][][][]	Research Assist. Initials [][]
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INTERVENTION SESSION 2

Treatment Receipt:

1. How long was the session (in minutes)? [][][]

Treatment Delivery:

Delivery Scale

- | | | | | |
|--|----------------------------------|---------------------------------|----------------------------------|---------------------------|
| 1. Review goal of project (p.19) | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |
| 2. Introduce Step 7: working on the project and addressing obstacles if applicable (p. 19) | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |
| 3. Work on the project with the participant (20). | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |
| 4. Explain Step 8. Discuss with family and make a detailed plan for next week. | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |

Treatment Delivery Notes and/or comments:

Primary Participant ID <input style="width: 100%; height: 20px;" type="text"/>	Date of Session 2 <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>
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INTERVENTION SESSION 2

Treatment Enactment:

1. Was the family contact at the session?

Yes No

2. Were others present at the session?

Yes No

3. Using a percentage (like a pie chart) that must add up to 100%...

a) How much of the work/talking **during the session** did the primary participant engage in or do:

%

b) How much of the work/talking **during the session** did you the interventionist do:

%

c) How much of the work/talking **during the session** did others (family/friends) do:

+

 %

*** if no others were present then record a "0" for their part*

100 %

4. Using a percentage (like a pie chart) that must add up to 100%...

a) How much of the work/talking **since the last session** did the primary participant engage in or do:

%

b) How much of the work/talking **since the last session** did you the interventionist do:

%

c) How much of the work/talking **since the last session** did others (family/friends) do:

+

 %

*** if no others helped then record a "0" for their part*

100 %

Treatment Enactment Notes and/or comments:

Primary Participant ID <input style="width: 100%; height: 20px;" type="text"/>	Date of Session 3 <input style="width: 20%; height: 20px;" type="text"/> / <input style="width: 20%; height: 20px;" type="text"/> / <input style="width: 40%; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 100%; height: 20px;" type="text"/>
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INTERVENTION SESSION 3

Treatment Receipt:

1. How long was the session (in minutes)?

Treatment Delivery:

Delivery Scale

- | | | | | | | | | |
|--|-----------------------|------------|-----------------------|-----------|-----------------------|------------|-----------------------|-----|
| 1. Discussion of Step 1. Living Well (p.22) | <input type="radio"/> | Not at all | <input type="radio"/> | Partially | <input type="radio"/> | Completely | <input type="radio"/> | N/A |
| 2. Discussion of Step 2: Focusing on current health and memory. (p. 23) | <input type="radio"/> | Not at all | <input type="radio"/> | Partially | <input type="radio"/> | Completely | <input type="radio"/> | N/A |
| 3. Discussion of Step 3. Focusing on thoughts of future care. (p. 23). | <input type="radio"/> | Not at all | <input type="radio"/> | Partially | <input type="radio"/> | Completely | <input type="radio"/> | N/A |
| 4. Discussion of Step 4. Common reactions to discussing future medical care. (p. 24) | <input type="radio"/> | Not at all | <input type="radio"/> | Partially | <input type="radio"/> | Completely | <input type="radio"/> | N/A |
| 5. Discussion of Step 5. Choosing an alternate decision maker. (p. 25) | <input type="radio"/> | Not at all | <input type="radio"/> | Partially | <input type="radio"/> | Completely | <input type="radio"/> | N/A |
| 6. Discussion of Step 6. Making a plan after today. (p. 26) | <input type="radio"/> | Not at all | <input type="radio"/> | Partially | <input type="radio"/> | Completely | <input type="radio"/> | N/A |
| 7. Assigning "homework" to talk with family before next session. (27) | <input type="radio"/> | Not at all | <input type="radio"/> | Partially | <input type="radio"/> | Completely | <input type="radio"/> | N/A |

Treatment Delivery Notes and/or comments:

Primary Participant ID <input style="width: 100%; height: 20px;" type="text"/>	Date of Session 3 <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 40px; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 100%; height: 20px;" type="text"/>
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INTERVENTION SESSION 3

Treatment Enactment:

1. Was the family contact at the session?

Yes No

2. Were others present at the session?

Yes No

3. Using a percentage (like a pie chart) that must add up to 100%...

a) How much of the work/talking **during the session** did the primary participant engage in or do:

%

b) How much of the work/talking **during the session** did you the interventionist do:

%

c) How much of the work/talking **during the session** did others (family/friends) do:

+ %

*** if no others were present then record a "0" for their part*

100 %

4. Using a percentage (like a pie chart) that must add up to 100%...

a) How much of the work/talking **since the last session** did the primary participant engage in or do:

%

b) How much of the work/talking **since the last session** did you the interventionist do:

%

c) How much of the work/talking **since the last session** did others (family/friends) do:

+ %

*** if no others helped then record a "0" for their part*

100 %

Treatment Enactment Notes and/or comments:

Primary Participant ID	Date of Session 4	Research Assist. Initials
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>

INTERVENTION SESSION 4

Treatment Receipt:

1. How long was the session (in minutes)?

Treatment Delivery:

Delivery Scale

- | | | | | |
|---|----------------------------------|---------------------------------|----------------------------------|---------------------------|
| 1. Discuss success of project (p. 28) | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |
| 2. Discuss satisfaction with project (p.28-29) | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |
| 3. Goal 1. Get the participant to share their progress with you the interventionist. (p. 28) | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |
| 4. Discuss plans for working on the project or continuing aspects into the future. (p. 28-29) | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |
| 5. Step 2. Discuss Using what you have learned to cope in the future. | <input type="radio"/> Not at all | <input type="radio"/> Partially | <input type="radio"/> Completely | <input type="radio"/> N/A |

Treatment Delivery Notes and/or comments:

Primary Participant ID <input style="width: 100%; height: 20px;" type="text"/>	Date of Session 4 <input style="width: 15%; height: 20px;" type="text"/> / <input style="width: 15%; height: 20px;" type="text"/> / <input style="width: 20%; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 100%; height: 20px;" type="text"/>
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INTERVENTION SESSION 4

Treatment Enactment:

1. Was the family contact at the session?

Yes No

2. Were others present at the session?

Yes No

3. Using a percentage (like a pie chart) that must add up to 100%...

a) How much of the work/talking **during the session** did the primary participant engage in or do:

%

b) How much of the work/talking **during the session** did you the interventionist do:

%

c) How much of the work/talking **during the session** did others (family/friends) do:

+ %

*** if no others were present then record a "o" for their part*

100 %

4. Using a percentage (like a pie chart) that must add up to 100%...

a) How much of the work/talking **since the last session** did the primary participant engage in or do:

%

b) How much of the work/talking **since the last session** did you the interventionist do:

%

c) How much of the work/talking **since the last session** did others (family/friends) do:

+ %

*** if no others helped then record a "o" for their part*

100 %

Treatment Enactment Notes and/or comments:



4625

Dyad Tracking Form

PIPAC Project- Patient Form

Primary Participant ID [][][][]	Date [][] / [][] / [][][][]	Research Assist. Initials [][][]
Family Contact ID [][][][]	<input type="radio"/> Intervention <input type="radio"/> Control	

1. Relationship to the primary participant (patient):

- Spouse
- Child
- Grandchild
- Sibling
- Niece/Nephew
- Paid Companion
- Friend
- Other

2. Primary participant's living situation:

- lives alone independently (senior apt, in community, etc.)
- assisted living
- lives in community with others (e.g., spouse)
- nursing home
- other

3. Completion status of primary participant:

- Completed project
- Baseline only because ineligible for study
- Baseline only for other reason
- Refused before baseline
- Screened but never did baseline
- Dropped out after baseline
- Died



4625

Primary Participant ID

--	--	--	--

Family Contact ID

--	--	--	--

4. Completion status of family contact:

- Completed project
- Baseline only because ineligible for study
- Baseline only for other reason
- Refused before baseline
- Screened but never did baseline
- Dropped out after baseline
- Died

5. Research assistants who did assessment:

- same assessor did baseline and post-intervention assmt.
- different assessors did baseline and post

6. Research assistant who was the interventionist or control caller:

- also did baseline assessment but not post-intervention assessment
- did not do any of the assessment for this family

7. Protocol status:

- family stayed on protocol throughout project
- family went off protocol during or after intervention session 1
- family went off protocol during or after intervention session 2
- family went off protocol during or after intervention session 3
- family went off protocol during or after intervention session 4
- family went off protocol during or after control call 1
- family went off protocol during or after control call 2

8. Number of baseline visits:

- one visit
- two visits
- three visits
- four or more visits

--



4625

Primary Participant ID

--	--	--	--

Family Contact ID

--	--	--	--

9. Length of baseline in minutes (total):

--	--	--

10. Length of post-intervention in minutes (total):

--	--	--

11. Length of intervention session 1 in minutes (total):

--	--	--

12. Length of intervention session 2 in minutes (total):

--	--	--

13. Length of intervention session 3 in minutes (total):

--	--	--

14. Length of intervention isession 4 in minutes (total):

--	--	--

15. Length of control call 1 in minutes (total):

--	--	--

16. Length of control call 2 in minutes (total):

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44658

DEMOGRAPHIC DATA PIPAC Project- Patient Form

Participant ID <input style="width: 100%; height: 20px;" type="text"/>	Date <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 40px; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 100%; height: 20px;" type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Intervention <input type="radio"/> Control <input type="radio"/> Patient <input type="radio"/> Family Contact <input type="radio"/> Post-Intervention		

1. What is your date of birth? / /

2. How old are you now?

3. What is your sex or gender? Male Female

If "other," please specify

4. How would you describe your primary racial or ethnic group?

White, Caucasian

Black, African-American

Native American, Eskimo, Aleut

Asian or Pacific Islander

Hispanic, Latino

No primary group

Other

If "other," please specify

5. How many years of education have you completed?

6. What was your primary occupation?

7. How hard is it for you to pay for the very basics like food, housing, medical care, and heating?

Very Difficult

Difficult

Not very difficult

Not at all difficult

Participant ID

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8. What are your primary medical complaints or diagnoses?

Primary Diagnosis 1:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Primary Diagnosis 2:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Primary Diagnosis 3:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Primary Diagnosis 4:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

9. Have you received a diagnosis related to your memory loss?

Yes No

10. What is your memory-related diagnosis?

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

11. How long has it been since you received your memory-related diagnosis? *(convert to months for data entry)*

--	--	--	--

 months

12. How long have you been experiencing memory problems? *(convert to months for data entry)*

--	--	--	--

 months

13. Are you currently taking any medications for your memory or mood?

Yes No

14. If so, what are they and how long have you been taking them?

Name of Medication 1:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

--	--	--	--

 months

Name of Medication 2:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

--	--	--	--

 months

Name of Medication 3:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

--	--	--	--

 months

Name of Medication 4:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

--	--	--	--

 months



44658

DEMOGRAPHIC DATA
PIPAC Project- Patient Form

Participant ID

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14. Have there been any modifications to your medications in the last 3 months?

Yes No

Medication Changes Description:

--



28608

**Bath Assessment of Subjective Quality of Life (BASQID)
PIPAC Project- Patient Form**

Participant ID

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In the next set of questions the answer choices change. Please rate how you are feeling based on the new scale provided on the card in front of you. (Point to response card in notebook)

13. To what extent do you suffer from physical discomfort?

- Not at all A little A moderate amount Quite a lot A great deal

14. To what extent do feel unwell?

- Not at all A little A moderate amount Quite a lot A great deal

15. To what extent are you able to do all the activities you want to?

- Not at all A little A moderate amount Quite a lot A great deal

16. To what extent do you feel frustrated with your ability to do things?

- Not at all A little A moderate amount Quite a lot A great deal

17. To what extent are you bothered by feelings of tiredness and fatigue?

- Not at all A little A moderate amount Quite a lot A great deal

18. To what extent are you able to do things that you enjoy?

- Not at all A little A moderate amount Quite a lot A great deal

19. To what extent do you feel bored?

- Not at all A little A moderate amount Quite a lot A great deal

20. To what extent do you feel you are in control of your life?

- Not at all A little A moderate amount Quite a lot A great deal

21. To what extent do you feel you have the choice to do the things that you want to do?

- Not at all A little A moderate amount Quite a lot A great deal

22. To what extent do you feel useful?

- Not at all A little A moderate amount Quite a lot A great deal

23. To what extent do you feel happy?

- Not at all A little A moderate amount Quite a lot A great deal

24. To what extent do you feel anxious?

- Not at all A little A moderate amount Quite a lot A great deal

Data Entry Note: All items are entered in data as 0-4. No reverse coding embedded in document.



23701

Subjective Health Measure

Levy-Cushman & Abeles, 1998

PIPAC Project- Patient Form

Participant ID	Date	Research Assist. Initials
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>
<input type="radio"/> Baseline	<input type="radio"/> Intervention	<input type="radio"/> Control
<input type="radio"/> Post-Intervention	<input type="radio"/> Patient	<input type="radio"/> Family Contact

I would like to ask you some questions about your health.

1. How would you rate your overall health at the present time?

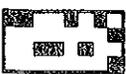
- Excellent
- Good
- Fair
- Poor

2. Is your health now: better, about the same, or not as good as it was 3 years ago?

- Better
- The same
- Not as good

3. Do your health problems stand in the way of doing things you want to do?

- Not at all
- A little
- A great deal



MEMORY SITUATIONS QUESTIONNAIRE

PIPAC Project- Patient Form

Participant ID <input style="width: 100%; height: 20px;" type="text"/>	Date <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 100%; height: 20px;" type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention	<input type="radio"/> Control <input type="radio"/> Patient <input type="radio"/> Family Contact

I am going to give you some examples of everyday situations where you might need to use your memory. I want you to think about your own memory, as it is now, and tell me how you think you would manage in that situation. I want you to choose the answer that best describes how you would do. The answers are on the card here. These are the situations:

SITUATION

1. You meet someone and are told their name. Later on you meet them again, and you need to remember their name.

(use response card to prompt choices)

2. You have made an appointment. You need to remember to go along.

3. You have promised to do something later in the day. You need to remember to do it at the right time.

4. You have got a set of items to sort out, some of which you have seen before and some of which are new to you. You need to pick out the ones you have seen before.

FREQUENCY

- Never
- Rarely
- Sometimes
- Often
- Always

- Never
- Rarely
- Sometimes
- Often
- Always

- Never
- Rarely
- Sometimes
- Often
- Always

- Never
- Rarely
- Sometimes
- Often
- Always

MEMORY SITUATIONS QUESTIONNAIRE
PIPAC Project- Patient Form

Participant ID

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SITUATIONFREQUENCY

5. You hear a news item on the radio.

(a) One of your family comes in at the end and asks you what was said.

- Never
 Rarely
 Sometimes
 Often
 Always

(b) Later on - say half an hour later - someone else asks you what you heard.

- Never
 Rarely
 Sometimes
 Often
 Always

6. You meet up with a group of people. Some of them you've met before and others are new. You need to recognize which ones you've met before.

- Never
 Rarely
 Sometimes
 Often
 Always

7. You go to a new building and you are learning to find your way around. Someone shows you a short route which you will need to remember.

(a) You need to retrace the route immediately.

- Never
 Rarely
 Sometimes
 Often
 Always

(b) You need to retrace the route again later on- say half an hour later.

- Never
 Rarely
 Sometimes
 Often
 Always

MEMORY SITUATIONS QUESTIONNAIRE
PIPAC Project- Patient Form

Participant ID

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SITUATION

8. You have been given a message to deliver to someone. You need to remember to give that person the message when you see them.

(a) You see them right away.

(b) You see them later on.

9. You are being asked to give some information about yourself, such as your age, address, date of birth and so on, and to answer a few basic general knowledge questions.

10. Someone asks you for today's date.

FREQUENCY

- Never
- Rarely
- Sometimes
- Often
- Always

- Never
- Rarely
- Sometimes
- Often
- Always

- Never
- Rarely
- Sometimes
- Often
- Always

- Never
- Rarely
- Sometimes
- Often
- Always

INDEX FOR MANAGING MEMORY LOSS (IMMEL)
PIPAC Project- Patient Form

Participant ID

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One way to deal with the signs of memory loss is:

7. Using lists and other memory aids help me remember.

- I don't use this
 I use this and find it:
 Very helpful

 Quite helpful

 Not really helpful

8. Writing a personal diary about my feelings.

- I don't use this
 I use this and find it:
 Very helpful

 Quite helpful

 Not really helpful

9. Regularly practicing relaxation techniques and the like.

- I don't use this
 I use this and find it:
 Very helpful

 Quite helpful

 Not really helpful

10. Relying on others to fill in the gaps when I am unable to remember.

- I don't use this
 I use this and find it:
 Very helpful

 Quite helpful

 Not really helpful

11. By not taking part in conversations.

- I don't use this
 I use this and find it:
 Very helpful

 Quite helpful

 Not really helpful

12. Believing that my memory loss is a normal part of getting older.

- I don't use this
 I use this and find it:
 Very helpful

 Quite helpful

 Not really helpful

13. By staying in familiar surroundings.

- I don't use this
 I use this and find it:
 Very helpful

 Quite helpful

 Not really helpful



INDEX FOR MANAGING MEMORY LOSS (IMMEL)
PIPAC Project- Patient Form

Participant ID

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One way to deal with the signs of memory loss is:

21. Actively seeking professional help and guidance in dealing with memory loss.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful

22. Not dwelling on the problems that I face.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful

23. Being thankful for the close support of family and others around me.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful

24. Having a good cry when no one is around.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful

25. Keeping any further memory loss to myself for as long as possible.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful

26. Ignoring my memory loss hoping that it will eventually go away.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful

27. Accepting that my memory loss is not my fault.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful

INDEX FOR MANAGING MEMORY LOSS (IMMEL)
PIPAC Project- Patient Form

Participant ID

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One way to deal with the signs of memory loss is:

35. Remembering all of the good days I have had.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful

36. Joining a local memory club (or support group) and the like.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful

37. Relying on myself to find answers to the problems I face.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful

38. Relying on others to perform the domestic chores in and around the home.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful

39. Thinking things through slowly and carefully before responding.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful

40. Making up stories to fill in the gaps in my memory.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful

41. Relying on the support of the person closest to me.

- I don't use this I use this and find it: Very helpful
 Quite helpful
 Not really helpful



INDEX FOR MANAGING MEMORY LOSS (IMMEL)
PIPAC Project- Patient Form

Participant ID

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One way to deal with the signs of memory loss is:

42. Trying to keep calm and relaxed at all times.

- I don't use this
- I use this and find it:
 - Very helpful
 - Quite helpful
 - Not really helpful

43. Please list any other methods of coping that you find helpful:

- Very helpful
- Quite helpful
- Not really helpful

- Very helpful
- Quite helpful
- Not really helpful

- Very helpful
- Quite helpful
- Not really helpful

- Very helpful
- Quite helpful
- Not really helpful



QUALITY OF LIFE SCALE PIPAC Project- Patient Form

Participant ID	Date	Research Assist. Initials
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention	<input type="radio"/> Control
	<input type="radio"/> Patient	<input type="radio"/> Family Contact

INSTRUCTIONS:

This set of questions describes different areas that may affect your quality of life. As best as you can, please rate the quality of your life across each of the following areas. Try to think about them recently (not a long time ago).

1. Physical health

Poor Fair Good Excellent

2. Energy

Poor Fair Good Excellent

3. Mood

Poor Fair Good Excellent

4. Living situation

Poor Fair Good Excellent

5. Memory

Poor Fair Good Excellent

6. Family

Poor Fair Good Excellent

7. Marriage

Poor Fair Good Excellent

8. Friends

Poor Fair Good Excellent

9. Self as a whole

Poor Fair Good Excellent

10. Ability to do chores around the house

Poor Fair Good Excellent

11. Ability to do things for fun

Poor Fair Good Excellent

12. Money

Poor Fair Good Excellent

13. Life as a whole

Poor Fair Good Excellent

Meaning in Life

PIPAC Project- Patient Form

Participant ID <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	Date <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention	<input type="radio"/> Control
<input type="radio"/> Patient <input type="radio"/> Family Contact		

This next set of questions is going to ask how much you agree or disagree with some statements. Please indicate how much you agree with each statement using the card in front of you.

1. I have a system of values and beliefs that guide my daily activities.
 Disagree Strongly Disagree Somewhat Agree Somewhat Agree Strongly
2. I have a philosophy of life that helps me understand who I am.
 Disagree Strongly Disagree Somewhat Agree Somewhat Agree Strongly
3. I have really come to terms with what is important in my life.
 Disagree Strongly Disagree Somewhat Agree Somewhat Agree Strongly
4. In terms of my life, I see a reason for my being here.
 Disagree Strongly Disagree Somewhat Agree Somewhat Agree Strongly
5. I feel like I am living life fully.
 Disagree Strongly Disagree Somewhat Agree Somewhat Agree Strongly
6. I feel like I have found a really significant meaning in my life.
 Disagree Strongly Disagree Somewhat Agree Somewhat Agree Strongly
7. I have discovered a satisfying life purpose.
 Disagree Strongly Disagree Somewhat Agree Somewhat Agree Strongly
8. In my life, I have clear goals and aims.
 Disagree Strongly Disagree Somewhat Agree Somewhat Agree Strongly
9. I have a sense of direction and purpose in life.
 Disagree Strongly Disagree Somewhat Agree Somewhat Agree Strongly
10. I have a good sense of what I am trying to accomplish in the rest of my life.
 Disagree Strongly Disagree Somewhat Agree Somewhat Agree Strongly
11. I feel good when I think about what I have done in the past.
 Disagree Strongly Disagree Somewhat Agree Somewhat Agree Strongly



57486

Meaning in Life
PIPAC Project- Patient Form

Participant ID

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12. I find it satisfying to think about what I have accomplished in life.

- Disagree Strongly
 Disagree Somewhat
 Agree Somewhat
 Agree Strongly

13. I am able to make sense of unpleasant things that have happened in the past.

- Disagree Strongly
 Disagree Somewhat
 Agree Somewhat
 Agree Strongly

14. I am at peace with my past.

- Disagree Strongly
 Disagree Somewhat
 Agree Somewhat
 Agree Strongly

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Social Engagement PIPAC Project- Patient Form

Participant ID	Date	Research Assist. Initials
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention <input type="radio"/> Control	<input type="radio"/> Patient <input type="radio"/> Family Contact

This next set of questions is going to ask about your level of social involvement or activity.

1. Are you at ease interacting with others?
 Yes
 No

2. Are you at ease doing planned or structured activities?
 Yes
 No

3. Are you at ease doing self-initiated activities?
 Yes
 No

4. Are you establishing your own goals?
 Yes
 No

5. Are you involved in social activities?
 Yes
 No

6. Are you accepting of invitations into group activities?
 Yes
 No

Emotional Support and Anticipated Support PIPAC Project- Patient Form

Participant ID <input style="width: 100%; height: 20px;" type="text"/>	Date <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 20px; height: 20px;" type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Intervention <input type="radio"/> Control <input type="radio"/> Patient <input type="radio"/> Family Contact <input type="radio"/> Post-Intervention		

For this set of questions think about the how often you have gotten the type of emotional support you have needed. Use the card in front of you to pick your answer.

1. How often has someone been right there with you (physically) in a stressful situation?
 Never Once in a while Fairly often Very often
2. How often has someone comforted you by showing you physical affection?
 Never Once in a while Fairly often Very often
3. How often has someone listened to you talk about your private feelings?
 Never Once in a while Fairly often Very often
4. How often has someone expressed interest and concern in your well-being?
 Never Once in a while Fairly often Very often

The answer choices for this next set of questions is slightly different. Again use the card in front of you to pick the best choice for you.

1. If you were sick in bed, how much could you count on the people around you to help out?
 Not at all A little Some A great deal
2. If you needed to talk about your problems and private feelings, how much would the people around you be willing to listen?
 Not at all A little Some A great deal
3. If you needed to know where to go to get help with a problem you were having, how much would the people around you be willing to help?
 Not at all A little Some A great deal



35199

Decisional Conflict Scale PIPAC Project- Patient Form

Participant ID <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Date <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Research Assist. Initials <input type="text"/> <input type="text"/> <input type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention <input type="radio"/> Control	<input type="radio"/> Patient <input type="radio"/> Family Contact

For this set of questions, think about the different kinds of medical treatments you might prefer in the future. For example, who would make decisions for you if you could not say what you wanted yourself, or what types of medical procedures you might want.

This next set of questions is going to ask about your comfort making decisions about your health care. Refer to the card in front of you for the answer choices.

1. Do you know which options are available to you?
 Yes Unsure No
2. Do you know the benefits of each option?
 Yes Unsure No
3. Do you know the risks and side effects of each option?
 Yes Unsure No
4. Are you clear about which benefits matter most to you?
 Yes Unsure No
5. Are you clear about which risks and side effects matter most to you?
 Yes Unsure No
6. Do you have enough support from others to make a choice?
 Yes Unsure No
7. Are you choosing without pressure from others?
 Yes Unsure No
8. Do you have enough advice to make a choice?
 Yes Unsure No
9. Are you clear about the best choices for you?
 Yes Unsure No
10. Do you feel sure about what to choose?
 Yes Unsure No
11. Finally, how much do you agree with the following statement?
"I am satisfied with the plans I have made for my future medical care."
 Strongly agree Agree Neither agree nor disagree Disagree Strongly Disagree



53752

EuroQol EQ-5D Instrument PIPAC Project- Patient Form

Participant ID <input style="width: 100%; height: 20px;" type="text"/>	Date <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 40px; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 40px; height: 20px;" type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Intervention <input type="radio"/> Control <input type="radio"/> Patient <input type="radio"/> Family Contact <input type="radio"/> Post-Intervention		

Using the card in front of you, pick the statement that best describes your health state today. If you are not sure, take your best guess. Do not pick more than one choice per group.

1. MOBILITY

- I have no problem in walking about
- I have problems in walking about
- I am confined to bed

2. SELF-CARE

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

3. USUAL ACTIVITIES (e.g., work, study, housework, family or leisure activities)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

4. PAIN/DISCOMFORT

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

5. ANXIETY/DEPRESSION

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed



53752

EuroQol EQ-5D Instrument PIPAC Project- Patient Form

Participant ID

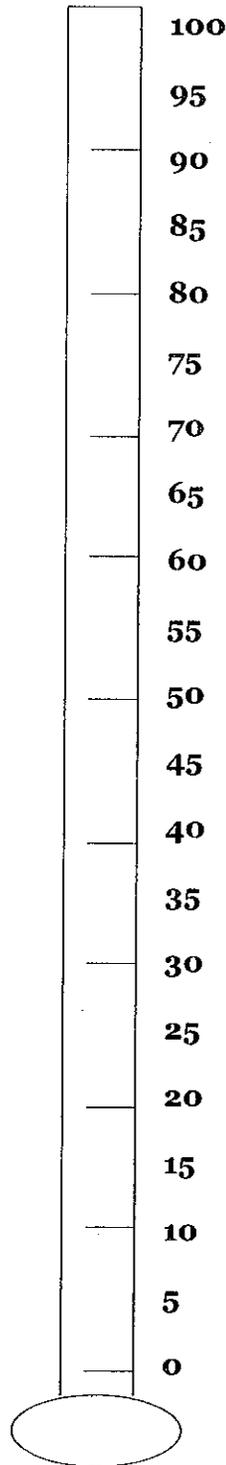
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Visual Analog Scale

To help people say how good or bad their health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked a 0 (zero).

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your Health



Note: Research assistant should record the number that best describes where the line is drawn. (e.g., 0-100) Do not need to round to nearest number shown, it can be any number (e.g., 23, 12, etc.).

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54573

DRS-2 DATA SUMMARY SHEET

PIPAC Project- Patient Form

Participant ID <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Date <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Research Assist. Initials <input type="text"/> <input type="text"/> <input type="text"/>
<input type="radio"/> Baseline	<input type="radio"/> Intervention	<input type="radio"/> Control
<input type="radio"/> Post-Intervention	<input type="radio"/> Patient	<input type="radio"/> Family Contact

After the session is completed and you have scored the DRS-2. Copy the Summary Table from the top page of the protocol onto this form.

Appendix Table Used: A1 A2 A3 A4 A5 A6 A7 A8

ATTENTION

ATT-1: (Range 0-18 pts) <input type="text"/> <input type="text"/>	Attention Raw Score (Sum of Att 1, 2, & 3) <input type="text"/> <input type="text"/>
ATT-2: (Range 0-11 pts) <input type="text"/> <input type="text"/>	Attention AMSS <input type="text"/> <input type="text"/>
ATT-3: (Range 0-8 pts) <input type="text"/> <input type="text"/>	Attention Percentile <input type="text"/> <input type="text"/>

INITIATION / PERSEVERATION

I/P-1: (Range 0-30 pts) <input type="text"/> <input type="text"/>	Initiation/Pers. Raw Score (Sum of I/P-1 & 2) <input type="text"/> <input type="text"/>
I/P-2: (Range 0-7 pts) <input type="text"/> <input type="text"/>	Initiation/Pers. AMSS <input type="text"/> <input type="text"/>
	Initiation/Pers. Percentile <input type="text"/> <input type="text"/>

CONSTRUCTION

Const: (Range 0-6 pts) <input type="text"/> <input type="text"/>	Construction Raw Score <input type="text"/> <input type="text"/>
	Construction AMSS <input type="text"/> <input type="text"/>
	Construction Percentile <input type="text"/> <input type="text"/>

CONCEPTUALIZATION

Concept: (Range 0-39 pts) <input type="text"/> <input type="text"/>	Concept Raw Score <input type="text"/> <input type="text"/>
	Concept AMSS <input type="text"/> <input type="text"/>
	Concept Percentile <input type="text"/> <input type="text"/>

MEMORY

Mem-1: (Range 0-16 pts) <input type="text"/> <input type="text"/>	Memory Raw Score (Sum of Mem-1 & 2) <input type="text"/> <input type="text"/>
Mem-2: (Range 0-9 pts) <input type="text"/> <input type="text"/>	Memory AMSS <input type="text"/> <input type="text"/>
	Memory Percentile <input type="text"/> <input type="text"/>

TOTAL Score Raw (Sum of All Raw Scores) <input type="text"/> <input type="text"/> <input type="text"/>	Total Percentile <input type="text"/> <input type="text"/>
Total AMSS <input type="text"/> <input type="text"/> <input type="text"/>	AEMSS (Appendix B) <input type="text"/> <input type="text"/> <input type="text"/>



8052

CLINICAL DEMENTIA RATING (CDR)
PIPAC Project- Patient Form



Participant ID <input style="width: 100%; height: 20px;" type="text"/>	Date <input style="width: 15%; height: 20px;" type="text"/> / <input style="width: 15%; height: 20px;" type="text"/> / <input style="width: 10%; height: 20px;" type="text"/> <input style="width: 10%; height: 20px;" type="text"/> <input style="width: 10%; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 15%; height: 20px;" type="text"/> <input style="width: 15%; height: 20px;" type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention	<input type="radio"/> Control <input type="radio"/> Patient <input type="radio"/> Family Contact

After the session is completed and you have scored the DRS-2, ADL-IADL, and other family contact and patient measures (MARS, etc.). Complete the CDR estimate for each domain based on your previous training, clinical judgment, and the description summary on the attached page. Use the scoring website to get a final score.

MEMORY

- None (0) Questionable (0.5) Mild (1) Moderate (2) Severe (3)

ORIENTATION

- None (0) Questionable (0.5) Mild (1) Moderate (2) Severe (3)

JUDGMENT & PROBLEM SOLVING

- None (0) Questionable (0.5) Mild (1) Moderate (2) Severe (3)

COMMUNITY AFFAIRS

- None (0) Questionable (0.5) Mild (1) Moderate (2) Severe (3)

HOME and HOBBIES

- None (0) Questionable (0.5) Mild (1) Moderate (2) Severe (3)

PERSONAL CARE

- None (0) Questionable (0.5) Mild (1) Moderate (2) Severe (3)

The scoring algorithm to get the total score can be accessed at:

<http://www.biostat.wustl.edu/~adrc/cdrpgm/index.html>

OVERALL CDR SCORE

- None (0) Questionable (0.5) Mild (1) Moderate (2) Severe (3)





52444

Cornell Scale for Depression in Dementia PIPAC Project- Patient Form

Participant ID <input style="width: 100px; height: 20px;" type="text"/>	Date <input style="width: 30px; height: 20px;" type="text"/> / <input style="width: 30px; height: 20px;" type="text"/> / <input style="width: 60px; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 40px; height: 20px;" type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention <input type="radio"/> Control	<input type="radio"/> Patient <input type="radio"/> Family Contact

Scoring System

A = unable to evaluate 0 = absent 1 = mild or intermittent 2 = severe

Ratings should be based on symptoms and signs occurring during the week prior to interview.
No score should be given in symptoms resulting from physical disability or illness.

A. Mood-Related Signs

- | | | | | |
|---|-------------------------|-------------------------|-------------------------|-------------------------|
| 1. Anxiety: anxious expression, ruminations, worrying | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 2. Sadness: sad expression, sad voice, tearfulness | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 3. Lack of reactivity to pleasant events | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 4. Irritability: easily annoyed, short-tempered | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |

B. Behavioral Disturbance

- | | | | | |
|--|-------------------------|-------------------------|-------------------------|-------------------------|
| 5. Agitation: restlessness, handwringing, hairpulling | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 6. Retardation: slow movement, slow speech, slow reactions | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 7. Multiple physical complaints (score 0 if GI symptoms only) | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 8. Loss of interest: less involved in usual activities
(score only if change occurred acutely, i.e. in less than 1 month) | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |

C. Physical Signs

- | | | | | |
|---|-------------------------|-------------------------|-------------------------|-------------------------|
| 9. Appetite loss: eating less than usual | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 10. Weight loss (score 2 if greater than 5lb. in 1 month) | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 11. Lack of energy: fatigues easily, unable to sustain activities
(score only if change occurred acutely, i.e. in less than 1 month) | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |

D. Cyclic Functions

- | | | | | |
|---|-------------------------|-------------------------|-------------------------|-------------------------|
| 12. Diurnal variation of mood: symptoms worse in the morning | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 13. Difficulty falling asleep: later than usual for this individual | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 14. Multiple awakenings during sleep | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 15. Early morning awakening: earlier than usual for this individual | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |

E. Ideational Disturbance

- | | | | | |
|--|-------------------------|-------------------------|-------------------------|-------------------------|
| 16. Suicide: feels life is not worth living, has suicidal wishes, or makes suicide attempt | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 17. Poor self esteem: self-blame, self-deprecation, feelings of failure | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 18. Pessimism: anticipation of the worst | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |
| 19. Mood congruent delusions: delusions of poverty, illness, or loss | <input type="radio"/> A | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 |



41196

Cornell Scale for Depression in Dementia PIPAC Project- Family Contact Form

Participant ID <div style="border: 1px solid black; width: 100%; height: 20px; margin-top: 5px;"></div>	Date <div style="border: 1px solid black; width: 100%; height: 20px; margin-top: 5px; display: flex; justify-content: space-around;"> [] [] / [] [] / [] [] [] [] </div>	Research Assist. Initials <div style="border: 1px solid black; width: 100%; height: 20px; margin-top: 5px;"></div>
<input type="radio"/> Baseline <input type="radio"/> Intervention <input type="radio"/> Control <input type="radio"/> Patient <input type="radio"/> Family Contact <input type="radio"/> Post-Intervention		

Scoring System

A = unable to evaluate 0 = absent 1 = mild or intermittent 2 = severe

Ratings should be based on symptoms and signs occurring during the week prior to interview. No score should be given in symptoms resulting from physical disability or illness.

A. Mood-Related Signs

- | | |
|---|---|
| 1. Anxiety: anxious expression, ruminations, worrying | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 2. Sadness: sad expression, sad voice, tearfulness | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 3. Lack of reactivity to pleasant events | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 4. Irritability: easily annoyed, short-tempered | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |

B. Behavioral Disturbance

- | | |
|--|---|
| 5. Agitation: restlessness, handwringing, hairpulling | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 6. Retardation: slow movement, slow speech, slow reactions | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 7. Multiple physical complaints (score 0 if GI symptoms only) | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 8. Loss of interest: less involved in usual activities
(score only if change occurred acutely, i.e. in less than 1 month) | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |

C. Physical Signs

- | | |
|---|---|
| 9. Appetite loss: eating less than usual | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 10. Weight loss (score 2 if greater than 5lb. in 1 month) | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 11. Lack of energy: fatigues easily, unable to sustain activities
(score only if change occurred acutely, i.e. in less than 1 month) | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |

D. Cyclic Functions

- | | |
|---|---|
| 12. Diurnal variation of mood: symptoms worse in the morning | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 13. Difficulty falling asleep: later than usual for this individual | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 14. Multiple awakenings during sleep | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 15. Early morning awakening: earlier than usual for this individual | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |

E. Ideational Disturbance

- | | |
|--|---|
| 16. Suicide: feels life is not worth living, has suicidal wishes, or makes suicide attempt | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 17. Poor self esteem: self-blame, self-deprecation, feelings of failure | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 18. Pessimism: anticipation of the worst | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |
| 19. Mood congruent delusions: delusions of poverty, illness, or loss | <input type="radio"/> A <input type="radio"/> 0 <input type="radio"/> 1 <input type="radio"/> 2 |



40379

PIPAC Project Evaluation / Satisfaction Summary Patient Form

Participant ID <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Date <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Research Assist. Initials <input type="text"/> <input type="text"/> <input type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention <input type="radio"/> Control	<input type="radio"/> Patient <input type="radio"/> Family Contact

This final set of questions asks about your experience as a participant in the PIPAC Project. Your feedback is one of the best ways we have of developing future services and projects for older adults living with memory problems and their families. We want your honest feedback about your experiences, your feelings, and your opinions about the PIPAC Project. None of your responses will affect your relationship with the PIPAC Project in any way. Do you have any questions before we begin?

OVERVIEW

1. Was the PIPAC Project clearly explained to you from the time we first contacted you until now?
 - Yes
 - No
 - Unsure
2. Do you feel that you and your relative were treated with the proper respect during the course of this project?
 - Yes
 - No
 - Unsure
3. Overall, how much do you think you benefited from participating in this project?
 - Not at all
 - Some
 - A great deal
4. Was the PIPAC research team friendly and professional?
 - No
 - Yes
 - Unsure
5. What was your reaction to answering questions like the ones completed today? Thinking about the topics and answering questions was:
 - Positive - I enjoyed it.
 - Interesting or important but not really enjoyable.
 - A neutral experience - neither positive nor negative.
 - A negative experience.

Please explain why:



PIPAC Project Evaluation / Satisfaction Summary Patient Form

Participant ID

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INTERVENTION GROUP ONLY

1. What was your reaction to recalling and telling your life story?

- Positive - I enjoyed it.
- Interesting or important but not really enjoyable.
- A neutral experience - neither positive nor negative
- A negative experience.

Please explain why:

2. What was your reaction to the advance care planning (medical decisions) part of the project?

- Positive - I enjoyed it.
- Interesting or important but not really enjoyable.
- A neutral experience - neither positive nor negative
- A negative experience.

Please explain why:

3. How satisfied are you with the progress you made on your life project?

- Very dissatisfied
- Dissatisfied
- Neither dissatisfied nor satisfied
- Satisfied
- Very satisfied

4. Will you and your family continue working on your personal Legacy after the research staff is no longer involved?

- Yes
- No
- Unsure

5. Do you feel like the Legacy activity (recording a piece of your life story) helped you communicate with your loved ones?

- Yes
- No
- Unsure

6. Do you feel like the Advance Care Planning activity (talking about medical decisions) helped you communicate your wishes?

- Yes
- No
- Unsure



40379

PIPAC Project Evaluation / Satisfaction Summary Patient Form

Participant ID

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7. How satisfied are you with the advance care planning (medical decisions) part of the project?

- Very dissatisfied
- Dissatisfied
- Neither dissatisfied nor satisfied
- Satisfied
- Very satisfied

8. Do you plan to change any of your plans based on this part of the project?

- Yes
- No
- Unsure

9. How helpful was the Participant Notebook that was used during the project?

- Not very helpful
- Somewhat helpful
- Very helpful

10. Do you think you or your family will look at the Participant Notebook more in the future?

- Yes
- No
- Unsure

11. Do you feel like the project helped **you** cope with the stress of memory problems?

- Yes
- No
- Unsure

12. Do you feel like the project helped **your family member** cope with the stress of memory problems?

- Yes
- No
- Unsure

13. Did the project make you uncomfortable in any way?

- Yes
- No

If yes, please explain.



40379

PIPAC Project Evaluation / Satisfaction Summary Patient Form

Participant ID

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CONTROL GROUP AND INTERVENTION GROUP:

1. What do you think was the most useful part of this project?

2. What was the least useful part of this project?

3. What would you change about this project to make it better?

4. Would you recommend this project to others in similar situations?

- No
- Yes
- Unsure

If no, please explain.

DEMOGRAPHIC DATA
PIPAC Project- Family Contact Form

55464

Participant ID <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Date <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Research Assist. Initials <input type="text"/> <input type="text"/> <input type="text"/>		
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention	<input type="radio"/> Control	<input type="radio"/> Patient	<input type="radio"/> Family Contact

1. What is your date of birth? / /

2. How old are you now?

3. What is your sex or gender? Male Female

4. How would you describe your primary racial or ethnic group?
 White, Caucasian
 Black, African-American
 Native American, Eskimo, Aleut
 Asian or Pacific Islander
 Hispanic, Latino
 No primary group
 Other

If "other," please specify

5. How many years of education have you completed?

6. What was your primary occupation?

7. How hard is it for you to pay for the very basics like food, housing, medical care, and heating?
 Very Difficult
 Difficult
 Not very difficult
 Not at all difficult

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8. What are your loved one's primary medical complaints or diagnoses?

Primary Diagnosis 1:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Primary Diagnosis 2:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Primary Diagnosis 3:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Primary Diagnosis 4:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

9. Has your loved one received a diagnosis related to their memory loss?

Yes No

10. What is your loved one's memory-related diagnosis?

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

11. How long has it been since your loved one received their memory-related diagnosis? (convert to months for data entry)

--	--	--	--

 months

12. How long have they been experiencing memory problems? (convert to months for data entry)

--	--	--	--

 months

13. Are they currently taking any medications for their memory or mood?

Yes No

14. If so, what are they and how long have they been taking them?

Name of Medication 1:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

--	--	--	--

 months

Name of Medication 2:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

--	--	--	--

 months

Name of Medication 3:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

--	--	--	--

 months

Name of Medication 4:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

--	--	--	--

 months

DEMOGRAPHIC DATA
PIPAC Project- Family Contact Form

Participant ID

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14. Have there been any modifications to their medications in the last 3 months?

Yes No

Medication Changes Description:

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QUALITY OF LIFE SCALE PIPAC Project- Family Contact Form

Participant ID <input style="width: 100%; height: 20px;" type="text"/>	Date <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention	<input type="radio"/> Control <input type="radio"/> Patient <input type="radio"/> Family Contact

INSTRUCTIONS:

This set of questions describes different areas that may affect the quality of your loved one's life. As best as you can, please rate the quality of your loved one's life across each of the following areas. Try to think about them recently (not a long time ago).

1. Physical health

Poor Fair Good Excellent

2. Energy

Poor Fair Good Excellent

3. Mood

Poor Fair Good Excellent

4. Living situation

Poor Fair Good Excellent

5. Memory

Poor Fair Good Excellent

6. Family

Poor Fair Good Excellent

7. Marriage

Poor Fair Good Excellent

8. Friends

Poor Fair Good Excellent

9. Self as a whole

Poor Fair Good Excellent

10. Ability to do chores around the house

Poor Fair Good Excellent

11. Ability to do things for fun

Poor Fair Good Excellent

12. Money

Poor Fair Good Excellent

13. Life as a whole

Poor Fair Good Excellent

MEMORY SITUATIONS QUESTIONNAIRE
PIPAC Project- Family Contact Form

12512

Participant ID	Date	Research Assist. Initials
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention	<input type="radio"/> Control <input type="radio"/> Patient <input type="radio"/> Family Contact

Below are some examples of everyday situations where a person might need to use his/her memory. Please think about your partner's memory, as it is now, and rate how you think he/she would manage in that situation.

SITUATION

FREQUENCY

1. S/he meets someone and is told their name. Later on s/he meets them again, and needs to remember their name.

I think my partner would be able to do this:

- Never
- Rarely
- Sometimes
- Often
- Always

2. S/he has made an appointment and needs to remember to go along.

I think my partner would be able to do this:

- Never
- Rarely
- Sometimes
- Often
- Always

3. S/he has promised to do something later in the day, and needs to remember to do it at the right time.

I think my partner would be able to do this:

- Never
- Rarely
- Sometimes
- Often
- Always

4. S/he has got a set of items to sort out, some of which s/he has seen before and some of which are new to her/him. S/he needs to pick out the ones s/he has seen before.

I think my partner would be able to do this:

- Never
- Rarely
- Sometimes
- Often
- Always



12512

MEMORY SITUATIONS QUESTIONNAIRE

PIPAC Project- Family Contact Form

Participant ID

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Below are some examples of everyday situations where a person might need to use his/her memory. Please think about your partner's memory, as it is now, and rate how you think he/she would manage in that situation.

SITUATION

FREQUENCY

5. S/he hears a news item on the radio.
(a) One of the family comes in at the end and asks what was said.

- Never
- Rarely
- Sometimes
- Often
- Always

I think my partner would be able to do this:

(b) Later on - say half an hour later - someone else asks what was said.

- Never
- Rarely
- Sometimes
- Often
- Always

I think my partner would be able to do this:

6. S/he meets up with a group of people. Some of them s/he has met before and others are new. S/he needs to recognize which ones s/he has met before.

- Never
- Rarely
- Sometimes
- Often
- Always

I think my partner would be able to do this:

7. S/he goes to a new building and is learning to find the way around. Someone shows her/him a short route which s/he needs to remember.

(a) S/he needs to retrace the route immediately.

- Never
- Rarely
- Sometimes
- Often
- Always

I think my partner would be able to do this:

(b) S/he needs to retrace the route again later on- say half an hour later.

- Never
- Rarely
- Sometimes
- Often
- Always

I think my partner would be able to do this:



12512

MEMORY SITUATIONS QUESTIONNAIRE

PIPAC Project- Family Contact Form

Participant ID

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Below are some examples of everyday situations where a person might need to use his/her memory. Please think about your partner's memory, as it is now, and rate how you think he/she would manage in that situation.

SITUATION

FREQUENCY

8. S/he has been given a message to deliver to someone and needs to remember to give that person the message when s/he sees them.

(a) S/he sees them right away.

I think my partner would be able to do this:

- Never
- Rarely
- Sometimes
- Often
- Always

(b) S/he sees them later on.

I think my partner would be able to do this:

- Never
- Rarely
- Sometimes
- Often
- Always

9. S/he is being asked to give some information about her/himself, such as age, address, date of birth and so on, and to answer a few basic general knowledge questions.

I think my partner would be able to do this:

- Never
- Rarely
- Sometimes
- Often
- Always

10. Someone asks her/him for today's date.

I think my partner would be able to do this:

- Never
- Rarely
- Sometimes
- Often
- Always



23571

Social Engagement PIPAC Project- Family Contact Form

Participant ID	Date	Research Assist. Initials
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>
<input type="radio"/> Baseline	<input type="radio"/> Intervention	<input type="radio"/> Control
<input type="radio"/> Post-Intervention	<input type="radio"/> Patient	<input type="radio"/> Family Contact

This next set of questions is going to ask about your loved one's level of social involvement or activity.

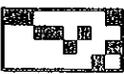
1. Is your loved one at ease interacting with others?
 Yes
 No
2. Is your loved one at ease doing planned or structured activities?
 Yes
 No
3. Is your loved one at ease doing self-initiated activities?
 Yes
 No
4. Is your loved one establishing their own goals?
 Yes
 No
5. Is your loved one involved in social activities?
 Yes
 No
6. Is your loved one accepting of invitations into group activities?
 Yes
 No



Participant ID <input style="width: 100%; height: 20px;" type="text"/>	Date <input style="width: 15%; height: 20px;" type="text"/> / <input style="width: 15%; height: 20px;" type="text"/> / <input style="width: 10%; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 100%; height: 20px;" type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Intervention <input type="radio"/> Control <input type="radio"/> Patient <input type="radio"/> Family Contact <input type="radio"/> Post-Intervention		

This set of questions describes feelings you may have about caring for your loved one with dementia. Please answer them carefully and honestly.

1. Do you feel that because of the time you spend with your loved one that you don't have enough time for yourself?
 Never Rarely Sometimes Quite frequently Nearly Always
2. Do you feel stressed between caring for your loved one and trying to meet other responsibilities (like work and family)?
 Never Rarely Sometimes Quite frequently Nearly Always
3. Do you feel angry when you are around your loved one?
 Never Rarely Sometimes Quite frequently Nearly Always
4. Do you feel that your loved one currently affects your relationship with family members or friends in a negative way?
 Never Rarely Sometimes Quite frequently Nearly Always
5. Do you feel strained when you are around your loved one?
 Never Rarely Sometimes Quite frequently Nearly Always
6. Do you feel that your health has suffered because of your involvement with your loved one?
 Never Rarely Sometimes Quite frequently Nearly Always
7. Do you feel that you don't have as much privacy as you would like because of your loved one?
 Never Rarely Sometimes Quite frequently Nearly Always
8. Do you feel that your social life has suffered because you are caring for your loved one?
 Never Rarely Sometimes Quite frequently Nearly Always



13321

Caregiver Feelings Scale
PIPAC Project- Family Contact Form

Participant ID

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9. Do you feel that you have lost control of your life since your loved one became ill?

- Never
- Rarely
- Sometimes
- Quite frequently
- Nearly Always

10. Do you feel uncertain about what to do about your loved one?

- Never
- Rarely
- Sometimes
- Quite frequently
- Nearly Always

11. Do you feel that you should be doing more for your loved one?

- Never
- Rarely
- Sometimes
- Quite frequently
- Nearly Always

12. Do you feel that you could do a better job in caring for your loved one?

- Never
- Rarely
- Sometimes
- Quite frequently
- Nearly Always





Participant ID [][][][]	Date [][] / [][] / [][][][]	Research Assist. Initials [][][]
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention	<input type="radio"/> Control
	<input type="radio"/> Patient	<input type="radio"/> Family Contact

In each category, bubble the item that most closely describes your loved one's highest level of functioning. If you are not sure, take your best guess.

1. TOILET

- Care for self at toilet completely; no incontinence
- Needs to be reminded, needs help cleaning self, or has rare accidents
- Soiling or wetting while asleep more than once a week
- Soiling or wetting while awake more than once a week
- No control of bowels or bladder

2. FEEDING

- Eats without assistance
- Eats with minor assistance and/or needs help with preparation or clean up
- Feeds self with moderate assistance and is untidy
- Requires extensive assistance for all meals
- Does not feed self at all and resists efforts of others to feed him/her

3. DRESSING

- Dresses, undresses, and selects clothes from own wardrobe
- Dresses and undresses self with minor assistance
- Needs moderate assistance in dressing and selection of clothes
- Needs major assistance in dressing, but cooperates with efforts of others to help
- Completely unable to dress self and resists effort of others to help

4. GROOMING

- Always neatly dressed, well-groomed, without assistance
- Grooms self adequately with occasional minor assistance (e.g., with shaving)
- Needs moderate and regular assistance or supervision with grooming
- Needs total grooming care, but can remain well-groomed after help from others
- Actively negates all efforts of others to maintain grooming



58197

Activities of Daily Living Scale
PIPAC Project- Family Contact Form

Participant ID

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5. PHYSICAL AMBULATION

- Goes about grounds or city independently
- Ambulates within residence or within one block of residence
- Ambulates with assistance from another person or support device
- Sits unsupported in chair or wheelchair but cannot propel self without help
- Bedridden more than half the time

(a) If your loved one requires assistance, which does he/she use:

- Another person
- Railing
- Cane
- Walker
- Wheelchair

(b) If your loved one requires assistance, can he/she:

- Get in and out without help
- Needs help getting in and out

6. BATHING

- Bathes self (tub, shower, sponge bath) without help
- Bathes self with help getting in and out of tub
- Washes face and hands only, but cannot bathe rest of body
- Does not wash self, but is cooperative with those who bathe him/her
- Does not try to wash self and resists efforts to keep him/her clean



6010

**Instrumental Activities of Daily Living
PIPAC Project- Family Contact Form**

Participant ID <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Date <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Research Assist. Initials <input type="text"/> <input type="text"/> <input type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention	<input type="radio"/> Control <input type="radio"/> Patient <input type="radio"/> Family Contact

Directions: This set of questions is about the specific kinds of activities that may be difficult for your loved one to complete on their own. For each activity it will ask you: (1) if he/she needed any kind of help, (2) whether you were the one who provided that help, and (3) how much it bothered you to provide that help. ("Help" can mean any kind of supervision, direction, or personal assistance.) For this set of questions, try to answer by thinking only about your loved one's abilities in the last week.

1. During the past week, has your loved one needed any kind of help using the telephone?

- No
- Yes
- Don't know

1 (a). If YES, Did you help with this?

- No
- Yes
- Don't know

1 (b). If YES, How much does helping with this bother or upset you?

- Not at all
- A little
- Moderately
- Very much
- Extremely
- Don't know



2. During the past week, has your loved one needed any kind of help with shopping (going to the store for light groceries)?

- No
- Yes
- Don't know

2 (a). If YES, Did you help with this?

- No
- Yes
- Don't know

2 (b). If YES, How much does helping with this bother or upset you?

- Not at all
- A little
- Moderately
- Very much
- Extremely
- Don't know

3. During the past week, has your loved one needed any kind of help with food preparation (making lunch or a light meal)?

- No
- Yes
- Don't know

3 (a). If YES, Did you help with this?

- No
- Yes
- Don't know

3 (b). If YES, How much does helping with this bother or upset you?

- Not at all
- A little
- Moderately
- Very much
- Extremely
- Don't know

Participant ID

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6010

Instrumental Activities of Daily Living
PIPAC Project- Family Contact Form

4. During the past week, has your loved one needed any kind of help with housekeeping? (making the bed, vacuuming, dusting)

- No
- Yes
- Don't know

4 (a). If YES, Did you help with this?

- No
- Yes
- Don't know

4 (b). If YES, How much does helping with this bother or upset you?

- Not at all
- A little
- Moderately
- Very much
- Extremely
- Don't know

5. During the past week, has your loved one needed any kind of help doing laundry?

- No
- Yes
- Don't know

5 (a). If YES, Did you help with this?

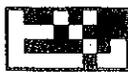
- No
- Yes
- Don't know

5 (b). If YES, How much does helping with this bother or upset you?

- Not at all
- A little
- Moderately
- Very much
- Extremely
- Don't know

Participant ID

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6010

Instrumental Activities of Daily Living
PIPAC Project- Family Contact Form

6. During the past week, has your loved one needed any kind of help traveling by car, bus, or other means of transportation?

- No
- Yes
- Don't know

6 (a). If YES, Did you help with this?

- No
- Yes
- Don't know

6 (b). If YES, How much does helping with this bother or upset you?

- Not at all
- A little
- Moderately
- Very much
- Extremely
- Don't know

7. During the past week, has your loved one needed any kind of help taking his/her medications in the correct dosages or at the correct times?

- No
- Yes
- Don't know

7 (a). If YES, Did you help with this?

- No
- Yes
- Don't know

7 (b). If YES, How much does helping with this bother or upset you?

- Not at all
- A little
- Moderately
- Very much
- Extremely
- Don't know

Participant ID

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6010

Instrumental Activities of Daily Living
PIPAC Project- Family Contact Form

8. During the past week, has your loved one needed any kind of help handling his/her finances?

- No
- Yes
- Don't know

8 (a). If YES, Did you help with this?

- No
- Yes
- Don't know

8 (b). If YES, How much does helping with this bother or upset you?

- Not at all
- A little
- Moderately
- Very much
- Extremely
- Don't know

9. On average, how much time do you spend per day helping with all of the above activities?

minutes per day

hours per day

Notes or Comments:

Participant ID

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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EuroQol EQ-5D Instrument
PIPAC Project- Family Contact Form

Participant ID <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	Date <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	Research Assist. Initials <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention <input type="radio"/> Control	<input type="radio"/> Patient <input type="radio"/> Family Contact

Fill in the bubble next to the statement which best describes your loved one's health state today. If you are not sure, take your best guess. Do not pick more than one choice per group.

1. MOBILITY

- He/she has no problem in walking about
- He/she has problems in walking about
- He/she is confined to bed

2. SELF-CARE

- He/she has no problems with self-care
- He/she has some problems washing or dressing him/herself
- He/she is unable to wash or dress him/herself

3. USUAL ACTIVITIES (e.g., work, study, housework, family or leisure activities)

- He/she has no problems with performing his/her usual activities
- He/she has some problems with performing his/her usual activities
- He/she is unable to perform his/her usual activities

4. PAIN/DISCOMFORT

- He/she has no pain or discomfort
- He/she has moderate pain or discomfort
- He/she has extreme pain or discomfort

5. ANXIETY/DEPRESSION

- He/she is not anxious or depressed
- He/she is moderately anxious or depressed
- He/she is extremely anxious or depressed



39529

EuroQol EQ-5D Instrument PIPAC Project- Family Contact Form

Participant ID

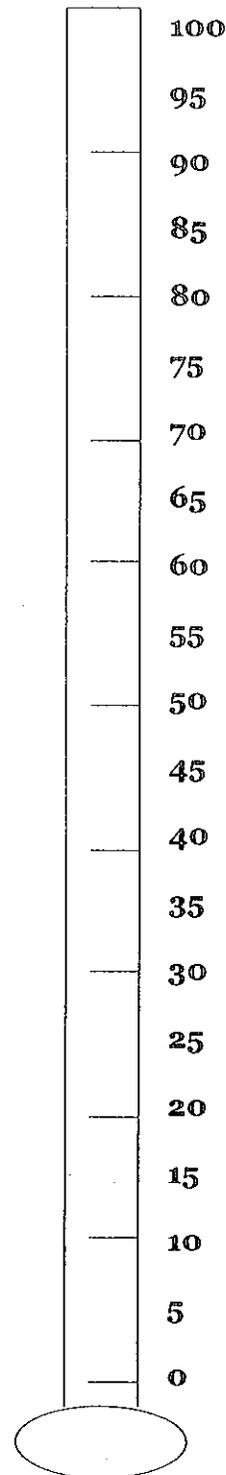
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Visual Analog Scale

To help people say how good or bad their health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked a 0 (zero).

We would like you to indicate on this scale how good or bad **your loved one or partner's health is** today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your partner's health state is today.

Your Partner's Health



Note: Research assistant should record the number that best describes where the line is drawn. (e.g., 0-100) Do not need to round to nearest number shown, it can be any number (e.g., 23, 12, etc.).

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60521

PIPAC Project Evaluation / Satisfaction Summary Family Contact Form

Participant ID [][][][]	Date [][] / [][] / [][][][]	Research Assist. Initials [][][]
<input type="radio"/> Baseline <input type="radio"/> Post-Intervention	<input type="radio"/> Intervention <input type="radio"/> Control	<input type="radio"/> Patient <input type="radio"/> Family Contact

This final set of questions asks about your experience as a participant in the PIPAC Project. Your feedback is one of the best ways we have of developing future services and projects for older adults living with memory problems and their families. We want your honest feedback about your experiences, your feelings, and your opinions about the PIPAC Project. None of your responses will affect your relationship with the PIPAC Project in any way. Do you have any questions before we begin?

OVERVIEW

1. Was the PIPAC Project clearly explained to you from the time we first contacted you until now?
 - Yes
 - No
 - Unsure
2. Do you feel that you and your relative were treated with the proper respect during the course of this project?
 - Yes
 - No
 - Unsure
3. Overall, how much do you think you benefited from participating in this project?
 - Not at all
 - Some
 - A great deal
4. Was the PIPAC research team friendly and professional?
 - No
 - Yes
 - Unsure
5. What was your reaction to answering questions like the ones completed today? Thinking about the topics and answering questions was:
 - Positive - I enjoyed it.
 - Interesting or important but not really enjoyable.
 - A neutral experience - neither positive nor negative.
 - A negative experience.

Please explain why:



60521

PIPAC Project Evaluation / Satisfaction Summary Family Contact Form

Participant ID

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INTERVENTION GROUP ONLY

1. What was your reaction to recalling and telling your life story?

- Positive - I enjoyed it.
- Interesting or important but not really enjoyable.
- A neutral experience - neither positive nor negative
- A negative experience.

Please explain why:

2. What was your reaction to the advance care planning (medical decisions) part of the project?

- Positive - I enjoyed it.
- Interesting or important but not really enjoyable.
- A neutral experience - neither positive nor negative
- A negative experience.

Please explain why:

3. How satisfied are you with the progress you made on your life project?

- Very dissatisfied
- Dissatisfied
- Neither dissatisfied nor satisfied
- Satisfied
- Very satisfied

4. Will you and your family continue working on your personal Legacy after the research staff is no longer involved?

- Yes
- No
- Unsure

5. Do you feel like the Legacy activity (recording a piece of your life story) helped you communicate with your loved ones?

- Yes
- No
- Unsure

6. Do you feel like the Advance Care Planning activity (talking about medical decisions) helped you communicate your wishes?

- Yes
- No
- Unsure



60521

PIPAC Project Evaluation / Satisfaction Summary Family Contact Form

Participant ID

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7. How satisfied are you with the advance care planning (medical decisions) part of the project?
- Very dissatisfied
 - Dissatisfied
 - Neither dissatisfied nor satisfied
 - Satisfied
 - Very satisfied
8. Do you plan to change any of your plans based on this part of the project?
- Yes
 - No
 - Unsure
9. How helpful was the Participant Notebook that was used during the project?
- Not very helpful
 - Somewhat helpful
 - Very helpful
10. Do you think you or your family will look at the Participant Notebook more in the future?
- Yes
 - No
 - Unsure
11. Do you feel like the project helped **you** cope with the stress of memory problems?
- Yes
 - No
 - Unsure
12. Do you feel like the project helped **your family member** cope with the stress of memory problems?
- Yes
 - No
 - Unsure
13. Did the project make you uncomfortable in any way?
- Yes
 - No

If yes, please explain.



60521

PIPAC Project Evaluation / Satisfaction Summary Family Contact Form

Participant ID

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CONTROL GROUP AND INTERVENTION GROUP:

1. What do you think was the most useful part of this project?

2. What was the least useful part of this project?

3. What would you change about this project to make it better?

4. Would you recommend this project to others in similar situations?

- No
- Yes
- Unsure

If no, please explain.