

**CONCORDANCE OF RACE/ETHNICITY OF INTERVENTIONISTS AND
CAREGIVERS OF DEMENTIA PATIENTS:
RELATIONSHIP TO STUDY OUTCOMES**

by

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ABSTRACT

Purpose: To assess the effects of racial/ethnic concordance between caregivers and interventionists on several study outcomes in a multisite randomized clinical trial with racially/ethnically diverse caregivers and interventionists.

Design and Methods: Family caregivers of patients with Alzheimer's disease were randomized to intervention or control groups at 5 sites from 2002 to 2004. Interventionists provided tailored multicomponent interventions aimed at improving quality of life in 3 racial/ethnic caregiver groups. This analysis included the 323 caregivers assigned to the intervention group and a subgroup of those who received at least one face-to-face intervention. To examine the relationship of concordance with outcomes, the following outcomes were modeled using random effects logistic and linear mixed models, as appropriate: loss to follow-up, mean changes in burden, problems, depression, and social support, number of sessions attended, and satisfaction with the study. The main models included the covariates concordance, caregiver gender/race/ethnicity, and interventionist race/ethnicity; interventionist was specified as the random effect.

Results: Of those who received a face-to-face intervention, concordance was not statistically significantly associated with any of the outcomes examined. There were some differences in outcomes by caregiver gender/race/ethnicity. Based on the main multivariate model, mean

change in problems was statistically significantly greater (worse) for African-American men than for white women ($p=.010$), African-American women ($p=.03$), white men ($p=.004$), Latina women ($p=.002$), and Latino men ($p=.004$). African-American men and Latino/a men and women were more likely to report higher satisfaction with the study compared to white men and women and African-American women.

Conclusions: No differences were found in outcomes by racial/ethnic concordance between caregivers and interventionists. However, a difference was found by race/ethnicity for change in problems and satisfaction. Research studies need to continue to assess and address the disparity in outcomes by participant race/ethnicity.

Public Health Significance: To eliminate racial/ethnic disparities in health, potential disparities in health research settings also need to be evaluated and eliminated.

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1.0 INTRODUCTION

Racial/ethnic differences in health, healthcare, medical research, participation in medical research, and perception of healthcare persist. I present evidence from the literature supporting that racial/ethnic concordance between patients and providers and between research participants and interventionists helps to diminish some of the differences. In the literature there has also been a growing emphasis on cultural competency training for healthcare providers and researchers. The first part of this document provides an overview of the history and studies relevant to these differences.

To help to address the question of whether racial/ethnic concordance in health intervention research studies is associated with better outcomes, I analyzed data from the Resources for Enhancing Alzheimer's Caregiver Health program (REACH II). Data from REACH II consists of a racially/ethnically diverse sample of white, African-American, and Latino/a participants who were caregivers to Alzheimer's patients. The group of interventionists, who provided multiple face to face interventions to caregivers in the intervention group, is also racial/ethnically diverse. Because the interventionists were trained in cultural competency, comments and inferences are made regarding the role and success of cultural competency training in the REACH II study. Methods and findings of this work are presented in the second part of this document.

2.0 REVIEW OF THE LITERATURE

The purpose of this literature is to demonstrate the need for studies that evaluate whether outcomes in health research vary by racial/ethnic matching between study participants and researchers and cultural competency trained researchers by focusing on the literature examining 1) research participant and researcher relationships; 2) mechanisms by which study participant and researcher relationships may affect participation in research and outcomes; 3) racial/ethnic matching of participants with health researchers/research staff; and 4) cultural competency training for health researchers.

There are few studies focusing on study participant and researcher racial/ethnic concordant/discordant relationships, but, in comparison, many studies focusing on patient-provider racial/ethnic concordant/discordant relationships. Therefore, this literature review also includes studies involving patient and provider relationships, as I believe this is similar to the participant-researcher relationship.

For the purposes of this paper, cultural competency is used in reference mainly to White, African-American, and Latino/a racial/ethnic cultural competency, although “culture” has a broader definition and can also apply to other characteristics such as gender, age, language, and sexual orientation.

The main sources for this literature review were identified using Google search, Google Scholar search, and PubMed. From Google search I was able to identify relevant government

reports from agencies such as the Department of Health and Human Services and the Centers for Disease Control. From Google Scholar and Pub Med, I identified relevant peer reviewed journal articles. The main search terms utilized in the searches were: “racial matching”, “racial concordance”, “cultural competence”, “cultural competency”, “cultural competency training”.

2.1 RESEARCH ON RACE/ETHNICITY AND RACIAL/ETHNIC CONCORDANCE

The health of the United States, as measured by estimated life expectancy, mortality rates, and infant death rates has been improving overall; however a difference persists between Whites and Blacks (CDC, 2002; Gornick ME et al., 1996). In 2000, Whites were expected to live an average of 77.4 years whereas Blacks were expected to live an average of 71.7 years (Arias A, 2002); the rate ratio (RR) of Black to White mortality was 1.39, and infant mortality rates were twice as high for Blacks as for Whites (13.5 vs. 5.7 per 1,000 live births, respectively) (2003a; 2003b). For many causes of death, differences in mortality are increasing between Blacks and Whites (Navarro V, 1990). Approximately 30% of the United States population is non-White or Hispanic, and it is projected that by the year 2050 approximately 50% of the United States population will be non-White or Hispanic (U.S.Census Bureau, 1996). As the proportion of minorities in the U.S. is projected to increase, the health of the U.S. in general will be influenced by the success of reducing health disparities (US Department of Health and Human Services, 2001).

In 1998, the Department of Health and Human Services (DHHS) made eliminating racial and ethnic differences in health a priority. Despite mandates and initiatives aimed at increasing the health of minorities, recent studies continue to find differences in health of minorities (2000a;

Ashton CM, Peterson NJ, Wray NP., & Yu HJ, 1998; Harada ND et al., 2002; Conigliaro J. et al., 2002; McGinnis et al., 2003; Gifford AL et al., 2002; Schneider EC, Zaslavsky Am, & Epstein AM, 2002; Sorlie PD, Backlund E, & Keller JB, 1995; Ayanian JZ, Weissman JS, Chasan-Taber S, & Epstein AM, 1999; Gornick ME et al., 1996; Tucker CM et al., 2003; Jones CP, 2000; Gorin SS, Heck JE, Cheng B, & S, 2006; Virnig BA, Baxter NN, Habermann EB, Feldman RD, & Bradley CJ, 2009; Tehranifar P et al., 2009; 2000b). This difference is attributed mainly to factors related to poverty, including a lack of access to health care (Geiger JH, 2001). Minorities are also underrepresented in health research (Hussain-Gambles M, Atkin K, & Leese B, 2004; Murthy VH, Krumholz HM, & Gross CP, 2004) and health research can have direct and indirect effects on health. For example, for people with conditions such as cancer and HIV disease, participating in clinical trials can provide access to cutting-edge treatments. Furthermore, results from research studies are applicable only to groups represented in the research (Stone VE, Mauch MY, Steger K, Janas SF, & Craven DE, 1997).

2.1.1 Racial/Ethnic Concordance in Health Care and Health Research

The National Institutes of Health (NIH) Revitalization Act of 1993 issued guidelines for including minorities in NIH funded clinical trials in order to determine whether interventions affect members of minority groups differently than other subjects in trials (Freedman LS et al., 1995). Despite this Revitalization Act in which federal agencies “mandated that minorities be adequately represented in all clinical research” (Corbie-Smith G, Thomas SB, & St.George DM, 2002),^{page 2458} representation is still lacking (Gifford AL et al., 2002; Flaskerud JH & Nyamathi AM, 2000; Evelyn B et al., 2001) and minorities are less likely to participate in research (Gifford AL et al., 2002; Flaskerud JH & Nyamathi AM, 2000; Evelyn B et al., 2001; Stone VE et al.,

1997). A study by Gifford and colleagues of data from the HIV Cost and Services Utilization Study found that Blacks and Hispanics with HIV infection were less likely than Whites to participate in experimental treatment trials (Gifford AL et al., 2002). Participation by minorities in trials of FDA approved drug products decreased from 12% in 1995 to 6% in 1999 (Evelyn B et al., 2001). Murthy and colleagues used data from the National Cancer Institute Clinical Trial Cooperative Group to compare participation in cancer clinical trials between 2000-2002 to participation from 1996-1998 by race. They found that the representation of Blacks decreased from 1996-1998 to 2000-2002 compared to Whites, adjusting for age, cancer type, and gender (OR=0.76; 95% CI=0.65-0.89) (Murthy VH et al., 2004).

In order to improve minority participation in research, identifying barriers to participation is necessary. Corbie-Smith and colleagues undertook a literature review of the *Annals of Internal Medicine*, *JAMA*, and *New England Journal of Medicine* from the period January 1989 to October 2002 to examine reporting of race/ethnicity in reports of clinical trials related to areas of known racial/ethnic health disparities (diabetes, cardiovascular disease, HIV/AIDS, and cancer) (Corbie-Smith G, St.George DM, Moody-Ayers S, & Ransohoff DF, 2003). They identified reports of 253 eligible clinical trials. Of those, 40% did not report on racial categories at all, and only two studies reported results by race/ethnicity (Corbie-Smith G et al., 2003). Wendler and colleagues undertook a literature review to determine whether racial and ethnic minorities are less willing to participate in research (Wendler D et al., 2005). They identified 20 studies reporting on the enrollment decisions of over 70,000 individuals to review. They reported that there was very little difference in the willingness of minorities to participate in health research (Wendler D et al., 2005). Because of a lack of universal reporting of racial/ethnic enrollment decisions and attrition rates in studies, it is difficult to evaluate the reasons for minority under-

representation in research. However, the Wendler study indicates that it may not be due to lack of willingness.

Focus has been placed on using and researching the effects of racial/ethnic concordance and cultural competency training to improve the health and healthcare of minority patients. Similarly, racial/ethnic concordance and cultural competency training may improve minority participation and outcomes in health research.

2.1.2 Racial/Ethnic Differences in Health Care and Perception of Health Care

A limited number of studies focus on the relationships between race/ethnicity of participants in health research studies and participation and outcomes. However, quite a few studies examine patient race/ethnicity and health, utilization, treatment, and healthcare preferences.

A study of 26,575 Medicare beneficiaries with acute myocardial infarction found that Black men and women were less likely to receive reperfusion therapy, a potentially life-saving therapy, than White men and women (Canto JG et al., 2000). A study of Medicare managed care enrollees found that Blacks were less likely than Whites to receive breast cancer screening, eye examinations for diabetic patients, B-blocker medication after myocardial infarction, and follow-up after hospitalization for mental illness (Schneider EC et al., 2002). Ibrahim and colleagues found that at public hospitals, of patients scheduled for coronary angiography, African-American patients were less likely than Whites to be recommended for revascularization (Ibrahim SA et al., 2003). A study of 10,984 Black and White patients diagnosed with lung cancer between 1985 and 1993 included in the Surveillance, Epidemiology, and End Results (SEER) program found that Black patients were less likely than White patients to have surgery (64.0% vs. 76.7%,

respectively, $p < .001$) and less likely to survive to five years (26.4% vs. 34.1%, respectively, $p < .001$) (Bach PB, Cramer LD, Warren JL, & Begg CB, 1999).

Based on previous studies, Ashton and colleagues reported that African-Americans and Latinos use services requiring a referral less often than Whites (Bach PB et al., 1999; Canto JG et al., 2000; Petersen, Wright, Petersen, & Daley, 2002), even when access to care, diagnosis and severity of illness were accounted for (Ashton CM et al., 2003). Bach and colleagues studied a nationally representative sample of primary care physicians treating Medicare enrollees and found that physicians treating Black patients were less likely to be board certified and more likely to report they were unable to provide high quality care to all patients than physicians treating White patients (Bach PB, Pham HH, Schrag D, Tate RC, & Hargraves JL, 2004). Sleath and colleagues examined antidepressant adherence by physician-patient communication and Hispanic ethnicity using data collected in 1995 at the University of New Mexico Health Sciences Center's general medicine and family practice clinics of 27 resident physicians and 403 Hispanic and non-Hispanic White patients. Patient-physician visits were audio taped, and physicians filled out a questionnaire about each visit and patients were interviewed after each visit. Physicians were more likely to provide antidepressant information to White patients than to Hispanic patients, and White patients were more likely to provide information about antidepressants than Hispanic patients. Hispanic patients were less likely to adhere to their medication in the 100 days following their visit compared to White patients (Sleath B, Rubin RH, & Huston SA, 2003).

In a telephone survey of 1,816 adults who had recently visited a primary care practice, African-American adults rated their physicians as less participatory than White adults (Cooper-Patrick L et al., 1999). A study by Johnson and colleagues analyzed data from 458 African-American and White patients and their corresponding 61 physicians to evaluate patient-physician

communication during medical visits. The outcome measures of communication were assessed by independent raters listening to audiotapes of the visits and coded using the Roter Interaction Analysis System, a coding system that is widely used to assess medical encounters. Physicians were more verbally dominant and less patient centered with African-American than with White patients. Additionally, physician positive-affect scores were higher for the White patient visits than for African-American patient visits (Johnson RL, Roter D, Powe NR, & Cooper LA, 2004).

Stone and colleagues surveyed 64 HIV health care providers at Boston City Hospital about their confidence, ability, and reluctance to discuss AIDS clinical trials with patients of different racial/ethnic backgrounds. Providers were also asked about perception of clinical trial interest and their practices for informing patients about available trials to patients of different racial/ethnic backgrounds. Providers reported being more confident giving an “overview of clinical trials in culturally appropriate terms to White patients than to patients of other races/ethnicities ($p < .05$)” (Stone VE, Mauch MY, & Steger KA, 1998) ^{page 245}.

2.1.3 Racial/Ethnic Concordance in Health Care and Health Research

Studies indicate that African-Americans prefer and report receiving better health care from health care professionals of the same race (Saha S, Arbelaez JJ, & Cooper LA, 2003; Saha S, Komaromy M, Koepsell TD, & Bindman AB, 1999; Saha S, Taggart SH, Komaromy M, & Bindman AB, 2000; Cooper-Patrick L et al., 1999; Garcia JA, Paterniti DA, Romano PS, & Kravitz RL, 2003; Saha S et al., 1999; LaVeist TA & Nuru-Jeter A, 2002). Saha and colleagues used data from the Commonwealth Fund 1994 National Comparative Survey of Minority Health Care, a telephone survey on health care, health status, and demographic characteristics of 3,789 adults in the United States to examine racial preferences for physicians. Their analysis included

2045 Black, Hispanic, and White adults with a regular physician and they found that Blacks and Hispanics “sought care from physicians of the same race because of personal preference and language”, not just because of geographic accessibility (Saha S et al., 2000). Another study by Saha and colleagues using data from the Commonwealth Fund 1994 National Comparative Survey of Minority Health Care, included 2201 White, Black, and Hispanic participants with a regular physician. They found that Black respondents with Black physicians were more likely to rate their physicians as excellent compared to Black respondents with non-Black physicians (adjusted OR = 2.40; CI =1.55-3.72); Hispanics with Hispanic physicians were more likely to report being very satisfied with their health care overall compared to Hispanics with non-Hispanic physicians (adjusted OR = 1.74; CI = 1.01-2.99) (Saha S et al., 1999). They also reported that Black respondents with Black physicians were more likely to report receiving preventive care and all needed medical care during the previous year compared to Black respondents with non-Black physicians (adjusted OR=2.94, CI=1.10-7.87, respectively).

Cooper and colleagues conducted a cohort study of 242 patients visiting 31 primary care physicians to evaluate communication, ratings of care, and racial concordance between patient and physician. They found that in racially concordant visits in models adjusted for patient and physician demographic characteristics, visits were an average of 2.15 minutes longer ($p=.01$) (17.54 minutes for concordant pairs and 15.39 minutes for discordant pairs), providers used more participatory decision making styles ($p<.001$), and patients were more satisfied ($p=.04$) compared to racially discordant visits (Cooper L et al., 2003). Cooper developed a conceptual model showing that patient-physician concordance impacts patient ratings both directly and through patient-centered communication.

Saha and colleagues used data from the 2001 Commonwealth Fund's Health Care Quality Survey, a telephone survey of adults that asks about health care, health preferences, and demographics, to examine racial differences in patient-physician relationships and quality of health care. Their analysis included 6,229 adults (1,037 Blacks, 1,153 Hispanics, 621 Asians, and 3,488 White). Race concordance and satisfaction were associated for Whites (OR = 1.84, 95% CI = 1.32-2.56). Treating patients with respect was the strongest predictor of satisfaction with health care for Blacks, Whites, and Asians, and spending adequate time was the strongest predictor of satisfaction among Hispanics. For Hispanics, participatory decision making was associated with use of appropriate services (Coef.=0.26, $p<.001$) (Saha S et al., 2003). Gray and Stoddard used data from the 1987 National Medical Expenditure Survey (NMES) to examine whether minorities are more likely to use a regular physician of the same race/ethnicity (Gray & Stoddard JJ, 1997). NMES is a national survey designed to assess the use and expense of health care by the U.S. population. A supplement was used to collect information on access to care. They found that minorities were more likely to have a minority for their regular physician compared to non-minorities (16.9% vs. 4.4%), even adjusting for SES factors (OR = 2.5). They say this is evidence that minorities see minority physicians at a disproportionate rate. Their analysis included 30,038 participants who completed the supplement.

A study by Chen and colleagues examined the association between patient preferences for physician race and satisfaction with care using data from the 1999 Kaiser Family Foundation Survey of Race, Ethnicity, and Medical Care: Public Perceptions and Experiences. This study involved a telephone survey of adults ages 18 and over including 1,479 Whites, 1,189 African-Americans, and 983 Latinos. They found that African-Americans who preferred a physician of the same race and had a physician of the same race were more likely to rate their physicians as

excellent compared to African-Americans who preferred a physician of the same race but had a physician of a different race (57% vs. 20%, $p < .001$). A similar pattern was seen for White and Latino adults, but the difference was not statistically significant for Latinos (54% vs. 29%, $p < .001$; 40% vs. 20%, NS) (Chen FM, Fryer GR Jr, Phillips RL Jr, Wilson E, & Pathman DE, 2005).

A study by King and colleagues examined time to receipt of protease inhibitors among HIV positive patients by racial concordance between the patient and physician. This study included 1,241 adults linked to 287 providers from a cohort study of a national probability sample. White patients received protease inhibitors sooner than African-American patients overall (median 277 vs. 439 days, $p < .001$). No difference was found between African-American patients with African-American providers and White patient with White providers. However, African-American patients with White providers received protease inhibitors significantly later than White patients with White providers (461 vs. 342 days, $p < .001$) (King WD, Wong MD, Shapiro MF, Landon BE, & Cunningham WE, 2004).

A study of 233 youth at risk for out of home placement and their families in multisystematic therapy (66 therapists included) found that adherence ratings were higher when caregiver and therapist were ethnically matched (Schoenwald SK, Halliday-Boykins CA, & Henggeler SW, 2003; Halliday-Boykins CA, Schoenwald SK, & Letourneau EJ, 2005). A similar study found better youth outcomes – decreases in symptoms, longer time in treatment, and increased likelihood of meeting goals – when youth caregivers were ethnically matched to therapists in a multisystemic therapy (Halliday-Boykins CA et al., 2005).

A recent literature review was undertaken by Meghani and colleagues that identified 27 studies reporting on minority patient outcomes by patient-provider race concordance. They

reported that of the 27 studies, patient-provider concordance resulted in positive health outcomes for minorities for nine studies, eight showed no association, and ten reported mixed findings. They conclude that more research is needed examining the effect of racial concordance on minority patient outcomes.

2.1.4 Conceptualizing the Relationship Between Racial/Ethnic Concordance and Outcomes

Differences in health care and access to health care by race/ethnicity are multifaceted. Van Ryn asserts that there is “sufficient evidence to support that provider behavior contributes to racial/ethnic disparities” (van Ryn, 2002), ^{page I-147}. A prospective study by Van Ryn showed that racial stereotyping rather than clinical data predicted refusal to recommend bypass surgery for African-American patients (Geiger JH, 2001; van Ryn & Burke J, 2000). Van Ryn and Burke used survey data of 193 physicians and 683 White and Hispanic patients at post-angiograph visits to assess physician beliefs about patient behaviors and personal and psychosocial characteristics by patient race/ethnicity. They reported that in models adjusted for SES and demographic characteristics, physicians were more likely to report that White patients were less likely to abuse alcohol or drugs and to fail to comply with medical advice and were more likely to participate in rehabilitation, want a physically active lifestyle, to be intelligent, educated, pleasant and to be the type of person with whom the physician would be friends (van Ryn & Burke J, 2000).

A study by Rathore examined the diagnoses assigned by 164 nonminority and minority medical students after viewing videos of a Black woman and a White man with identical symptoms of angina. Nonminority students were more likely to think the Black woman had a

lower quality of life, and was less likely to receive follow-up care, they were less likely to assign her a definite angina diagnosis than the White man. However, the minority medical students assessed the Black woman and White man similarly (Rathore SS et al., 2000). This suggests that minority providers may not share the biases exhibited by their White counterparts. A study by East and Peterson studied revascularization rates between Black and White patients at a Veterans hospital that primarily consisted of Black patients and physicians. They found no statistically significant differences in revascularization rates between Black and White patients (East MA & Peterson ED, 2000). Brach and Frasier purport that “racial and ethnic concordance has the potential to remedy disparities resulting from discrimination” (Brach C, Fraserirector I, & Agency for Healthcare Research and Quality, 2000),^{page I-197}.

Ashton has hypothesized that poor communication contributes to differences in health care utilization, health, and satisfaction of African-Americans and Latinos relative to Whites. She asserts that “the race and ethnicity of doctor and patient can affect their ability to communicate....”(Ashton CM et al., 2003),^{page 148} Van Ryn provides a hypothesized model, shown in Figure 1, for “mechanisms through which provider factors influence race/ethnicity disparities in treatments received (independent of clinical appropriateness, payer, and treatment site)” (van Ryn, 2002),^{page I-143}. In her model provider interpersonal behavior impacts patient satisfaction and/or “patient cognitive and affective factors (eg. acceptance of medical advice, attitude, self-efficacy, and intention)”, which also impact patient behavior in medical encounters “(eg. question-asking, self-disclosure, assertiveness)” and patient behavior after medical encounter“ (eg. adherence, self-management, utilization)” (van Ryn, 2002),^{page I-143}.

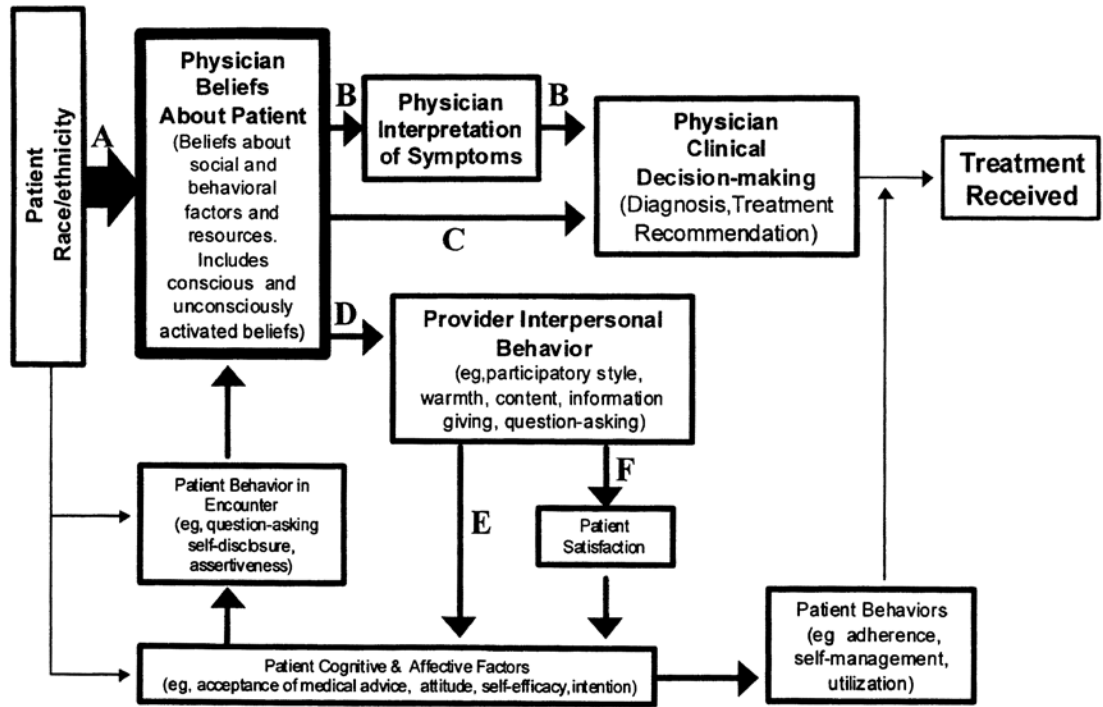


Figure 1. Hypothesized mechanisms through which provider factors influence race/ethnicity disparities in treatments received (independent of clinical appropriateness, payer, and treatment site)

SOURCE: Van Ryn, 2002

Street and colleagues undertook a study to better understand mechanisms through which concordance leads to better outcomes. They evaluated whether patients’ perceptions of similarity to their physicians was associated with their quality of care ratings; and whether perceived similarity was associated with racial concordance and physician communication. Their study included 214 patients and 29 primary care physicians from 10 outpatient clinics and they used a personal similarity scale and an ethnic similarity scale, both based on a 100 point scale, to assess perceived similarity to provider. Both African-American and White patients in “concordant interactions reported more personal and ethnic similarity” (Street RL, O’Malley KJ, Cooper LA,

& Haidet P, 2008)^{page 198} to their physicians (mean score, 84.4 and 78.8, respectively) than did African-American (81.4 and 41.2, respectively) and White patients (84.4 and 41.9, respectively) in racially discordant interactions (Street RL et al., 2008).

Many studies have shown that African-Americans are less likely than Whites to trust physicians and researchers. Boulware and colleagues analyzed data from 125 adults surveyed about trust in physicians, health insurers, and hospitals in the Baltimore metropolitan area. They found that Blacks were less likely to trust their physician than Whites (absolute difference = 37%, $p=.01$), adjusting for demographic and patient socioeconomic characteristics (Boulware LE, Cooper LA, Ratner LE, LaVeist TA, & Powe NR, 2003). Corbie-Smith and colleagues analyzed data from a study of 382 White adults and 527 African-American adults using a telephone survey. They found that African-Americans were less likely than Whites to trust their physician to fully explain research participation (41.7% vs. 23.4%, respectively, $p<.01$). Adjusting for social class variables, African-Americans had higher distrust scores than Whites (OR = 4.7, 95% CI = 2.9-7.7) (Corbie-Smith G et al., 2002).

Halbert and colleagues, using data from a national survey of 954 non-Hispanic African-Americans ($n=432$) and Whites ($n=522$), evaluated trust in health care providers by asking “how much of the time they think they can trust physicians or health care providers to do what is best for patients” (Halbert CH, Armstrong K, Gandy OH, & Shaker L, 2006)^{page 897}. Responses were dichotomized into two categories: almost all of the time and most of the time vs. some and almost none of the time. They reported that African-Americans were more likely to report lower trust than White patients (44.7% vs. 33.5%, $p<.001$). They also compared trust by patient-provider racial concordance by patient race. They found that a lower percent of White patients with concordant providers had low trust compared to those with discordant providers (31% vs.

41%), but this difference was only “marginally” statistically significant. There was no statistically significant difference in trust by concordance for African-American patients (48% vs. 43%) (Halbert CH et al., 2006).

A study of 103 patients in a large southern Veterans Affairs hospital for treatment of suspicious pulmonary nodules or lung cancer surveyed patients on their perception of quality of physician communication and trust in the physician and health care system previsit and postvisit using 10 point scales. Previsit trust was similar for African-American and White patients; however, postvisit trust was lower for African-American patients than White patients (mean score: 8.0 vs. 9.3, $p=.02$). More specifically, African-American patients thought the communication was less informative (7.3 vs. 8.5, $p=.03$), less supportive (8.1 vs. 9.3, $p=.03$), and less partnering (6.4 vs. 8.2, $p=.001$). The authors also compared trust by racial concordant/discordant groups: White patient/White provider; White patient/non-White provider; and African-American patient/non-African-American provider (there were no African-American concordant interactions). Patients in African-American discordant and White discordant visits reported that their physicians “shared less information, engaged in less partnership building, and were less supportive” ($p<.05$) compared with patients in White concordant visits (Gordon HS, Street RL, Sharf BF, Kelly PA, & Soucek J, 2006)^{page 906}. Previsit trust in the physician was not statistically significant different between concordant and discordant pairs; however, postvisit trust in physician was lower for African-American discordant pairs than for White concordant and discordant pairs (8.0 and 9.5 and 9.0; all $p<.05$) (Gordon HS et al., 2006).

Studies have found that patients who feel that they have participated in the decision-making of their treatment have better outcomes than patients with more controlling physicians (Kaplan SH, Greenfield S, Gandek B, Rogers WH, & Ware JE Jr, 1996). Kaplan and colleagues

used data from the Medical Outcomes Study, a cross-sectional study of 22,463 adult patients enrolled during a nine day period in 1986. Approximately half the patients were asked questions about participatory decision-making styles and had physicians who completed a background questionnaire. Participatory scores were based on three questions asked of patients (each response on a five point scale): “If there were a choice between treatments, would this doctor ask you to help make the decision? (definitely yes to definitely no)”, “How often does this doctor make an effort to give you some control over your treatment? (very often to never)?”, and “How often does this doctor ask you to take some of the responsibility for your treatment (very often to not at all)?” Higher physician participatory scores were associated with greater patient satisfaction. Physicians with primary care training or interview training had higher participatory skills than physicians without training (Kaplan SH et al., 1996) ^{page 498}. A study by Cooper-Patrick of 1816 adults recently attending a primary care practice found that patients who saw physicians of the same race rated their visits as more participatory than patients in race-discordant relationships ($p=.02$), based on the participatory decision-making styles (mean difference=2.6, S.E.=1.1) (Cooper-Patrick L et al., 1999). Applying similar mechanisms to health intervention research, health intervention study participants may rate health researchers of the same race/ethnicity as more participatory, with better communication, more trust, more supportive, more informative, and this may lead to better participation and attrition rates, and better study outcomes.

2.1.5 Summary and Discussion

Research indicates that patients are more satisfied, have more trust in, rate more favorably, and have more participatory style communication with providers of the same race/ethnicity.

Additionally, providers report feeling more comfortable providing information to patients of the same race/ethnicity. Themes that emerge as important in these relationships are interpersonal behavior and similarity between people, communication – particularly a participatory style, and trust. Relationships containing these factors could potentially lead to more favorable health and intervention research outcomes. A few studies show that patients receive better health care when providers are of the same race/ethnicity. However, there are few studies that examine study outcomes by racial/ethnic concordance between study participants and interventionists in research studies.

Van Ryn's model (Figure 2) could be adapted to apply to health researchers. Researcher/research staff interpersonal behavior could influence participant satisfaction and/or cognitive and affective factors (acceptance of advice, attitude, self-efficacy, and intention), which also could impact participant behavior in health study encounters and in adherence, self-management, and utilization of that study and future studies.

Despite the need for more minority physicians and health researchers (Saha S et al., 2000), and evidence of greater satisfaction and better outcomes for patients with healthcare providers of the same race/ethnicity, there are potential pitfalls of racial/ethnic matching in health care and research. First, promoting racial/ethnic matching could lead to segregated research and health care. Segregation could lead to tiered health care and research in which minorities are not receiving the same quality of care and research as Whites. Second, as Sawyer points out, it is not always economically or logistically feasible or desirable to provide racially/ethnically matched healthcare providers or research study staff (Sawyer L et al., 2007). Therefore, training healthcare providers and researchers in cultural competence is important in helping to eliminate racial/ethnic differences in health, healthcare, and health research.

2.2 CULTURAL COMPETENCY IN HEALTH INTERVENTION RESEARCH

2.2.1 The Increasing Importance of Cultural Competency

The need for culturally competent physicians and researchers is of increased importance (Geiger JH, 2001; Tucker CM et al., 2003; Doyle EI, Liu Y, & Ancona L, 1996; Thomas SB & Quinn SC, 1993) as the population of the United States is becoming more diverse. The Office of Minority Health (OMH) of the Department of Health and Human Services promotes cultural competence in health care (Office of Minority Health, 2004). Using effective cultural competency in health research studies also needs to be promoted. Without cultural awareness, “researchers tend to impose their beliefs, values and patterns of behaviour among cultures other than their own”(Papadopoulos I & Lees S, 2002)^{page258}. Cultural competency in health research could lead to greater recruitment and retention of minority participants.

The Department of Health and Human Services (DHHS) put forth a request for applications (RFA) for “Cultural competence and health disparities academic award” (RFA-HL-04-012). The objective of this RFA is to “enhance the ability of physicians and other health care professionals, to address disparities in the occurrence” of particular health problems “among various population groups in the U.S. in a culturally sensitive manner.” They point to a lack of “didactic courses and training programs that enhance physician knowledge of the manifold factors that influence the health needs and attitudes of people from diverse backgrounds, and of ways to apply this knowledge to patient care.”

A study by Brotherton et. al. of 8,000 graduate medical schools surveyed found that residency programs have responded to this need. The percent of residency programs offering cultural competence training is up from 36% in 2001-2002 to 51% in 2003-2004 (Brotherton SE,

Rockey PH, & Etzel SI, 2004). This increase is a good sign, but the programs vary widely and may not include training in cross-cultural medicine which may be the “most relevant and memorable” training (Kripalani S, Bussey-Jones J, Katz MG, & Genao I, 2006)^{page 1116}. And obviously, if 51% of residency programs are providing cultural competency training, the other 49% of residency programs still need to incorporate cultural competency training.

2.2.2 Defining of and Methods for Achieving Cultural Competency

In the RFA mentioned above, cultural competence is defined as “the health care provider’s ability to deliver culturally appropriate and specifically tailored care to patients with diverse values, beliefs, and behaviors.” According to Kim-Godwin, “culture is comprised of shared rules, values, beliefs and meanings that act as guidelines for decisions about a population’s lifestyle activities” (Kim-Godwin YS, Clarke PN, & Barton L, 2001). Similarly, the OMH states that culture refers to “the thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups” (Office of Minority Health (OMH), 2001), page 4.

The OMH uses a definition for cultural competence set forth by Cross and colleagues: “cultural competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency or those professionals to work effectively in cross-cultural situations” (Office of Minority Health, 2004; Cross TL, Bazron BJ, Dennis KW, & Isaacs MR, 1999). They describe cultural competence as “a process or continuum whereby an individual’s view of other cultures transforms from destructive or unaware to proficient” (Office of Minority Health, 2004; Cross TL et al., 1999).

The OMH reviewed literature on cultural competence, including theoretical and methodological definitions and models and describes several methods for health providers to use

to increase their cultural competency. Carballeira recommends the LIVE and LEARN model to health care providers for providing cross-cultural care. “LIVE” stands for Like, Inquire, Visit, and Experience, and “LEARN” stands for Listen, Evaluate, Acknowledge, Recommend, and Negotiate (Office of Minority Health, 2004; Carballeira N, 1997). Leininger provides a method for assessing patients in order to provide culturally sensitive care called the Sunrise Model. This model involves evaluating the following seven dimensions of clients: 1) cultural values and lifeways, 2) religious, philosophical, and spiritual beliefs, 3) economic factors, 4) educational factors, 5) technological factors, 6) kinship and social ties, and 7) political and legal factors (Office of Minority Health, 2004; Leininger M, 1993). According to Leininger, these dimensions should be used to guide treatment and interventions.(Office of Minority Health, 2004; Leininger M, 1993) Davidhizar and Giger propose that health care professionals should receive training in using the following six factors to assess the health beliefs of culturally diverse patients in order to provide appropriate treatment and education: 1) communication, 2) space, 3) time, 4) social organization, 5) environmental control, and 6) biological variations (Office of Minority Health, 2004; Davidhizar R, Bechtel G, & Giger JN, 1998). The OMH identified nine domains important in the development of a measurement profile of cultural competence in health care settings: 1) values and attitudes, 2) cultural sensitivity, 3) communication, 4) policies and procedures, 5) training and staff development, 6) facility characteristics, capacity, and infrastructure, 7) intervention and treatment model features, 8) family and community participation, and 9) monitoring, evaluation, and research (Office of Minority Health, 2004). Table 1 summarizes the various models described above for achieving cultural competence.

Table 1. Summary of Models for Achieving Cultural Competency

<p>LIVE AND LEARN Model was created for healthcare providers to develop mutually acceptable objectives for changing behavior(Carballeira N, 1997)</p> <ul style="list-style-type: none">• Like• Inquire• Visit• Listen• Evaluate• Acknowledge• Recommend• Negotiate
<p>The Sunrise Model involves evaluating the following dimension of patients:(Leininger M, 1993)</p> <ul style="list-style-type: none">• Cultural values and lifeways• Religious, philosophical, and spiritual beliefs• Economic factors• Educational factors• Technological factors• Kinship and social ties• Political and legal factors

Table 1. (Continued)

<p>Davidhizar and Giger propose that healthcare professionals use 6 factors to evaluate health beliefs of patients: (Davidhizar R et al., 1998)</p> <ul style="list-style-type: none">• Communication• Space• Time• Social organization• environmental control• Biological variations
<p>OMH identified 9 domains to measure cultural competence in healthcare settings:(Office of Minority Health, 2004)</p> <ul style="list-style-type: none">• Values and attitudes• Cultural sensitivity• Communication• Policies and procedures• Training and staff development• Facility characteristics, capacity, and infrastructure• Intervention and treatment model features• Family and community participation• Monitoring, evaluating, and research
<p>Papadopoulos Model for developing CC researcher:(Papadopoulos I & Lees S, 2002)</p> <ul style="list-style-type: none">• 4 Concepts<ul style="list-style-type: none">○ Cultural awareness – reflecting on how values, perceptions, and behavior of self and respondent affect data being collected○ Cultural knowledge – achieved through “contact with people from different cultural groups” and other disciplines○ Cultural sensitivity – “considering participants as true partners” and offering choices○ Cultural competence – synthesizing awareness, knowledge, and sensitivity• 2 Layers of CC<ul style="list-style-type: none">○ Generic – “the acquisition of knowledge and skills that are applicable across ethnic groups”○ Specific – “the knowledge and skills that related to a particular ethnic group”

Tucker and colleagues conducted focus group interviews with 38 European American, 52 African American, and 45 Latino American low-income primary care patients to determine what patients consider as culturally sensitive health care. Patients identified as important “people skills, individualized treatment, effective communication, and technical competence”. “Culturally sensitive art, pictures, music, and reading materials” were also important (Tucker CM et al., 2003),^{page 859}.

Papadopoulos and colleagues define a culturally competent researcher as “one who is able to apply the related skills and knowledge in project design, data collection, analysis, report writing and dissemination” (Papadopoulos I & Lees S, 2002). Papadopoulos and colleagues recommend a model for developing culturally competent researchers. The model consists of four concepts: cultural awareness - reflecting on how values, perceptions, and behavior of self and respondent affect data being collected; cultural knowledge – this is achieved through “contact with people from different cultural groups” as well as other disciplines such as anthropology, sociology, and psychology; cultural sensitivity – “considering participants as true partners;” and offering choices, an example provided is to match the ethnicity of the participant and interviewer when possible; and cultural competence – synthesizing awareness, knowledge, and sensitivity – being able to recognize and challenge discrimination. They also discuss two layers of cultural competence: culture-generic competence – “the acquisition of knowledge and skills that are applicable across ethnic groups”; and culture-specific competence – “the knowledge and skills that relate to a particular ethnic group and that would enable the researcher to understand the values and cultural prescription of operating within the respondent’s culture”(Papadopoulos I & Lees S, 2002).

2.2.3 Conceptualizing the Relationship Between Cultural Competency and Outcomes

Equally as important as training health researchers to be culturally competent is evaluating the effects of cultural competency training on processes and outcomes (Resnicow K, Baranowski T, Ahluwalia JS, & Braithwaite RL, 1999; Betancourt JR, Green AR, Carrillo E, & Park ER, 2005). There is a plethora of interest in providing cultural competency training to medical providers (Geiger JH, 2001), and many models of cultural competency training exist. Evaluation of cultural competency training on process and outcomes is crucial (Tucker CM et al., 2003) and lacking – what really works remains unknown (Geiger JH, 2001; Betancourt JR et al., 2005). Tucker points out that there is a lack of theory and research on cultural sensitivity and that without evaluating the effects of cultural sensitivity training, programs are likely to fail (Tucker CM et al., 2003). Without evaluation of current theories and models, resources are very likely being wasted on models and theories that are not successful.

Smith and colleagues randomly assigned nursing students to 8.5 hours of a cultural competency program or an informatics program and compared cultural competency between the groups using previously validated cultural self-efficacy and knowledge scales. They found that students who attended the cultural competency programs demonstrated significantly greater cultural self-efficacy and knowledge (Smith LS, 2001). However, this study did not evaluate patient outcomes.

A systematic review of cultural competence in health care provider educational interventions by Beach and colleagues found report of 34 studies from 1980 to 2003 that evaluated interventions designed to improve cultural competence. They found evidence that cultural competency training improves knowledge and that it improves attitude and skills among health care providers and patient satisfaction. There is poor evidence of cultural competency

training impacting patient adherence, patient outcomes, and equity of services. They conclude that future research should focus on these outcomes and on determining which teaching methods are most effective (Beach MC et al., 2005).

A systematic review of the rigor of studies evaluating cultural competency training of health professionals by Price and colleagues identified 64 articles between 1980 and 2003. Of these the majority targeted nurses and physicians for training. Only 27 of the 64 studies objectively evaluated the outcome with “written examinations, direct observation, performance audit, validated self-efficacy scales” (Price EG et al., 2005) ^{page 581}. Only three studies used “blinded outcome assessors” (Price EG et al., 2005) ^{page 583}. They conclude that future cultural competency studies need better design, implementation, evaluation, and reporting of the training programs (Price EG et al., 2005). Gozu and colleagues also reviewed articles from 1980 to 2003 and found that of 45 articles reviewed, 45 unique instruments were used, only 1/3 of the tools had demonstrated either validity or reliability, and only 13% demonstrated both (Gozu A et al., 2007).

Saha and colleagues used data from the Commonwealth Fund’s 2001 Health Care Quality Survey, as described previously, and they found that there was a positive correlation between cultural sensitivity measures and quality of interactions ($p < .001$). Cultural sensitivity measures were based on patient response to “I feel that my doctor understands my background and values” (strongly agree to strongly disagree) and “I often feel as if my doctor looks down on me and the way I live my life” (strongly agree to strongly disagree) (Saha S et al., 2003; Kumas-Tan Z, Beagan B, Loppie C, MacLeod A, & Frank B, 2007) ^{page 1714}.

Kumas-Tan and colleagues examined quantitative measures of cultural competence most commonly used in medicine and among health professionals by reviewing 20 years of literature.

They identified 54 instruments and closely analyzed the 10 most widely used instruments. In general, they found that the instruments “equate culture with ethnicity and race and conceptualize culture as an attribute possessed by the ethnic or racialized Other”, and that cultural incompetence arises from a “lack of exposure to and knowledge of the Other, and also from individual biases, prejudices, and acts of discrimination” (Kumas-Tan Z et al., 2007; Kumas-Tan Z et al., 2007). They conclude that the “existing measures embed highly problematic assumption about what constitutes cultural competence”, and “ignore the power relations of social inequality and assume that individual knowledge and self-confidence are sufficient for change”. Measures “that assess actual practice are needed” (Kumas-Tan Z et al., 2007),^{page 548}.

2.2.4 Summary and Discussion

With the increasing proportion of minorities in the United States and the continued health care disparities and underrepresentation of minorities in health research, cultural competency has become more important. There are several models recommended for achieving cultural competency. The overlapping themes between the existing models are: improving communication and understanding values and attitudes. There is sparse evidence of models and training being validated and evaluated, and literature supports the need for more research that explains, evaluates and validates measures of cultural competency.

2.3 RACIAL/ETHNIC CONCORDANCE VS. CULTURAL COMPETENCY TRAINING

Many studies indicate that there is an association between racial/ethnic concordance and patient satisfaction and outcomes (Cooper L et al., 2003). There is evidence that provider bias plays a role in the difference in patient satisfaction and outcomes by racial/ethnic concordance. Additionally, there is evidence that racial/ethnic concordance is associated with longer visit times, and duration is thought to be an important component of quality of care according to both patients and physicians (Howie JG, Porter AM, Heaney DJ, & Hompton JL, 1991). Similarly, length of encounter is also likely associated with quality of research outcomes in research studies. However, as previously mentioned, there could be negative consequences to providing racial/ethnic concordance in healthcare and research settings. Firstly, racial/ethnic matching is often not feasible or economically prudent as it would require greater human resources to be used than may be necessary or available. Secondly, racial/ethnic matching could lead to even less cultural competency as providers and researchers would then only be exposed mainly to people of their own racial/ethnic group. And lastly, racial/ethnic matching could lead to separate/segregated health care and research.

Cultural competency training in research studies has been emphasized in recent years as an important component in successful interventions for minorities (Gallagher-Thompson D et al., 2003a). Many conceptual models support cultural competency training as an important mechanism for reducing health disparities. Interestingly, the Papadopoulos model incorporates racial/ethnic matching as a component of cultural competency. Some models also promote hiring providers or research staff that reflect the demographic of the population served. One component that seems to be missing in the discussion of mechanisms for effectiveness of cultural

competency training is that hiring a more diverse staff in itself may increase cultural competency among staff as it would increase knowledge of different cultures through working together.

There is difficulty with assessing the effects of cultural competency training. Standardized and validated tools for evaluating the impact of training are often not used (or often not reported in the literature). Furthermore, even if impact of training is validated, there also needs to be an assessment of outcomes. For the most rigorous evaluation, one would need to compare outcomes in a cultural competency trained setting to those in a non-cultural competency trained setting, also accounting for race/ethnicity and racial/ethnic matching. However, providing non-culturally trained interventionists in a research setting seems unethical given the evidence of and theories behind cultural competency being associated with greater satisfaction and better outcomes. One method for evaluating the success of cultural competency training is to determine whether cultural competency training is as effective as racial/ethnic matching. This could be done in settings in which cultural competency training is provided and due to the distribution of patient/provider or participant/researcher demographics, racially/ethnically concordant/discordant pairs are available for comparison.

In Figure 2, I show my proposed conceptual model for using racial/ethnic concordance to evaluate and improve cultural competency training when it is provided to a culturally diverse staff. I theorize that having a diverse staff working together will itself improve cultural competency among the staff. Some participant/staff interactions will be racially/ethnically concordant and some discordant, not necessarily by design. Communication, trust, and participant outcomes should be evaluated and compared between the concordant/discordant groups. If concordant groups have better communication, trust, and/or outcomes, the cultural competency training program would be re-evaluated and improved to try to obtain

communication, trust, and outcomes that are as good for participants in discordant groups as in concordant groups. Due to the long history of issues with communication and trust between minority participants and patients with discordant researchers and providers, this may not occur right away, but it is a goal that should be strived for.

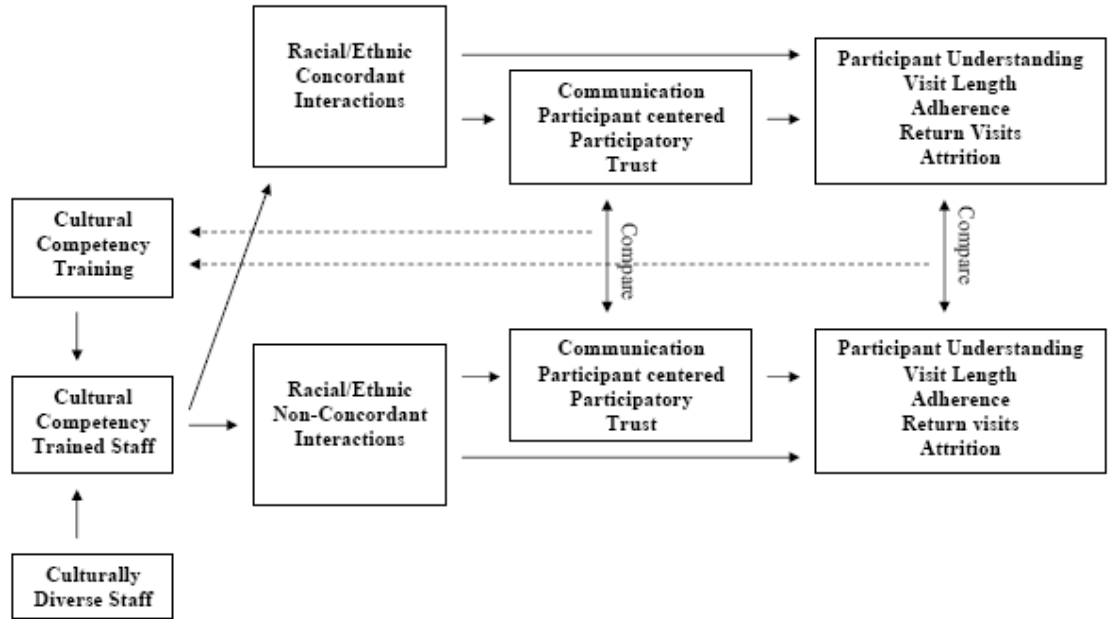


Figure 2. Proposed Conceptual Model for Using Racial/Ethnic Concordance to Evaluate and Improve Cultural Competency Training

Data from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program were used to conduct secondary analysis to assess whether outcomes in an intervention study differed by racial/ethnic concordance between participant and study interventionist (McGinnis KA, Schulz R, Stone RA, Klinger J, & Mercurio R, 2006). Culturally competency training was provided to interventionists and research staff, and I retrospectively evaluated the cultural competency provided using the training documentation and based on the criterion in the Papadopoulos model (Figures 2 and 4).

REACH was designed to test psychosocial interventions for maintaining the health and functioning of family caregivers for persons with mild or moderate impairment from Alzheimer's disease (Wisniewski SR et al., 2003; Schulz R et al., 2003). Because the caregiving experience in minority families is a particularly neglected research area, the REACH study emphasized the inclusion of African-American and Latino/a caregivers. Site-specific assessments and interventions were tailored to meet the needs of racially/ethnically diverse populations (Schulz R et al., 2003; Gallagher-Thompson D et al., 2003b). Sites recruiting Latino/a caregivers also recruited Latino/a interventionists so that Latino/a caregivers could be offered the intervention in Spanish or English. The first phase of REACH (REACH I) enrolled 1,222 caregiver/care recipient dyads from 1996 to 2000. Of the caregivers, 56.0% were White, 24.2% were African American, 19.0% Latino/a, and 0.8% other race/ethnicity (Wisniewski SR et al., 2003).

REACH 1 research study staff, interviewers, and interventionists were required to read selected literature from journal articles, books, and pamphlets intended to enhance cultural awareness and sensitivity. They discussed cultural differences in their group training sessions involving recruiting, intervention sessions, and interviewing. Interviewers and interventionists trained with pilot groups containing participants from various cultures. Because different sites targeted different racial/ethnic groups, training and recruitment varied between sites. For example, the Miami and Palo Alto sites focused on Latino/a cultural awareness and sensitivity training, and Latino/a participants could choose to have interviews and interventions in Spanish.

REACH I provided training for at least 3 of the 4 concepts identified by Papadopoulos's model for cultural competency and training was both generic and specific (cultural awareness, cultural knowledge, cultural sensitivity, and cultural competence). Cultural awareness and

sensitivity was at least partially addressed through the readings focused on cultural differences; however, it is unclear whether the readings focused on how different cultural perspectives can affect data being collected. Training with pilot groups of people from different cultural backgrounds, including receiving feedback from participants and other research staff, would have enabled interventionists and interviewers to gain cultural knowledge. Participants' cultural preferences were respected and valued - participants were offered interviews and intervention sessions in Spanish. Participants care giving needs were assessed and interventions were tailored to individuals, offering participant-centered care. Additionally, an effort was made to hire research staff that reflected the racial/ethnic demographics of the targeted participants, and racial/ethnic matching was attempted at some sites. However, no process assessments were made to determine whether the training provided was successful in creating culturally aware, knowledgeable and sensitive interviewers and interventionists.

The scales used to measure various concepts need to have the same meaning in different cultures and languages and findings should be disseminated to all stakeholder groups (Papadopoulos I & Lees S, 2002). Further evaluation is necessary to determine whether these aspects of cultural competence were achieved in REACH I. In retrospect, it is impossible to determine definitively whether cultural competency was achieved because one cannot go back in time and measure whether study staff cultural competency training was effective. However, based on the Papadopoulos Model, I believe that at least most components of culturally competency were achieved. Comparing whether participant outcomes varied by whether they had an interventionist of the same or different race/ethnicity could also help determine whether culturally competency was achieved.

To assess whether outcomes in the REACH I intervention study differed by racial/ethnic concordance between participant and study interventionist, data from the 694 caregivers in the REACH I study who received a face-to-face intervention from one of the 36 culturally competency trained interventionists were utilized. Twelve month attrition and changes in caregiver depression and burden by racial/ethnic concordance between caregivers and interventionists were assessed. The association of caregiver loss to follow-up at 12 months with racial/ethnic concordance was assessed using a random effects logistic regression model. Changes in CES-D and RMBPC at 12 month follow-up were compared between racial/ethnic concordance groups using generalized linear random effects regression models (Rabe-Hasketh SA, Pickles A, & Taylor C, 2000). We accounted for the clustering of caregivers within interventionists (i.e. interventionists were assigned to multiple caregivers) by specifying interventionist as a random effect. For each outcome, we included racial/ethnic concordance, caregiver race/ethnicity, interventionist race/ethnicity, and caregiver characteristics.

Loss to follow-up at 12 months did not vary significantly by caregiver race/ethnicity or by racial/ethnic concordance overall or within any caregiver racial/ethnic group. However, the non-significant effect was in the hypothesized direction (i.e. lower odds of loss to follow-up associated with concordance). Change in depression was not significantly different between racial/ethnic concordance groups either unadjusted or adjusted for baseline characteristics overall or for White and Latino/a caregivers. However, among African-Americans, caregivers with an interventionist of the same race/ethnicity reported significantly greater decreases in depression over time than caregivers with an interventionist of a different race/ethnicity. This finding needs to be interpreted with caution because there were only two African-American interventionists.

3.0 OVERVIEW

3.1 BACKGROUND

Understanding how racial/ethnic concordance between participants and interventionists in research studies is important in maximizing the effectiveness of interventions. It is possible that racial/ethnic concordance impacts study outcomes differently for participants of different racial/ethnic groups. If this is true, racial/ethnic concordance between participants and interventionists could provide another source of variation in studies involving interventions delivered via personal interaction. In studies in which White subjects are more likely to have an interventionist of the same race/ethnicity, and possibly better communication with the interventionist than subjects of other race/ethnic groups, White subjects may receive greater benefits from study participation, such as greater participation and retention and health outcomes. Ensuring that all racial/ethnic groups are benefiting equally from study participation is crucial for eliminating health disparities.

If the effectiveness of the intervention varies depending on the amount of participant/researcher racial/ethnic concordance, outcomes of a wide variety of intervention studies possibly could be enhanced by careful matching of study participants with interventionists. However, a more desirable option may be to provide cultural competency training programs that use validated methods. And if racial/ethnic concordant and discordant

pairs exist, comparing them would help to determine whether cultural competency is as effective as racial/ethnic matching.

Several studies have examined the relationship of patients and providers and health outcomes in clinical settings and have reported that African-American patients prefer to receive and report receiving better health care from physicians of the same race (Saha S et al., 2003; Cooper-Patrick L et al., 1999; Garcia JA et al., 2003; Saha S et al., 1999; Saha S et al., 2000; LaVeist TA & Nuru-Jeter A, 2002). Ashton and colleagues have hypothesized that poor communication contributes to lower health care utilization, health status and satisfaction in minority patients compared to white patients. Communication is an important aspect of many intervention studies as well. Few studies have evaluated the effects of racial/ethnic concordance matching between participants and interventionists in research; two studies evaluating outcomes by ethnic concordance between caregivers and therapists reported better outcomes with ethnic matching (Schoenwald SK et al., 2003; Halliday-Boykins CA et al., 2005). In REACH I African-American caregivers with an interventionist of the same race/ethnicity had greater improvements in one of three outcomes assessed (change in depression) than African-American participants with an interventionist of a different race/ethnicity. However, this pattern was not seen in the white and Hispanic participant groups.(McGinnis KA et al., 2006)

The REACH II study provides an opportunity to examine whether racial/ethnic concordance is associated with better outcomes in a study of racially/ethnically diverse caregivers of Alzheimer's disease patients receiving tailored interventions from cultural sensitivity trained interventionists (Belle SH et al., 2006a). REACH occurred in two phases – REACH I and REACH II. In REACH I several different interventions were tested at 6 sites to identify the best approaches to decreasing caregiver depression and burden (Wisniewski SR et

al., 2003; Schulz R et al., 2003). Results from REACH I informed the more tailored interventions that were provided in the second phase, REACH II. As mentioned previously, REACH I data were also used previously to assess whether there is an association between caregiver/interventionist racial/ethnic concordance and study outcomes. Results did not provide conclusive evidence, although suggested that concordance may be associated with better outcomes among African American caregivers.(McGinnis KA et al., 2006) The second phase of REACH (REACH II) provides another opportunity to assess racial/ethnic concordance in an intervention study. REACH II is a smaller, but more racially diverse study that incorporated cultural competency training and provided tailored interventions to a racially/ethnically diverse population of caregivers for Alzheimer's patients. REACH II provides an additional opportunity to evaluate caregiver/interventionist racial/ethnic concordance in a completely different group of caregivers and using a larger set of outcome measures.

3.2 OBJECTIVES

The main objective is to compare study outcomes of caregivers (participants) in REACH II who had an interventionist of the same race/ethnicity to caregivers who had an interventionist of a different race/ethnicity (concordance vs. discordance). There are two sub-aims. The first sub-aim is to compare study outcomes by caregiver race/ethnicity. The second sub-aim is to determine whether the association between concordance and study outcomes varies by caregiver race/ethnicity.

3.3 HYPOTHESES

The main hypothesis is that study outcomes will be better for caregivers who had a racial/ethnic concordant interventionist compared to caregivers with a racial/ethnic discordant interventionist

The first sub-hypothesis is that outcomes will differ by caregiver race/ethnicity. The second sub-hypothesis is that the association between concordance and study outcomes will vary by caregiver race/ethnicity.

4.0 METHODS

4.1 DATA FOR REACH II

4.1.1 Analytic Sample

REACH II is a multisite intervention study of caregivers of Alzheimer's disease patients. Caregiver-care recipient dyads were enrolled at five intervention sites in Birmingham, AL; Memphis, TN; Miami, FL; Palo Alto, CA; and Philadelphia, PA. Enrollment began in June 2002 and the six-month follow-up ended in August 2004. Recruitment occurred in memory disorder and primary care clinics, social service agencies, physician offices, churches, and community centers. The coordinating center for the study was in Pittsburgh, PA (Belle SH et al., 2006a).

Eligibility criteria included being Hispanic or Latino, white or Caucasian, or black or African-American race/ethnicity; being 21 years of age or older; sharing cooking facilities or living with the care recipient; providing care for a relative diagnosed with Alzheimer's disease or a related disorder for at least 4 hours per day for at least the past 6 months. Additional criteria included reporting distress associated with care giving, having not participated in REACH I, and having access to a telephone; plans to remain in the area for the next 6 months; and competency in either the English or Spanish language (Belle SH et al., 2006a; Belle SH et al., 2006a).

All intervention materials and assessment instruments were translated into Spanish for the Hispanic or Latino participants by using forward-and-back translation. Bilingual and bicultural staff was used at the 3 sites that recruited Hispanic or Latino participants: Palo Alto, Philadelphia, and Miami. Assessors and interventionists received cultural sensitivity training and were certified before beginning (Belle SH et al., 2006a). Cultural sensitivity training consisted of readings, group discussions, pilot testing, and feedback.

Caregivers were randomized into either an intervention or control group at each site. Interventions were tailored to individual needs and participants were assessed for high risk in five areas: depression, burden, self-care and healthy behaviors, social support, and problem behaviors. A high-risk assessment “triggered the most active treatment strategies and techniques within a target area”. The intervention included 9 in-home sessions (90 minutes each) and 3 telephone sessions (30 minutes each), and 5 structured telephone support sessions over a 6 month timeframe designed to address caregiver depression, burden, self-care, social support, and care recipient problem behaviors. The interventionist assignment was based on scheduling and Spanish vs. English as primary language. The control group caregivers received two brief telephone calls during the 6 month period. The main study found that the intervention group experienced greater improvement in outcomes overall compared to the control group (Belle SH et al., 2006a).

Out of the 642 caregivers in the REACH II study, for this analysis the 319 who were randomized into the control group were excluded because they didn’t have a face-to-face intervention. Of the 323 assigned to the intervention group, 89.1% (288) received at least one face-to-face intervention. Participants who had a care recipient who died or was institutionalized,

or was lost to follow-up were included if data were available from a corresponding follow-up survey (Table 2).

4.1.2 Variable Description

Caregiver race/ethnicity is based on two questions from self-report from the baseline survey. Race was determined by the question “How would you describe your primary racial group?” Possible responses were “White, Caucasian,” “Black, African-American,” “American Indian or Alaska native,” “Asian,” Native Hawaiian or other Pacific Islander,” or “Other.” Ethnicity was determined by the question “Do you describe yourself as Hispanic or Latino/a?” with possible responses of “yes” or “no.” Interventionist race/ethnicity was determined from self-report on the interventionist characteristic survey “What is interventionists primary racial group?” and “Does the interventionist describe himself/herself as Hispanic or Latino/a?” Response options are the same as described for caregivers. A combined racial/ethnic group variable was created to represent White, African-American, Latino/a, or other. Racial/ethnic concordance was based on whether the caregiver and interventionist were of the same combined racial/ethnic group. Since no caregivers in the analytic sample were in the “other” category, there was no issue with linking up the “other” category.

Lost to follow-up included those who formally withdrew from the study and those who could not be located while the study was ongoing. A variable was also created to reflect participation in the study that combined those who didn’t receive a face-to-face intervention and those who were lost to follow-up.

Because caregivers were provided with tailored interventions, types of intervention received were compared by caregiver race/ethnicity and racial/ethnic concordance, and site.

There were 6 main components of interventions: safety training, physical well-being (health passport), emotional well-being (stress management, pleasant events, mood), identifying and reducing behavior problems in dementia (ABC Process), behavioral prescription, and social support.

Burden scores were calculated using the brief 12-item version of Zarit Caregiver Burden Interview (Zarit SH, Orr NK, & Zarit JM, 1985; Bedard M et al., 2001). Caregivers rated the items on a 5 level response with 0 indicating “never” and 4 indicating “nearly always”. Scores ranged from 0 to 48 with higher scores indicating greater burden.

Problems scores were calculated using 3 items from the Revised Behavior Modification and Problems Checklist about cognitive, behavioral, and mood improvement or decline in care recipient (RMBPC) (Teri L et al., 1992). There were five response options ranging from “substantial decline” to “substantial improvement”. Scores ranged from 3-15 with a higher score indicating greater decline.

Depression scores were calculated using the 10-item version of the Center for Epidemiologic Studies - Depression Scale (Radloff L, 1977; Andersen EM, Malmgren JA, Carter WB, & Patrick DL, 1994). Question responses ranged from rarely or never (0) to most or all of the time (3). Depression scores were calculated by summing the scores for the 10 items; scores ranged from 0-30 with a higher score indicating greater depression symptoms.

Social support was assessed using 10 items that caregivers rated on a 4 point scale that ranged from never (0) to very often (3). 4 items had to be reverse coded so that item responses were in the same direction. Then items were summed and scores ranged from 0 to 40, with a higher score indicating more social support. (Krause N & Markides K, 1990; Barrera M, Sandler I, & Ramsay T, 1981)

Number of face-to-face intervention sessions attended was calculated by summing the number of in home interventions attended for at least 15 minutes. The intervention included 9 in home and 3 telephone sessions. An overall number of interventions received for at least 15 minutes was calculated.

At the end of the study caregivers were asked to rate 7 items regarding how much they benefitted from study participation. Response options were “not at all,” “some,” and “a great deal.” These items were evaluated individually, and were also summed to create a summary score of study satisfaction ranging from 7-21. From this score a dichotomous variable was created representing highly satisfied (score of 20 or 21) vs. not highly satisfied (score of less than 20).

Change scores from baseline to follow-up were created for problems, burden, and depression, by subtracting the follow-up score from the baseline score. For social support the change score was created by subtracting the baseline from the follow-up score. A positive change score indicates improvement whereas a negative score indicates decline.

4.2 STATISTICAL METHODS

4.2.1 Descriptive Analysis

Details about attrition and face-to-face intervention receipt are provided for caregivers who were randomized into the intervention group by caregiver race/ethnicity. For caregivers who received a face-to-face intervention, the number in each racial/ethnic concordance group was described

and demographic characteristics were compared by caregiver race/ethnicity and racial/ethnic concordance with interventionist.

Types of intervention received were described by caregiver race/ethnicity and racial/ethnic concordance, and site. Number of face-to-face intervention sessions attended were compared by race/ethnicity and racial/ethnic concordance using the Kruskal-Wallis test.

Outcome variables of interest (problems, burden, depression, and social support) were compared at baseline and follow-up by caregiver race/ethnicity and concordance. At follow-up the following outcomes were compared by caregiver race/ethnicity and concordance: mean number of sessions attended, mean change in problems, mean change in burden, mean change in depression, mean change in social support, and median satisfaction with study. Baseline characteristics and 6 month outcomes were compared by caregiver race/ethnicity by using chi-square tests for categorical variables, analysis of variance for approximately normally distributed variables and Kruskal-Wallis tests for nonnormally distributed continuous variables. Baseline caregiver characteristics and 6 month outcomes were compared by racial/ethnic concordance of caregivers and interventionists using chi-square tests for categorical variables, t tests for approximately normally distributed variables, and Wilcoxon rank-sum tests for nonnormally distributed continuous variables.

4.2.2 Multivariable Modeling

To determine characteristics associated with having at least one face-to-face intervention, predictors with $p < .15$ in univariate analyses were included in a multivariate logistic regression model. The predictors assessed in univariate models are: caregiver age, race/ethnicity, gender, site, education, relationship to care recipient (spouse vs. non-spouse) and site.

Among caregivers who had at least one face-to-face intervention, the association of concordance with the following outcomes was assessed: caregiver loss to follow-up, change in problems, burden, depression, and social support, number of sessions attended, and satisfaction with the study. Dichotomous outcomes (caregiver loss to follow-up and being highly satisfied at 6-months) were first assessed using a random effects logistic regression model (Rabe-Hasketh SA et al., 2000). Continuous approximately normally distributed outcomes (change in burden, problems, depression, social support, and number of sessions attended) were first assessed using linear mixed models (Rabe-Hasketh SA et al., 2000). For both the random effects logistic regression and linear mixed models a main model was used for each outcome which included the following covariates: caregiver gender and race/ethnicity, interventionist race/ethnicity, and racial/ethnic concordance between caregiver and interventionist. Interventionist was specified as a random effect so that random effect of interventionist could be tested.

For each outcome, racial/ethnic concordance, caregiver race/ethnicity and interventionist race/ethnicity were included in the main model (Model 1). Variables tested in univariate models include caregiver characteristics (age, gender, relationship to care recipient, income, education) and care recipient baseline ADL, and site. Variables with $p < .15$ in univariate models were added to the main model.

Preliminary analyses suggested that there may be an interaction between CG gender and race/ethnicity, so a variable combining caregiver gender and race/ethnicity was created for ease of interpretation. Prior analyses suggested that there may be an interaction between spousal relationship and race/ethnicity (Belle SH et al., 2006b), so this interaction was tested for each outcome by adding the interaction term to Model 1 (the combined caregiver/race/ethnicity/gender variable was replaced with caregiver gender in these models).

Other interactions tested include spousal relationship with concordance and caregiver gender, concordance with caregiver race/ethnicity and interventionist race/ethnicity, and caregiver race/ethnicity with caregiver gender. Tests of overall variables were conducted for categorical variables with more than two levels (caregiver race/ethnicity/gender and interventionist race/ethnicity). For mixed models and logistic models, the chi-square test was used to test whether the overall variables were statistically significant. Because Latino/a caregivers were primarily matched to concordant caregivers, an overall test was also run, but without including the Latino/as, to determine whether the caregiver race/ethnicity/gender variable is statistically significant without Latino/a caregivers included. Tests were also run to compare all of the caregiver race/ethnicity and gender categories to each other.

Model fit was evaluated by examining Cook's Distance for identifying any influential points by measuring the effect of deleting any given observation.(Cook RD, 1979) Residuals and plots of residual values vs. fitted values were created to identify any poorly fit points or potential outliers.

To determine whether outcomes varied by interventionist, multivariate models were run for each outcome as described above, except the covariates included in the models were caregiver gender/race/ethnicity and concordance, and site was specified as a random effect so that random effect of site could be tested.

Statistical analyses were conducted using Stata 12.0. (StataCorp, 2011) Differences were considered to be statistically significant if $p \leq 0.05$, with no adjustment made for multiple comparisons. For the outcomes number of sessions, change in problems, burden, depression, and social support, a clinically meaningful difference was identified and calculated as being one half of the standard deviation for the measure. As an example of a clinically meaningful change for

depression would be one of the 10 items changing from "rarely or none of the time" (0) to "most or almost all of the time" (3). This clinically meaningful threshold is helpful for interpreting results in addition to using p-values.

5.0 RESULTS

5.1 DESCRIPTIVE RESULTS

REACH II enrolled and randomly assigned 642 caregivers into intervention and control groups. This analysis includes 323 caregivers randomized into the intervention group: 113 were White, 104 were African-American, and 106 were Latino/a. Of the 323 caregivers in the intervention group, 287 had at least one face-to-face intervention and an interventionist who was white, African-American, or Latino/a. Of the 287 with a face-to-face intervention, 22 had a care recipients who was institutionalized, 18 care recipients died, and 13 were lost to follow-up (Table 2).

5.1.1 Face-to-face Intervention

The percent of the 323 who received at least one face-to-face intervention of at least 15 minutes in length was compared by demographic characteristics. Overall, 89.5% received at least one face-to-face intervention. A higher percent of white caregivers received a face-to-face intervention (96%) compared to African-American and Latino/a caregivers (88% and 84%, $p=.018$). Over 88% received a face-to-face intervention at all of the sites except for one site at which only 69% received a face-to-face intervention. Caregivers who were 60 years and older

Table 2. Summary of Participants in REACH II Intervention Group

	Total	White	African-American	Latino/a
Randomized (n)	323	113	104	106
Had at least 1 face-to-face intervention at least 15 minutes in length	289	108	92	89
Non-Missing Concordance	289	108	91	90
Interventionist of White, African-American or Latino/a Race/Ethnicity	288	108	90	90
Had at least 1 face-to-face intervention at least 15 minutes in length and Non-Missing Concordance and with Interventionist of White, African-American or Latino/a Race/Ethnicity	287	108	90	89
CR Institutionalized	24	16	7	1
CR Died	25	7	12	6
Lost to Follow-up	28	7	9	12
Withdrew Consent	19	6	5	8
Location Unknown	9	1	4	4

were more likely receive a face-to-face intervention compared to younger caregivers (93% vs. 86%, $p=.03$) and those who were spouses were more likely to receive a face-to-face intervention compared to non-spouses (94% vs. 86%, $p=.03$). Gender and education were not statistically significantly associated with having a face-to-face intervention (Table 3). In the multivariate model predicting having a face-to-face intervention, caregiver age, race/ethnicity and spousal relationship were not statistically significantly associated with having a face-to-face intervention, although Site 4 was associated with having a lower likelihood of having a face-to-face intervention ($OR = .04$, $p<.003$) (Table 4). Because it is difficult to disentangle site and race/ethnicity, percent with a face-to-face intervention for each race/ethnicity and site group is shown in Table 5. From this table it is apparent that for white caregivers the lowest percent of

face-to-face intervention is at Site 4; for African-American caregivers, the lowest percent is at Sites 2 and 4; and for Latino/as, the lowest percent is at Site 4.

Table 3. Percent Receiving a Face-to-Face Intervention by Baseline Characteristics (n=323)

	% Who Received a Face-to-face Intervention	P
Caregiver Age		.03
<60	86	
60+	93	
Gender		.9
Female	89	
Male	90	
Caregiver Race/Ethnicity		.018
White	96	
African-American	88	
Latino/a	84	
Relationship to CR		.03
Spouse	94	
Non-Spousee	86	
Site		<.001
Birmingham	98	
Memphis	89	
Miami	93	
Palo Alto	69	
Philadelphia	97	
Education		.9
<HS	90	
HS	89	
Some College or Tech	89	
College Graduate	90	

Table 4. Multivariate Logistic Regression Model Predicting Having a Face-to-Face Intervention of Those Assigned to Intervention Group (n=323)

	OR	P
Caregiver Age		
<60 (referent)		
60+	1.90	.18
Caregiver Race/Ethnicity		
White (referent)		
African-American	.32	.06
Latino/a	.36	.09
Site		
Birmingham (referent)		
Memphis	.13	.06
Miami	.23	.2
Palo Alto	.04	.003
Philadelphia	.51	.6
Relationship to CR		
Non-Spouse (referent)		
Spouse	1.28	.6

Table 5. Percent with Face-to-face Intervention by CG Race/Ethnicity and Site (n=323)

	Caregiver Race/Ethnicity		
	White % (n)	African- American % (n)	Latino/a % (n)
Site			
Birmingham	100 (30)	97 (31)	-
Memphis	96 (28)	81 (27)	-
Miami	94 (18)	100 (15)	91 (55)
Palo Alto	81 (16)	67 (12)	64 (33)
Philadelphia	100 (21)	89 (19)	100 (18)

5.1.2 Care Recipient Institutionalization, Death, and Loss to Follow-up

For the 323 in the intervention group, there were 24 care recipients institutionalized during the study. There were no statistically significant differences between those with and without a care recipient who was institutionalized by caregiver age, gender, racial/ethnic concordance with interventionist, site, spousal relationship to care recipient, or education. However, white caregivers (14%) were more likely to have care recipients who were institutionalized during the study compared to African American (7%) and Latino/a caregivers (1%) ($p=.001$) (Table 6).

For the 323 in the intervention group, there were 25 care recipient deaths during the study. There were no statistically significant differences for caregivers with and without a care recipient death by caregiver age, race/ethnicity, racial/ethnic concordance with interventionist, gender, site, spousal relationship to care recipient, or education. However, care recipients who died were older compared to care recipients who didn't die (mean age 83.1; s.d.=1.38 vs. 78.4, sd=.53) (Table 6).

For the 323 in the intervention group, 28 (9%) were lost to follow-up. There were no statistically significant differences in caregivers who were and were not lost to follow-up by caregiver age, race/ethnicity, gender, racial/ethnic concordance with interventionist, site, spousal relationship to care recipient, or education (Table 6).

Table 6. Summary of Caregivers With a Care Recipient Who was Institutionalized or Died, or who were Lost to Follow-up During Study by Baseline Characteristics (n=323)

	Care Recipient Institutionalization		Care Recipient Death		Caregiver Lost to Follow-Up	
	%	P-Value	%	P-Value	%	P-Value
Caregiver Age		.6		.5		.9
<60	7		7		9	
60+	8		9		9	
Caregiver Race/Ethnicity		.001		.2		.4
White	14		6		6	
African-American	7		12		9	
Latino/a	1		6		11	
Gender		.7		.4		.7
Female	7		8		8	
Male	8		5		10	
Site		.1		.7		.8
Birmingham	10		10		5	
Memphis	11		11		7	
Miami	3		6		10	
Palo Alto	3		8		10	
Philadelphia	12		5		10	
Relationship to CR		.8		.2		.9
Spouse	7		6		9	
Non-Spouse	8		9		9	
Education		.08		.1		.1
<HS	5		10		7	
HS	3		3		11	
Some College or Tech	13		12		13	
College Graduate	7		5		3	
Care Recipient Institutionalized						.4
Yes	-		-		4	
No	-		-		9	
Care Recipient Died						.5
Yes	-		-		12	
No	-		-		8	
Concordance (n=287)		.7		.6		.9
Yes	8		7		5	
No	7		9		5	

Note: Of those care recipients who died, mean age was statistically significantly higher than for care recipients who didn't die with mean (SD) = 83.1 (9) vs. 78.4 (7), p=.01

5.1.3 Racial/Ethnic Concordance between Caregivers and Interventionists

Of the 287 caregivers who had a face-to-face intervention and a white, African-American, or Latino/a interventionist, 108 were white, 90 African-American, and 89 Latino/a. The interventionist for these caregivers are comprised of 14 who were white, 2 who were African-American, 13 who were Latino (Table 7). Note that 1 interventionist was of Asian or

Table 7. Caregiver Race/Ethnicity by Racial/Ethnic Concordance with Interventionists (n=287 caregivers; 29 interventionists)

Interventionist Race/Ethnicity	Caregiver Race/Ethnicity		
	White (n=108)	African-American (n=90)	Latino/a (n=89)
White (n=14)	80	50	1
African-American (n=2)	7	21	3
Latino/a (n=13)	21	19	85
	Females		
White (n=14)	63	41	1
African-American (n=2)	5	19	1
Latino/a (n=13)	20	15	69
	Males		
White (n=14)	17	9	0
African-American (n=2)	2	2	2
Latino/a (n=13)	1	4	16

Pacific Islander race/ethnicity and was not included in this analysis. Table 8 displays how concordance and caregiver race/ethnicity breaks down by site. In this table it is clear that sites vary by caregiver race/ethnicity and concordance. In Site 2 there is no opportunity for African-American caregivers to have a concordant interventionist or for white caregivers to have a discordant interventionist. In Site 3 there is no opportunity for white or African-American caregivers to have a concordant interventionist, nor can Latino/a caregivers have a discordant interventionist. In Site 5 there was no opportunity for African-Americans to have a concordant

interventionist, but it appears that an effort may have been made to match concordance for white and Latino/a caregivers, likely due to matching Spanish speaking caregivers to Spanish speaking interventionists.

5.1.4 Specific Interventions Administered

Because REACH 2 administered tailored interventions, the six intervention components administered are summarized by caregiver race/ethnicity, racial/ethnic concordance with interventionist, and site. The intervention was considered as administered if >15 minutes were recorded. Of the six components, there were no statistically significant differences by caregiver race/ethnicity, concordance with interventionist, or site with two exceptions: Safety training was administered for 81% of African American caregivers compared to 85% for white and 94% for Latino/a caregivers ($p=.04$); and Health passport and Behavioral Prescription varied by site ($p<.001$ for both).

5.1.5 Caregiver Characteristics by Race/Ethnicity and Concordance with Interventionist

Caregivers who were white were more likely to have a spouse as a care recipient, had a higher income, and were more likely to be a college graduate compared to African-American and Latino/a caregivers. There were no statistically significant differences by age, gender, or ADL between the caregiver racial/ethnic groups. Caregivers with a concordant interventionist were more likely to be white or Latino/a, to have a care recipient who is a spouse, and to have less than a high school education. There were no statistically significant differences in age, gender, income or ADL between concordant groups (Table 9).

At baseline, African-American caregivers had statistically significantly lower median of burden and problems, and Latino/a caregivers had lower median social support. Caregivers with a discordant interventionist had lower median problems reported. At follow-up, African-American caregivers had statistically significantly lower median burden. There were no statistically significant differences in depression, problems or social support at follow-up by caregiver race/ethnicity or by concordance (Table 10).

5.1.6 Caregiver Loss to Follow-Up of Those with a Face-to-face Intervention

Of the 287 caregivers who received at least one face-to-face intervention, 5% (13) were lost to follow-up (Table 11). Based on univariate models, the percent lost to follow-up didn't vary statistically significantly by race/ethnicity, site, or racial/ethnic concordance with interventionist. In multivariate models, no variables were statistically significantly associated with loss to follow-up (Table 12).

5.2 MAIN OUTCOMES

5.2.1 Random Effects of Main Models

For problems, burden, depression, and social support change scores, and number of sessions attended, the main mixed models with interventionist specified as the random effect were run and the effect of the interventionist was tested (covariates included in the model: caregiver race/ethnicity/gender, interventionist race/ethnicity, and concordance). For the problem

and burden change scores, the random effect of the interventionist is minimal. The random effect is statistically significant for the change in depression, change in social support, and number of sessions attended.

5.2.2 Change in Caregiver Burden Scores

Mean change in caregiver burden was not statistically significantly different by race/ethnicity or by concordance with interventionist (Table 11). In univariate regression models, no variables were associated with change in burden at $p < .15$. Based on the main multivariate model, mean change in burden was not statistically significantly different by race, gender, concordance, and interventionist race/ethnicity (Table 13), and none of the coefficients were as high as the clinically meaningful difference identified of 4.21.

5.2.3 Change in Caregiver Problems Scores

Change in problems was negative, indicating became worse, for African-American caregivers and the difference in change in problems was statistically significantly different between the three caregiver racial/ethnic groups ($p = .005$). Change in problems did not vary statistically significantly by caregiver/interventionist racial/ethnic concordance.

In univariate regression models, variables associated with change in problems at $p < .15$ are: caregiver race/ethnicity and concordance. Based on the main multivariate model, mean

Table 8. Racial/Ethnic and Concordance Distribution (N), by Site (n=287)

Site	N	Interventionist			Caregiver					
		White	African-American	Latino/a /Other	White		African-American		Latino/a	
					Same	Different	Same	Different	Same	Different
Birmingham	60	5	1	0	26	4	18	12	0	0
Memphis	49	3	0	0	27	0	0	22	0	0
Miami	82	0	0	6	0	17	0	15	50	0
Palo Alto	41	3	1	4	8	5	3	3	17	4
Philadelphia	56	3	0	3	19	2	0	17	18	0

Table 9. Baseline Caregiver Characteristics, by Caregiver Race/Ethnicity and by Racial/Ethnic Concordance with Interventionist (n=287)

	Caregiver Race/Ethnicity			<i>p</i> Value	Racial/Ethnic Concordance		
	White (n=108)	African- American (N=90)	Latino/a (n=89)		Different (n=101)	Same (n=186)	<i>p</i> Value
Mean Age (SD), years	63 (12)	61 (12)	60 (14)	.16	60 (12)	62 (13)	.2
Female (%)	82	83	80	.8	82	81	.8
Caregiver Race/Ethnicity (%)							<.001
White	-	-	-		28	43	
African-American	-	-	-		68	11	
Latino/a	-	-	-		4	46	
Care recipient is spouse (%)	58	32	45	.001	38	51	.04
Annual Income (%)				<.001			.9
<\$20,000	21	41	60		40	39	
\$20,000-39,999	26	33	25		28	28	
\$40,000+	52	26	16		33	33	
Education (%)				<.001			.03
Less than High School	9	12	36		10	23	
High School Graduate	17	30	19		25	20	
Some College or Tech School	39	34	20		38	28	
College Graduate	35	23	25		28	28	
Median ADL (IQR)	3 (1.5-5)	4 (2-5)	4 (2-5)	.28	4 (2-5)	4 (2-5)	.6

Table 10. Baseline and Follow-up Measures, by Caregiver Race/Ethnicity and by Racial/Ethnic Concordance with Interventionist (n=287)

	Caregiver Race/Ethnicity			Racial/Ethnic Concordance			
	White	African-American	Latino/a		Different	Same	
	Median (IQR)			<i>p</i> Value	Median (IQR)		<i>p</i> Value
Baseline	(n=108)	(N=90)	(n=89)		(n=101)	(n=186)	
Problems	11 (9-12.5)	9 (7-11)	11 (9-13)	<.001	9 (8-12)	11 (9-13)	.002
Burden	18 (13-24)	15 (10-20)	18 (9-24)	.03	16 (11-21)	18 (11-24)	.13
Depression	9 (5-13)	8 (5-13)	11 (6-16)	.21	8 (5-13)	9 (5-14)	.11
Social Support	19 (14-22)	19 (15-23)	16 (12-20)	<.001	18 (14-22)	18 (13-22)	.9
Follow-up							
Problems	10 (9-12)	9 (8-11)	9 (7-11)	.06	10 (8-11)	10 (8-12)	.6
Burden	17 (12-23)	12 (8-17)	14 (8-21)	<.001	12 (8-19)	16 (10-21)	.06
Depression	7 (4-11)	6 (3-11)	7 (4-12)	.6	6 (3-10.5)	7 (4-12)	.10
Social Support	21 (16-24)	21 (17.5-24.5)	17 (14-21)	<.001	21 (1.7-24)	19 (15-23)	.11

Table 11. Outcomes at 6-Month Follow-up by Caregiver Race/Ethnicity and by Racial/Ethnic Concordance (n=287)

	Caregiver Race/Ethnicity			<i>p</i> Value	Racial/Ethnic Concordance		<i>p</i> Value
	White	African-American	Latino/a		Different	Same	
N	108	90	89		101	186	
Loss to Follow-up (%)	5	4	7	.7	5	5	.9
Problems Mean Change (SD) ^{a,b}	.56 (2.90)	-.26 (3.17)	1.35 (2.89)	.005	.07 (3.09)	.82 (2.98)	.067
Burden Mean Change (SD) ^{a,c}	1.78 (7.06)	2.96 (6.70)	2.38 (7.84)	.5	2.67 (5.75)	2.13 (7.87)	.6
Depression Mean Change (SD) ^{a,d}	1.67 (5.45)	1.83 (5.37)	2.22 (4.83)	.7	2.04 (5.12)	1.81 (5.29)	.7
Social Support Mean Change (SD) ^{a,d}	1.89 (4.68)	1.92 (4.84)	1.62 (4.94)	.91	2.47 (4.33)	1.47 (5.01)	.10
Mean # Intervention Sessions Attended (S.D.)	8.63 (2.47)	7.91 (2.80)	8.73 (2.37)	.06	8.34 (2.64)	8.49 (2.53)	.9
Median Satisfaction (IQR) ^e	17 (14-19)	19 (16-20)	21 (18-21)	<.001	19 (15-20)	19 (16-21)	.09
High Satisfaction (%)	22	43	66	<.001	38	45	.3

^a Positive change indicates and improvement; negative change indicates became worse

^b For change in problems there were 96 whites, 74 African-American, and 74 Latino/as; 158 concordant and 86 discordant

^c For change in burden, there were 97 whites, 75 African-American, and 77 Latino/as; 162 concordant and 87 discordant

^d For change in depression and social support, there were 101 whites, 84 African-American, and 83 Latino/as; 174 concordant; 94 discordant

^e For Satisfaction there were 100 whites, 82 African-American, and 82 Latino/as; 171 concordant and 93 discordant

Table 12. Estimated Odds Ratio of Caregiver Loss to Follow-up at 6-Months, from Multivariate Logistic Regression Models (n=287)

	χ^2 (df)			
	<i>p</i> Value	OR	95% CI	<i>p</i> Value
Discordant Race/Ethnicity Caregiver	4.21 (5)	1.27	.24-6.66	.78
Race/Ethnicity/Gender ^a	.52			
White Male		1.06	.11-10.21	.96
African-American Female		.54	.07-4.12	.56
African-American Male		2.93	.35-24.68	.32
Latina Female		2.00	.27-15.09	.50
Latino Male		4.18	.45-38.69	.21
Interventionist Race/Ethnicity	0.53 (2)			
African-American	.77	.53	.06-5.19	.59
Latino/a		.56	.10-3.22	.52
Intercept		.05	.02-.16	<.001

^a Baseline is white female

change in problems was statistically significantly greater (worse) for African-American men than for white women ($p=.010$) (Table 13). Post test comparisons also showed that mean change in problems were statistically significantly greater for African-American men compared to African-American women ($p=.03$), white men ($p=.004$), Latina women ($p=.002$), and Latino men ($p=.004$) (not shown), and the statistically significant coefficients were as high as the clinically meaningful difference identified as 1.37.

5.2.4 Change in Caregiver Depression Scores

Mean change in caregiver depression was not statistically significantly different by race/ethnicity or by concordance with interventionist (Table 11). In univariate regression models, variables associated with change in depression at $p<.15$ are racial/ethnic concordance and education. Based on the main multivariate model, mean change in depression was not statistically

significantly different by caregiver race/ethnicity, gender, concordance, and interventionist race/ethnicity (Table 14), and none of the coefficients were as high as the clinically meaningful difference identified as 3.16. With education added to the main model, those with high school education or more had improvements in depression compared to those with less than a high school education. The variance component associated with interventionists in the main model was high (4.9 with SE=.23).

5.2.5 Change in Caregiver Social Support Scores

Mean change in caregiver social support was not statistically significantly different by race/ethnicity or by concordance with interventionist (Table 11). In univariate regression models, variables associated with change in social support at $p < .15$ are: caregiver race/ethnicity/gender, concordance, and spousal relationship. Based on the main multivariate model, mean change in social support was not statistically significantly different by any variables (Table 14), and none of the coefficients were as high as the clinically meaningful difference identified as 2.87. However, those with an African American interventionist had a greater improvement in social support (coef=2.3), but that p-value was not statistically significant ($p = .08$). With spousal relationship added to the main model, the African-American interventionist coefficient increased to 2.8 and is statistically significant ($p = .036$). The variance component associated with interventionists in the main model was high (4.5 with SE=0.21).

Table 13. Estimated Multivariable Linear Regression Coefficients and Standard Errors (S.E.) for Caregivers at 6-Month Follow-up

	Change in Zarit Burden Inventory (n=249)				Change in Revised memory and Behavior Problems Checklist (RMBPC) (n=244)			
	χ^2 (df)	Coef. ^b	S.E.	p Value	χ^2 (df)	Coef. ^c	S.E.	p Value
Discordant Race/Ethnicity Caregiver	2.82 (5)	.43	1.39	.80	2.46 (5)	.31	.57	.58
Race/Ethnicity/Gender ^a	.73				.03			
White Male		1.12	1.85	.54		.92	.77	.24
African-American Female		1.42	1.43	.34		-.44	.59	.45
African-American Male		-.52	2.31	.82		-2.54 ^d	.96	.008
Latina Female		1.63	1.76	.36		1.30	.72	.07
Latino Male		2.63	2.36	.26		1.55	.98	.11
Interventionist Race/Ethnicity	0.41 (2)				.23 (2)			
African-American	.81	.37	1.95	.85	.79	-.10	.68	.89
Latino/a		-.94	1.66	.57		-.42	.60	.49
Intercept		1.58	1.03	.12		.40	.38	.29

^a Baseline is white female

^b Positive coefficient indicates decrease in burden over time

^c Positive coefficient indicates decrease in problems over time

^d Problems became statistically significantly worse for African-American men compared to all other race/ethnicity/gender groups (all $p \leq .03$)

Table 14. Estimated Multivariable Linear Regression Coefficients and Standard Errors (S.E.) for Caregivers at 6-Month Follow-up

	Change in <u>Depression</u> (n=268)				Change in <u>Social Support</u> (n=268)			
	χ^2 (df)	Coef. ^b	S.E.	p Value	χ^2 (df)	Coef. ^c	S.E.	p Value
Discordant Race/Ethnicity		.71	.96	.46		1.37	.87	.11
Caregiver	2.72 (5)				4.38 (5)			
Race/Ethnicity/Gender ^a	.74				.5			
White Male		1.03	1.28	.42		.75	1.17	.52
African-American Female		.18	1.00	.86		-.92	.91	.31
African-American Male		-1.58	1.59	.32		1.41	1.45	.33
Latina Female		1.04	1.22	.40		.42	1.11	.71
Latino Male		.37	1.57	.81		-.48	1.43	.74
Interventionist	2.04 (3)				3.20 (2)			
Race/Ethnicity	.36				.20			
African-American		2.19	1.53	.15		2.32	1.31	.08
Latino/a		.34	1.27	.79		.14	1.10	.90
Intercept		1.16	.80	.15		1.34	.69	.052

^a Baseline is white female

^b Positive coefficient indicates decrease in depression over time

^c Positive coefficient indicates increase in social support over time

5.2.6 Number of Sessions Attended

In univariate comparisons, number of sessions attended was not statistically significantly different by race/ethnicity or by concordance with interventionist (Table 11). In univariate regression models, variables associated with number of sessions attended at $p < .15$ are: caregiver race/ethnicity and education. Based on the main multivariate model, number of sessions attended was not statistically significantly different for any variables, except for white males compared to African-American females ($p = .02$) (Table 15). The magnitude of this difference (1.76) is greater than the difference identified as clinically meaningful of 1.29. Education was not statistically significant associated with number of sessions attended when added to the main model.

5.2.7 Satisfaction

Median satisfaction and high satisfaction does not vary statistically significantly by caregiver/interventionist racial/ethnic concordance. However, median satisfaction and the percent with high satisfaction was greater for African-American and Latino/a caregivers compared to white caregivers (median = 19 and 21 vs. 17, $p < .001$; and 43% and 66% vs. 22%, $p < .001$) (Table 11). In univariate logistic regression models, variables associated with high satisfaction at $p < .15$ are: caregiver race/ethnicity, interventionist race/ethnicity, gender, income, and education. Based on the main multivariate model, African-American male and Latino/a caregivers have statistically significantly higher satisfaction compared to white caregiver men

Table 15. Estimated Multivariable Regression Coefficients (and Odds Ratios) Standard Errors (S.E.) for Active Caregivers at 6-Month Follow-up

	# Sessions Attended (n=287)				High Satisfaction with Participation (n=237)			
	χ^2 (df)	Coef.	S.E.	p Value	χ^2 (df)	OR	S.E.	p Value
Discordant Race/Ethnicity Caregiver	7.17 (5)	.28	.45	.63	29.8 (5)	1.44	.67	.43
Race/Ethnicity/Gender ^a	.21				<.001			
White Male		.99 ^b	.62	.12		2.45 ^c	1.42	.12
African-American Female		-.77 ^b	.47	.10		2.35 ^c	1.18	.09
African-American Male		-.34	.74	.67		7.33	5.67	.01
Latina Female		-.13	.58	.82		23.07 ^c	14.64	<.001
Latino Male		.12	.74	.87		28.33 ^c	22.99	<.001
Interventionist Race/Ethnicity ^a	1.01 (3)				5.31 (2)			
African-American	.60	-.09	.58	.88	.07	.85	.44	.76
Latino/a		.48	.51	.35		.29	.16	.021
Intercept		8.34	.32	<.001		.26	.09	<.001

^a Baseline is white female

^b Mean number of sessions attended is statistically significantly greater for white males compared to AA females (p=.02)

^c Satisfaction is statistically significantly higher for Latino/a females and males compared to white males and AA females (all p<.003)

and women (Table 15). Those with a Latino/a interventionist have lower satisfaction in the model; however, the number of caregivers with discordant Latino/a interventionists (4) needs to be considered when interpreting this finding. With education added to the main model, caregivers with a college education had lower satisfaction compared to those with a lower education.

5.2.8 Sensitivity Analyses

In each main model, the overall caregiver gender/race/ethnicity variable was tested for statistical significance as shown in Tables 14-16. Because the vast majority of the Latino/a group had a concordant interventionist, this post test was also run leaving out the Latino/a groups to examine whether this group was influencing the relationship to the outcome. The overall caregiver gender/race/ethnicity variable test results were similar for each model with and without the Latino/a caregivers included in the test. Models run excluding caregivers who were institutionalized were similar to the main models with no exclusions.

5.2.9 Interventionist association with outcomes

The 29 interventionists in this analysis saw from 1 to 27 caregivers, with a mean of 9.9 caregivers. Interventionist association with outcomes was assessed using linear mixed models adjusting for caregiver race/ethnicity/gender and concordance, and with site specified as a random effect. The interventionist used for the baseline value is the one who provided interventions to the greatest number of caregivers, and is a Latino/a female who saw 9 white, 5 African-American, and 13 Latino/a caregivers. Overall, interventionist was not statistically

significantly associated with change in problems or number of sessions attended. The overall interventionist variable is statistically significantly associated with the outcomes change in burden, depression, and social support. One interventionist was identified as having caregivers with higher (better) change scores for burden. This interventionist was a white male who saw 2 white caregivers. Two interventionists were identified as having caregivers with higher (better) change scores for both depression and social support. One interventionist was a female Latino who provided interventionists for 1 white, 1 African-American, and 1 Latino/a caregiver. The other interventionist was a female African-American who provided interventionists for 3 white, 3 African-American, and 3 Latino/a caregiver. Two interventionists were identified as having caregivers with lower change (worse) in depression scores and they were both white females. One saw 4 African-American and 2 Latino caregivers; the other saw 2 white, 3 African-American, and 1 Latino/a caregiver. Three interventionists were identified as having caregivers with lower (worse) satisfaction scores and they were all Latino females. Two saw caregivers of different race/ethnicities (2 white, 4 African-American, 12 Latino/a for one; 3 white, 1 African-American, and 14 Latino/a for the other) and one saw 10 Latinos/as.

6.0 SUMMARY

Of the 322 caregivers randomized to the intervention group, white caregivers were more likely to have received at least one face to face intervention compared to African-American and Latino/a caregivers, however this association was not statistically significant in the multivariate model adjusted for age, gender and spousal relationship. Site 4 had a lower percent of caregivers who received a face to face intervention compared to the other sites.

White caregivers were more likely to have a care recipient who was institutionalized compared to African-American and Latino/a caregivers. Care recipient death did not vary by caregiver race/ethnicity. Care recipients who were older were more likely to die during the study. Loss to follow-up was similar by caregiver race/ethnicity.

There was no statistically significant difference in mean change in burden, problems, depression, or social support by racial/ethnic concordance. Burden became worse for African-American men compared to other groups. African-American and Latino/a caregivers had higher satisfaction scores compared to white caregivers. Caregivers with a college education had lower satisfaction than caregivers with a lower education level. Caregivers with an African-American interventionist had greater improvement in social support than those with white or Latino/a interventionists; however since there were only two African-American interventionists, this finding should be interpreted with caution. For the statistically significant differences noted, the magnitude of these differences is also considered clinically meaningful (Table 16).

The interventionist variance components in the main models were high for depression and social support indicating that there was a high level of variation in the outcomes change in depression and social support between interventionists. In the models that included an individual interventionist variable as a predictor, the overall interventionist variable was statistically significantly associated with the outcomes change in depression, social support, and burden. The interventionists who were identified as having caregivers with statistically significantly better or worse outcomes saw a variety of racial/ethnic and concordant/discordant caregivers.

Table 16. Summary of Results of Seven Main Outcomes Based on Multivariate Models and Comparison to A-Priori Clinically Important Differences

Outcome	Range for Scores	Clinically Important Difference Based on 1/2 SD*	Summary of CG Race/Ethnicity/Gender and Racial/Ethnic Concordance Results	
			From Multivariate Models (baseline=White females)	Compared to Clinically Important Difference
Loss to follow-up	0/1	-	NS	
Change in burden	0-44	4.21	NS	None as high
Change in Problems	3-15	1.37	Became worse for AA men (coef = -2.54, p=.008) and better for Latino men (coef=1.55, NS)	Difference greater for AA men and Latino men
Change in Depression	0-30	3.16	NS	None as high
Change in Social Support	0-30	2.87	NS	None as high
Number of Sessions Attended	1-12	1.29	White males attended an average of 1.76 more sessions than AA females (p=.02)	Higher
High Satisfaction with Study (<20 vs. 20+ on scale of 7-21)	0/1	-	Greater % of AA males and Latino/a's reported high study satisfaction compared to AA female and white CGs	

7.0 DISCUSSION

This study used data from an observational study within a randomized trial and represents a way in which a secondary data analysis can be used to address whether racial/ethnic concordance is associated with outcomes in intervention studies. However, because this is a secondary analysis, the study design was not ideal for comparing outcomes by racial/ethnic concordance.

This study has several limitations. Racial/ethnic concordance wasn't equally distributed among the caregiver racial/ethnic groups. A large percent of the Latino/a caregivers were with a concordant interventionists whereas a small percent of African-Americans were with a concordant interventionist. There are few (only two) African-American interventionists which also contributed to few of the African-American caregivers having a concordant interventionist. Caregivers weren't randomly assigned to a concordant vs. discordant interventionist. Latino/a caregivers were recruited from two different sites so may not represent a homogenous group of Latino/as.

The study has many strengths as well. This is a secondary data analysis so although the study was not designed to address the hypotheses, the study represents an efficient and cost-effective use of resources. The sample is racially/ethnically diverse as it is approximately 1/3 white, 1/3 African-American, and 1/3 Latino/a, and geographically diverse as it includes 5 different U.S. sites. Although interventionist assignment wasn't random, it also wasn't based on caregiver preference which could introduce bias. Assignment was based on timing and availability of interventionists as well as matching Spanish speaking caregivers to Spanish speaking interventionists. REACH II interventionists received cultural sensitivity training and

the REACH II study provided participant-centered care as caregivers needs were assessed and the interventions provided were tailored to individual caregiver needs.

A similar secondary data analysis was conducted in REACH I and those findings indicated that outcomes didn't vary by racial/ethnic concordance, except for one outcome (change in depression) for the African-American caregivers. In REACH I, only three outcomes were evaluated: depression, burden, and loss to follow-up. REACH I differed from REACH II in that it had a larger sample size, however race/ethnicity wasn't equally distributed between caregivers. REACH II provided more intense and tailored interventions and evaluated more outcomes than REACH I. In both REACH I and REACH II the majority of white and Latino/a caregivers saw a concordant interventionist and the majority of African-American caregivers saw a discordant interventionist. Findings based on the REACH II study are similar to findings from REACH I in that both studies there is not conclusive evidence indicating that racial/ethnic concordance is associated with outcomes.

Given that several previous studies have reported that racial/ethnic concordance between patients and providers was associated with higher patient satisfaction and health outcomes, I expected to see a difference in outcomes by concordance in REACH II. However, in REACH II, findings don't support that racial/ethnic matching is associated with study outcomes. One possibility for this finding is that REACH II included interventionists who received cultural competency training and perhaps the cultural competency training was successful.

Since 2001 culturally and linguistically appropriate services (CLAS) in health and health care have been promoted and mandated in some states and cultural competency training has become more widespread. The methods used in this analysis could be applied to other intervention studies as one step in evaluating whether outcomes vary by racial/ethnic

concordance. If cultural competency is successful in intervention studies, perhaps there shouldn't be differences in outcomes by racial/ethnic concordance.

As this is a secondary data analysis, REACH II was not designed to address the main aim of comparing outcomes by racial/ethnic concordance between the caregivers (study participants) and interventionists. Through this process, I have been able to identify how a future randomized intervention study could be designed to allow for a better comparison of outcomes by racial/ethnic concordance between participants and interventionists. A study designed to evaluate whether concordance is associated with outcomes would need to include an equal percent of various racial/ethnic participant groups as REACH II did, but would also need to include an equal percent of various racial/ethnic interventionist groups which REACH II did not. Participants would need to be randomly assigned to a concordant or discordant interventionist.

Other barriers may exist such as age, gender, or economic differences in which the researcher would benefit from cultural competency training. Another consideration is that some interventionists may provide better interventions and/or could be more culturally competent than other interventionists despite any interventionist training. Personality, experience, empathy, and other characteristics such as these can be difficult to measure and control for.

In future health and medical research studies, attempts could be made to ensure that the race/ethnicity of research staff, including coordinators, interviewers, and interventionists, is representative of the study enrollment population. This may contribute to having a study that is more culturally competent and aware overall and could also lead to a more equal distribution of concordant/discordant pairs in intervention studies. Incorporating a formal evaluation of cultural competency training for staff and interventionists may help ensure that the training was successful or to allow for additional cultural competency training if it was not. Randomly

assigning participants to concordant/discordant interventionists as well as study staff would be ideal. Incorporating age and gender of interventionists into the design of the study would help to unmask other concordant/discordant demographic characteristics which could impact results. Possible ways to incorporate age and gender would be to 1) include racial/ethnic groups of interventionists that are demographically similar to each other or 2) by using a large enough sample to allow for comparisons to be made w/in different interventionist age and gender groups.

8.0 CONCLUSIONS

Identifying mechanisms of improving minority participation and outcomes in health research is necessary and an important component of improving minority health. Although evaluating the effects of racial/ethnic concordance in health care and health research may provide important information for improving participation and outcomes and for assessing cultural competency training, it is not advisable to promote racial/ethnic matching for health care and health research overall as in many cases it is not economically or structurally feasible, and more importantly it could lead to segregation. Employing a diverse research staff that reflects the population of recruitment could be one way to increase the cultural competency in research studies. Identifying and implementing effective cultural competency training techniques through rigorous evaluation and research are necessary for improving future minority participation in research and outcomes.

APPENDIX: SUPPLEMENTARY TABLES

Table 17. P-Values Comparing CG Race/Ethnicity/Gender Groups in Main Models

Main Model Outcome	White Female	White Male	AA Female	AA Male	Latina Female
Burden – NS					
Problems					
White Male	.2				
AA Female	.5	.12			
AA Male	.010	.004	.03		
Latina Female	.06	.7	.055	.002	
Latino Male	.1	.6	.08	.004	.8
# Sessions					
White Male			.01		
CESD – NS					
Social Support – NS					
Satisfaction					
Latina Female		.004	.003		
Latino Male		.008	.006		

Note: NS = no comparisons were statistically significant

Table 18. Interventionist Characteristics

Mean Age (sd)	32.29 (9.66)
Range	22.19-57.09
Race/Ethnicity	
White	14 (45.16%)
African-American	2 (6.45%)
Latino/a	14 (25.26%)
Other	1 (3.23%)
Gender	
Female	25 (83.33%)
Male	5 (16.67%)
Site	
1	6 (19.35)
2	3 (9.68)
3	6 (19.35)
4	10 (32.26)
5	6 (19.35)

Table 19. Clinically Important Difference in Outcome is Considered to be ½ Standard Deviation (SD)

Measure	Mean	SD	1/2 SD
CESD	9.78	6.32	3.16
Burden	17.18	8.41	4.21
Problems	10.30	2.74	1.37
Social	17.72	5.73	2.87
Support			

Table 20. Survey Sources of Questions/Batteries

	Baseline (ba)	Follow-up (fo)	Dis-continued (dc)	Bereave-ment (br)	Placement (pl)
Depression	X	X	X	X	X
Problems	X	X	X		X
Burden	X	X	X		X
Social Support	X	X	X	X	X
Satisfaction		X		X	X

Table 21. Type of Survey/Source of Battery Completed for Intervention Group

	Base-line (ba)	Follow-up (fo)	Dis-continued (dc)	Bereave-ment (br)	Place-ment (pl)	Total w/ outcome data	Also with non-missing concordance
Depression	321	257	5	22	9	293	272
Problems	321	252	5		9	266	248
Burden	323	255	5		9	269	251
Social Support	321	257	5	21	9	292	271
Satisfaction		255		20	9	284	266
Project Evaluation		255		20	9	284	266

Table 22. Percent of Caregivers with Specific Interventions Administered (>15 minutes), by Race/Ethnicity, Racial Concordance, and Site (n=287)

	Safety Training	Health Passport	Well Being	ABC Process	Behavioral Rx	Social Support
CG Race/Ethnicity						
White	0.85	0.83	0.96	0.96	0.94	0.63
African-American	0.81	0.9	0.96	0.94	0.96	0.67
Latino/a	0.94	0.94	1.00	1.00	1.00	0.55
Concordance						
Same	0.9	0.88	0.98	0.97	0.95	0.62
Different	0.81	0.90	0.96	0.96	0.99	0.63
Site						
1	0.84	0.68	0.96	0.94	0.86	0.54
2	0.83	0.96	0.93	0.93	0.97	0.77
3	0.94	0.95	1.00	1.00	1.00	0.65
4	0.82	0.9	1.00	0.97	0.97	0.53
5	0.86	0.93	0.96	0.96	1.00	0.60

Notes:

Statistically significant difference for Safety Training by CG race/ethnicity (p=.04); and Health Passport and Behavioral Prescription by site (both p<.001)

Health Passport (Physical Well-being)

Well Being Module (Stress management, pleasant events, mood)

ABC Process (Identifying and reducing behavior problems in dementia)

Behavioral Prescription (manage ADL and problem behaviors)

Table 23. Description and Information for Outcome Variables

Revised Memory and Behavior <u>Problems</u> Checklist (RMBPC) (5 item response ranging from "substantial decline" to "substantial improvement" ; score range is 3-15)
any cognitive improvement overall
behavioral improvement overall
improvements in mood overall
<u>Burden Interview</u> (five item response to "do you feel:" ranging from "never" to "nearly always"; range 0-48; for this use, didn't include item 7 so score range is 0-44)
you don't have enough time for yourself
stressed between caring and meeting other responsibilities
angry when around CR
relationships with family or friends is affected negatively
strained when around CR
health suffering because of CR
don't have enough privacy because of CR
social life has suffered because of CR
lost control of life since CRs illness
uncertain what to do about CR
should be doing more for CR
could do a better job caring for CR
Center for Epidemiologic Studies <u>Depression</u> Scale (CES-D) (4 item response ranging from "rarely or none of the time" to "most or almost all of the time"; score range is 0-30)
bothered by things that don't usually bother me
trouble keeping mind one what was doing
felt depressed
everything was an effort
hopeful about future
fearful
sleep was restless
happy
lonely
could not get "going"
<u>Social Support</u> (in reference to past month with 4 item response options; score range is 0-30)
how often received help
satisfied with help received
has someone been with you to offer support or comfort
satisfied with support received

Table 23. (Continued)

how often received helpful information and guidance
satisfaction with suggestions, clarifications...
others made too many demands
others been critical
others pried into your affairs
others taken advantage
Satisfaction with Participation (Project Evaluation) (three item response "not at all" to "a great deal"; score range from 7-21; for dichotomous variable, 7-19 vs. 20+)
benefited from participation
better understanding of memory loss and its effects
confidence dealing with memory problems
make your life easier
enhance ability to care for CR
improve CRs life
keep CR living at home

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