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Examining Interpersonal Diffnces Among Caregivers in Health Outcomes Using a Stress Process Model: The Influence of Adverse Social Experiences and Social Support

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EXAMINING INTERPERSONAL DIFFERENCES AMONG CAREGIVERS IN HEALTH OUTCOMES USING A STRESS PROCESS MODEL: THE INFLUENCE OF ADVERSE SOCIAL EXPERIENCES AND SOCIAL SUPPORT

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EXAMINING INTERPERSONAL DIFFERENCES AMONG CAREGIVERS IN HEALTH OUTCOMES USING A STRESS PROCESS MODEL: THE INFLUENCE OF ADVERSE SOCIAL EXPERIENCES AND SOCIAL SUPPORT

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LIFESPAN DEVELOPMENTAL PSYCHOLOGY

ABSTRACT

Many Americans are informal caregivers who are responsible for caring for their loved ones who have difficulty performing everyday functions. Black and White caregivers each have many of the same burdens associated with caregiving, but often the way in which burden is experienced differs between these two racial groups. Caregiving places unique burden on individuals, and this burden is associated with depression and worse quality of life (QoL). This study aimed to use the stress process model to describe differences between Black and White caregivers. This study also examined the role of adverse social experiences (negative interaction, experiences of discrimination (EOD), and low physician trust) in the context of this stress process model, and social support as a buffer against the stress caused by these experiences. This study utilized linear regression models with race as the predictor and social support and adverse social experiences as outcomes to examine racial differences in these factors. This study also examined the relationships among adverse social experiences, social support, and health outcomes using linear regression models. Linear regression analyses revealed racial differences in negative interaction and physician trust. Linear regression also revealed negative interaction as a predictor of more depressive symptoms and emotional support and satisfaction with support as predictors of less depressive symptoms and better mental health QoL. Linear regression did not reveal social support as a buffer against the effect of negative interaction on depressive symptoms. This study has important implications for caregiving researchers and mental health clinicians as it provides evidence for social support as a buffer against caregiver burden, and negative interaction as a tertiary stressor that has detrimental effects on caregiver mental health.

Keywords: stress process model, social support, caregiving, adverse social experiences, health disparities, aging

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INTRODUCTION

In the United States (US), a growing number of individuals have been and are taking on the role of informal caregiver for one or more family members (NAC/AARP, 2015, 2020). An informal caregiver is any close family member or friend who provides the overwhelming majority of at-home care for an individual who has had a stroke or traumatic brain injury (TBI), or has dementia, Alzheimer's disease (AD), or any other condition that causes some loss of cognitive, psychological, or physiological function. Caregivers may be responsible for cleaning, feeding, and all general functions, or they may provide care with only specific or more complex tasks that require use of whatever functionality was lost (Anderson et al., 1995; NAC/AARP, 2020; Clay et al., 2013; Goode et al., 1998; Pinquart & Sorensen, 2007; Russo & Vitaliano, 1995).

Caregiving is a role that carries with it many duties and responsibilities that a spouse, adult child, or other close family member may or may not struggle meeting regularly. The objective stressors that accompany caregiving for a loved one can place a heavy physical and psychological burden on the caregiver (Anderson et al., 1995; NAC/AARP, 2020; Clay et al., 2013; Goode et al., 1998; Nightingale et al., 2016; Pinquart & Sorensen, 2007; Russo & Vitaliano, 1995; Son et al., 2007). Objective stressors of caregiving factors that are directly or indirectly related to the act of caregiving such as memory and behavior problems or increased financial burden due to lost hours at work. Varying severity and types of conditions require various types of care, but in general, all caregivers devote several hours each week to providing care for their loved ones (Anderson et al., 1995; NAC/AARP, 2015, 2020; Russo & Vitaliano, 1995). Care recipients may have diminished cognitive capacity and may exhibit behavioral issues. Caregivers must take on the stress of dealing with these kinds of issues while maintaining a loving relationship with the care recipient. These are clearly unique stressors to this population.

Caregiving in the US

The caregiving role is currently on the rise in the US, as a result of increases in the average life expectancy, and the number of aging adults (NAC/AARP, 2015, 2020). Advancements in healthcare have made it possible to save individuals from traumatic events where they otherwise would not have survived, and to prolong the lives of those living with chronic health conditions. In 2015, an estimated 16.6% of Americans gave informal care to a loved one (NAC/AARP, 2015). In 2020, the prevalence of providing informal care to an adult care recipient increased to 19.2%, or 41.8 million (NAC/AARP, 2020). As of 2017, the estimated annual cost for informal care was $470 billion in the US (Reinhard et al., 2019).

In addition to the economic toll that caregiving places on the US population, caregiving has psychological, social, and physiological consequences for individual caregivers (Sawatzky & Fowler-Kerry, 2003). In 2020, the average caregiver provided approximately 24 hours of care per week for a loved one (NAC/AARP, 2020). This increase in caregiver responsibilities may result in the inability to assume additional responsibilities at work, at home, or time to engage with family and friends in leisure activities. For example, the caregiver may need to leave work early, come in late, or work less hours weekly in order to meet the demands that accompany caregiving (Sawatzky &

Fowler-Kerry, 2003). They may be required to get up earlier than necessary for work just to drop off their loved one at a formal care service or other loved one’s home. It may also take them longer to get home because they must pick the loved one up from the same location. In addition, many caregivers are often unable to leave home to run errands because of their loved ones’ dependency, their loved ones’ inability to be left alone, or anxieties about the loved one having another traumatic event (Anderson et al., 1995; Park et al., 2016; Stanfors et al., 2019).

The Stress Process Model

An adapted stress process model has been used for over two decades to shape research surrounding the deleterious effects of caregiving. The stress process model of caregiving posits that the transition to caregiving is a disruptive life event, and that disruption brings with it objective stressors (Pearlin et al., 1981). The stress process model looks at (1) background and context, (2) stressors and appraisals of stress, (3) buffers of stress, and (4) outcome variables. Caregivers’ background or context may affect their mental and physical health outcomes. Factors such as age, gender, and economic resources can contribute to positive or negative appraisals of objective stressors. There are a variety of different contexts in which an individual may be required to be a caregiver, and these situations will often have vastly different demands. Among caregivers, there are differences among races, between sexes, and among varying socioeconomic backgrounds and locations. Differences among these groups in resources and culture that are unrelated to caregiving often predict outcomes for these caregivers (Clay et al., 2013; Clay et al., 2008; Pinquart & Sorensen, 2005).

Primary stressors are objective stressors that are directly brought about by the caregiving role and have deleterious effects on psychological and physiological health of the caregiver (Clay et al., 2013; Goode et al., 1998; Pearlin et al., 1981; Pinquart & Sorensen, 2005). These include the physical, temporal, emotional, social, and economic demands of caregiving. For example, severity of the care recipient's condition is a stressor that is directly unique to persons providing care (Marsh et al., 2002).

Secondary stressors may also influence caregivers' appraisal of their burden. Secondary stressors are objective stressors that are not directly resultant from the caregiving role but are inadvertently created by demands of the caregiving role. For example, a caregiver may have reduced time to work due to the caregiving role. This may require them to limit their hours at their place of employment, which lowers their ability to earn extra money. This may place additional stress in the form of income difficulty on the caregiver. Income difficulty can be defined as the financial stress of not being able to provide basic needs due to lack or loss of income.

Tertiary stressors are objective stressors that may influence appraisals of caregiver burden and health outcomes but are not related to the caregiver role. For example, individuals may experience stress from outside sources such as discrimination, having negative experiences with physicians, and having poor interactions with their loved ones (Anderson & Dedrick, 1990; Antonio et al., 2016; Banks et al., 2006; Canady et al., 2008; Choi et al., 2013; Clay et al., 2013; Ong et al., 2009; Pearlin et al., 1981). These are all stressors that some individuals will experience at a greater rate than others. While these are not directly resulting from caregiving, they are included as tertiary stressors as they may influence caregivers' health outcomes such as depression and quality of life. For example, certain racial groups experience discrimination at higher rates than other groups. Discrimination may place additional stress on individuals already experiencing a stressful situation, which could contribute to worse appraisals of the burden of caregiving, and therefore worsened depressive symptoms and quality of life (Ong et al., 2009). The stress process model also includes factors that buffer against the effects of caregiver burden on outcomes such as depression and quality of life. Social support is one factor that has been repeatedly implicated in the protection against the objective stressors of caregiving (Clay et al., 2013; Clay et al., 2008; Roth et al., 2005; Roth et al., 2009). Additionally, an individual’s satisfaction with their support is a critical resilience factor against objective stressors of caregiving (Clay et al., 2013; Clay et al., 2008; Roth et al., 2005). Thus, it is important to examine social support in all forms when investigating protective factors against caregiver burden and negative caregiver outcomes.

Racial Differences in Caregiving

Racial group identification is one relevant background characteristic that has strong associations with caregiving outcomes. While there are no genetic differences that directly cause differences among races in caregiver resilience, there are differences among these groups in caregiver health due to differences in socioeconomic status (SES), culture, and varied experiences (Clay et al., 2013; Clay et al., 2008; Pinquart & Sorensen, 2005; Roth et al., 2001). The role of racial differences among caregivers is not as heavily researched as other topics within caregiver health and resilience; nevertheless, researchers have found many differences between White and Black caregivers in resilience factors and outcomes (Clay et al., 2013; Clay et al., 2008; Roth et al., 2001).

Additionally, a few researchers have compared Asian Americans and Hispanic Americans along with these other two racial groups (Pinquart & Sorensen, 2005).

In a meta-analysis of over 100 studies that examined health and support variables in caregivers, researchers noted several important findings about racial differences in caregivers' reported burden and mental health (Pinquart & Sorensen, 2005). In their analysis, they found that compared to White caregivers, ethnic minority caregivers spent more time caring and scored higher in filial obligations beliefs (belief that it is one's responsibility to care for aging loved ones). Ethnic minority caregivers had lower SES and were younger but reported receiving more informal social support than White caregivers. Despite having more informal social support than White caregivers, Hispanic and Asian-American caregivers reported more depression. While Black caregivers reported lower levels of depression and caregiver burden than Whites, all ethnic minority caregiver groups reported worse physical health on average (Pinquart & Sorensen, 2005).

Other studies examining caregiver health have uncovered similar findings concerning Black caregivers compared to White caregivers. One study examined differences between caregivers and non-caregivers in measures of depression, physical health, and life satisfaction, and compared Black and White caregivers in these same measures (Roth et al., 2001). Both Black and White caregivers' physical symptoms increased over time. White caregivers' life satisfaction decreased more compared to Black caregivers. Additionally, Black caregivers had lower depression scores across all time points compared to White caregivers (Roth et al., 2001).

Social support (the instrumental, informational, and emotional help one receives from their social network) receipt and satisfaction may provide some explanation for the resilience of Black caregivers. On average, Black caregivers report higher levels of satisfaction with social support, which may buffer against the stress of caregiving (Clay et al., 2013; Clay et al., 2008; Roth et al., 2001). A longitudinal study examined the trajectories of support and mental health outcomes in 166 Black and White dementia caregivers over the course of five years (Clay et al., 2008). They found that Black caregivers had less self-reported depressive symptoms and had higher life satisfaction than Whites. Additionally, they were more satisfied with their social support. Multilevel analyses also revealed a mediation effect of social support satisfaction on both depression and life satisfaction (Clay et al., 2008). These findings, along with others, suggest that satisfaction with support is an important resource for all caregivers, but it is higher in Black caregivers than Whites, thus providing them more benefit (Clay et al., 2013; Clay et al., 2008; Pinquart & Sorensen, 2005; Roth et al., 2001; Roth et al., 2005).

Adverse social experiences, such as negative interaction (members of an individual’s social network prying into their affairs, taking advantage of them, being critical of them, and making excessive demands on them), low physician trust, and experiences of discrimination occur more frequently in ethnic minority adults (Browning et al., 2020; Doescher et al., 2000; Pearlin et al., 2005; Williams et al., 2020). This may, in some cases, contribute to worsened mental health, quality of life, and appraisals of burden in caregivers; nonetheless, as mentioned previously, Black caregivers report less burden and fewer mental health problems (Clay et al., 2013; Clay et al., 2008; Roth et al., 2001). Thus, social support and other caregiver resources (buffers against the stressfulness of caregiving, such as coping mechanisms) may act to protect Black caregivers from adverse social experiences. To date, little work has been done to examine these experiences in the context of caregiving. More work is needed to understand the influence that adverse social experiences have on health outcomes for caregivers.

Adverse Social Experiences

Discrimination

In the context of the caregiver stress process model, adverse social experiences such as discrimination are tertiary stressors that may play a role in how a caregiver experiences burden. There is a wide body of research revealing the deleterious effect of experiences of discrimination on mental health. In one study, researchers examined the frequency of, and the stress caused by, experiences of discrimination in a sample of 168 Latinx participants. The researchers first found that individuals who experienced discrimination scored higher in depression, anxiety, and the aggregate distress score comprised of both. They also found that even if participants rated the events as not that stressful, they still had a negative impact on psychological distress (Huynh et al., 2012). These results reflect those of others that have found similar results looking at other racial and ethnic groups who experience discrimination (Antonio et al., 2016; Banks et al., 2006; Canady et al., 2008; Choi et al., 2013). Thus, it may be beneficial for researchers in caregiver health to examine the influence of discrimination on caregivers' depression and quality of life.

Discrimination is an adverse social experience that many caregivers face that can have detrimental effects on mental health (Antonio et al., 2016; Banks et al., 2006; Canady et al., 2008; Choi et al., 2013). Experiences of discrimination are associated with a wide variety of health outcomes such as depression, anxiety, and worsened quality of life (Antonio et al., 2016; Banks et al., 2006; Canady et al., 2008; Choi et al., 2013). Work that examines the discrimination experienced by caregivers and the effects of that discrimination on caregiver health is somewhat sparse. Literature that does exist suggests that experiences of age discrimination may negatively influence caregivers' appraisal of burden (Russo & Vitaliano, 1995). Studies examining the effect of racial discrimination on caregiver outcomes were not readily available at the time of this review.

In addition to having deleterious effects on mental health quality of life, racial discrimination is associated with worsened physical health quality of life. In particular, racial discrimination across the lifespan has been associated with hypertension, carrying more visceral fat, and increased allostatic load (Brody et al., 2014; Dolezsar et al., 2014; Lewis et al., 2011). Additionally, discrimination is associated with worse health behaviors and lifestyle factors such as smoking, having poorer sleep quality, and obesity (Borrell et al., 2010; Manns-James et al., 2020; Slopen & Williams, 2014). Finally, research reveals an association between racial discrimination and mortality (Barnes et al., 2008). Thus, it is imperative to study experiences of discrimination in the context of a stress process model of caregiving.

Negative Interactions

Negative interactions are adverse social experiences that in many ways work against the positive benefits of social support. Members of an individual's social network prying into their personal affairs, taking advantage of them (using them for money, constantly asking for help, always needing transportation, etc.), criticizing them, and making excessive demands on them are all negative interactions (Krause, 1995). These types of interactions can have deleterious effects on an individual's mental and, indirectly, physical health. In one study that looked at negative interaction and diabetes-related outcomes, we found that individuals with diabetes who scored high in negative interaction, on average, scored higher on diabetes distress, an important factor in predicting diabetes health outcomes (Browning et al., 2020).

In another study, which interviewed caregivers of stroke survivors who took part in the Reasons for Geographic and Racial Differences in Stroke (REGARDS) study, Clay and colleagues found that negative interaction was associated with reporting more stress due to caregiving stressors and worse mental health-related quality of life. As would be expected, negative interactions were also associated with less satisfaction with social support (Clay et al., 2013). These results suggest that it is important to study negative interaction in the context of caregiver health, as it may work against the benefits of social support in protecting against depression, mental health dysfunction, and worsened physical health

Low Physician Trust

Physician trust is an important factor in treatment of patients and their outcomes. It has a wide variety of benefits for individuals suffering from chronic conditions such as diabetes and cardiovascular disease (Lee & Lin, 2009; Piette et al., 2005; White et al., 2013). Research suggests that this is in part due to improved adherence to treatment regimens such as medication. Additionally, individuals who score high in physician trust often are more likely to perform prescribed self-care activities at home (Piette et al., 2005). As caregivers are likely to remain in constant contact with their loved ones' physicians, they are likely to form strong feelings about physicians, regardless of whether they are positive or negative. Physician trust also has important implications for how caregivers perform care for their loved ones (Litzelman et al., 2016). Caregivers who do not trust their physicians and are not performing self-care behaviors for themselves cannot be expected to do the same for their care recipients; therefore, it is imperative that caregivers place substantial trust in the expertise and concern of their loved ones' physicians. Extra attention should be paid to the relationships among physicians, caregivers, and care recipients to prevent caregiver burnout and to ensure that patients are getting the best possible formal and informal care.

Research examining the effects of low physician trust in caregivers is sparse. However, this remains an important area of focus as physician trust is linked to a multitude of outcomes for both care recipients and caregivers. In one study, researchers examining relationships among self-reported quality of care and relevant caregiver health measures found that individuals who scored low in physician trust on average scored higher in depressive symptoms. There were no associations between physician trust and quality of life measures. These findings must be interpreted with caution, as the study was small in scale with only 39 participants (Stenberg et al., 2010). Clearly, more work is needed to determine the effects of having low trust in physicians on caregivers' depressive symptoms and quality of life.

Caregiver Burden

Key to the stress process model are reported appraisals of stress such as caregiving burden and health outcomes, including depression and quality of life. The importance of an individual's appraisal of caregiving burden in predicting caregiver outcomes is well documented (Anderson et al., 1995; Gonyea et al., 2005; Marsh et al., 2002; Nightingale et al., 2016; Russo & Vitaliano, 1995). Caregiving burden is often reported in literature as a better predictor of caregiver health outcomes than objective stressors such as care recipients' illness severity (Anderson et al., 1995; Roth et al., 2009). Depression and quality of life in caregivers are both influenced heavily by their appraisal of the level of their burden (Haley et al., 2015; Roth et al., 2009). One study found that caregivers who did not report caregiver burden reported significantly less mental health symptoms than individuals who were not caregivers (Roth et al., 2009).

The Family Caregiving and Respite Evaluation Study (CARES) examined formal and informal care that individuals with Alzheimer's and dementia received and the health of their informal caregivers (Son et al., 2007). As part of the study, researchers interviewed 234 primary caregivers and asked questions about their physical health, self-care behaviors, use of healthcare services, care recipient behavioral problems, and caregiver overload (similar to burden, this is an individual's appraisal of the stressors of caregiving). They found that caregivers who had loved ones with more behavioral problems reported more overload, performed fewer self-care behaviors, and had worse physical health on average. Additionally, they found that overload partially explained the effect of behavioral problems on self-care behaviors and physical health, suggesting that objective stressors that are unique to caregiving increase the level of burden that caregivers feel. They also determined that burden, in turn, causes worse health behaviors and physical health (Son et al., 2007).

Depression and Quality of Life

Depression is important to study in the context of caregiving because rates of depression and numbers of depression symptoms are substantially higher in this population than in the general population. Caregivers who report having high caregiver burden have more depressive symptoms and are more likely to have depression than those low in caregiver burden (Clay et al., 2013; Clay et al., 2008; Goode et al., 1998; Haley et al., 2015; Roth et al., 2009). This points to the importance of the subjective experience of caregiving in caregivers' outcomes. A meta-analysis conducted in 2018 compiled findings from 30 studies of caregivers of patients with cancer (Geng et al., 2018). The goal of the analyses was to determine the prevalence of depression and anxiety in these caregivers. They revealed that 42.3% of caregivers included in the study had depression, and 46.6% had anxiety (Geng et al., 2018). These numbers are both far higher than in the general population, suggesting depression and other psychological issues are important markers for caregivers' health.

In addition to depression, quality of life is a key health outcome in caregivers due to the sometimes-extreme limitations placed on their time and responsibilities. Both mental and physical health quality of life are affected by caregiving. Caregivers who report more caregiver burden also report worse quality of life (Clay et al., 2013; Haley et al., 2015; Roth et al., 2009). The Reasons for Geographic and Racial Differences in Stroke (REGARDS) study examined caregiver outcomes as a part one of its aims (Howard et al., 2005). This large epidemiological dataset includes data related to caregivers' appraisals of burden, depressive symptoms, and quality of life. Findings from this study elucidated many important factors related to caregiver health and resilience. In a later analysis of this larger dataset, researchers found that individuals who reported more strain in relation to caregiving also reported more depressive symptoms on the Center for Epidemiological Studies-Depression scale (CESD-4) and worse mental and physical health quality of life on the 12-item short-form health survey (SF-12) (Roth et al., 2009). Clearly, mental and physical health quality of life, along with depression, are important to study in caregivers as they are affected considerably in this population.

Caregiver Resources and Resilience Factors

Caregivers also have resources on which they can rely to help them mitigate the stress of caregiving. Healthy coping mechanisms help to contribute to better appraisals of caregiver burden. (Goode et al., 1998; Pinquart & Sorensen, 2007; Sorensen & Conwell, 2011). Self-efficacy (an individual's belief that they are able to meet the physical and emotional demands of caregiving) also benefits caregivers' appraisals of burden (Gonyea et al., 2005). Having a large social network of multiple strong supports who can be relied upon is also a resource for individuals who have taken on the caregiving role (Roth et al., 2009). These all contribute to improving caregivers' appraisals of the amount of burden caregiving has placed upon them, which in turn predict the QoL caregivers experience.

Social Support

Social support is a broad construct that encompasses a variety of different supports that one receives from friends, family, neighbors, physicians, and other close contacts (Cobb, 1976; Cohen & Wills, 1985; House et al., 1988). This includes tangible support such as transportation or yardwork, as well as informational support such as helpful advice, and emotional support – being there during a time of crisis when called upon (Krause, 1995). Early social support researchers began examining this construct over 40 years ago (Cobb, 1976; Cohen & Wills, 1985; House et al., 1988). Social support has been elucidated as an important factor in the health of individuals with a wide variety of health conditions. Individuals who score higher in social support tend to have better outcomes with cardiovascular conditions, diabetes, and stroke recovery (Cobb, 1976; Cohen & Wills, 1985; House et al., 1988). Current literature suggests that social support likely benefits health outcomes by buffering against the stressful psychological effects of these conditions (Cobb, 1976; Cohen & Wills, 1985; House et al., 1988). Social support has a range of psychological benefits for the general population as well, including lower depressive symptoms and improved quality of life (Leung, 2005; Liu et al., 2016; Peirce et al., 2000).

Received Support

Researchers have found mixed results in examining forms of received support and the benefits for caregivers (Brand et al., 2016). Some studies have reported positive associations between social support and quality of life measures (Goode et al., 1998). Others have found that receipt of more social support is associated with reporting more physical health problems (Clay et al., 2013). Researchers suggest that this association, which is somewhat unintuitive, exists because caregivers who experience more health problems also likely need more informal support from others (Clay et al., 2013). More work is needed to determine the role that actual receipt of social support plays in protecting against primary, secondary, and tertiary caregiving stressors.

Specific types of received support may also have important benefits for caregivers. Researchers examining caregiver resources and health outcomes in individuals providing informal care for patients undergoing radiotherapy for head and neck cancer found caregivers who received more support on average had better quality of life (Nightingale et al., 2016). Each individual factor of social support that was examined (affectionate support, positive social support, emotional/emotional support, and tangible support) was associated with better overall quality of life. However, no social support measure was significantly associated with appraisal of caregiver burden (Nightingale et al., 2016).

Another study in which White and Black informal caregivers completed surveys about life satisfaction and social support found that all four examined types of support, tangible, appraisal, belonging, and self-esteem, were associated with better quality of life (Kaufman et al., 2010). These results are promising, but more work is needed to determine the importance of received support in caregiver health outcomes. More samples of caregivers receiving support are needed to understand how the effects of received support benefit differ from the benefits of satisfaction with support.

Satisfaction with Support

An individual's satisfaction with their social support is often a better predictor of health outcomes and caregiving burden than the receipt of support. One reason for this is that satisfaction with support is not as based on need for assistance as receipt (Clay et al., 2013; Clay et al., 2008; Haley et al., 2015; Roth et al., 2005). Social support satisfaction predicts less reported caregiving burden (Roth et al., 2005). Additionally, in caregivers, social support satisfaction is associated with better mental health quality of life (Clay et al., 2013). Caregivers who report more satisfaction with their social support networks also tend to have fewer depressive symptoms and greater life satisfaction (Clay et al., 2008; Haley et al., 1987).

In a seminal work in caregiver health research, Haley and colleagues utilized an adapted stress process model to assess predictors of health outcomes in 54 informal caregivers (1987). In their analyses, they included multiple measures of social support, coping responses, and appraisals of burden. Their aim was to determine which of these factors would predict depression, life satisfaction, and healthy. They found that, in addition to positive coping mechanisms and self-efficacy, satisfaction with support was associated with less depressive symptoms, more life satisfaction, and fewer physical health problems (Haley et al., 1987). These results, in conjunction with other findings from more recent works, suggest that an individuals’ satisfaction with their support system is a key factor in determining health outcomes for caregivers (Clay et al., 2013; Clay et al., 2008; Haley et al., 2015; Roth et al., 2005).

The Present Study

Address Gaps

There is currently an abundance of literature on the benefits of caregiver resources such as social support, self-efficacy, and coping strategies; but knowledge remains sparse on the racial differences in caregiver health and experiences. Much work is needed to elucidate tertiary stressors that influence caregiver health, such as adverse social experiences. The present study aimed to address these gaps in literature while continuing to adhere to the stress process model for caregiving. We examined the role of adverse social experiences in predicting caregiver health. Additionally, we aimed to determine the nature of racial differences between Black and White caregivers in adverse social experiences and social support. This study also investigated the role that social support plays in buffering against the negative effects of adverse social experiences.

Hypotheses

Based on current literature, we hypothesized that Black caregivers would report more adverse social experiences but would be more satisfied with their social support when compared to their White counterparts (Clay et al., 2013; Clay et al., 2008; Pinquart & Sorensen, 2005; Roth et al., 2001). Next, based on literature linking adverse social experiences to worsened mental and/or physical health, we hypothesized that adverse social experiences would be associated with more depressive symptoms and worse quality of life (Antonio et al., 2016; Banks et al., 2006; Browning et al., 2020; Canady et al., 2008; Choi et al., 2013; Clay et al., 2013; Lee & Lin, 2009; Piette et al., 2005; White et al., 2013; Williams et al., 2020). We also hypothesized that higher scores on measures of social support (received support and satisfaction with support) would be associated with lower levels of depressive symptoms and higher quality of life scores. This would provide further corroboration to a growing body of evidence that suggests social support is vital to caregiver health (Clay et al., 2013; Clay et al., 2008; Goode et al., 1998; Haley et al., 1987; Roth et al., 2005). Finally, in line with the stress process model, we hypothesized that social support would buffer the effect of adverse social experiences on depressive symptoms and quality of life.

METHODS

Sample

The sample for this study was derived from the Caring for Adults with Difficulties (CFAD) study. The study included adults (18 years and older) who provide at least five hours per week of unpaid care to a loved one with a debilitating health condition. Care recipients were at least 45 years of age and have suffered from conditions that require informal care. These conditions included AD, dementia, TBI, cognitive decline, physical disability due to accident, and physical disability due to aging. The inclusion/exclusion criteria are to ensure that there is a sample of the typical caregiving community, with accurate ages and caregiver demands included. The sample was primarily recruited from listservs and online sources, with the goal of recruiting a typical range of racial groups, ethnicities, ages, and locations. Because many of these listservs and online sources were focused primarily in the Southeast, an inordinate number of participants were recruited from that area.

Procedures

Data for this study was collected from the beginning of April 2021 to the end of June 2021. Participants were recruited using online advertisement on social media platforms. They were able to call to complete a screener and survey, or they were able to complete both online. All participants chose to complete the survey themselves online. After completion, they were informed about the study, and they provided consent virtually. While no signatures were obtained, assurance of consent was obtained via the online survey instrument. Once consent was obtained, participants then completed a questionnaire that took approximately one hour. Upon completion, participants entered a phone number and their address where their compensation, $25 prepaid gift card, would be sent. Participants were contacted using the phone number that they provided, and their payment was loaded onto their $25 gift card All survey materials were created in Qualtrics XM and were completed using the same software.

Measures

Demographics measures, including age, sex at birth, income difficulty, and race were collected as a part of the survey instrument. Aside from race, which was used as a predictor variable in certain analyses, these measures were planned to be used as covariates for regression analyses (race was used as a covariate in analyses in which it was not the predictor). Measures of marital status, education, caregiver-recipient relationship were also collected to help describe the sample. For education, participants were asked to answer the highest level in school achieved in years (High School = 12 years, Associate's = 14, Bachelor's Degree = 16, Master's Degree = 18, Ph.D. = 20). Income difficulty was assessed with a single item that asked, "All things considered, would you say your income …?" Answers to this question were, "Is not enough to make ends meet (coded as 1)," "Gives you just enough to get by on (2)," "Keeps you comfortable but permits no luxuries (3)," and, "Allows you to do more or less what you want (4)." Higher scores indicated less income difficulty. Length of time spent caregiving and number of hours spent caregiving weekly were also collected as potential covariates. We also collected measures of adverse social experiences: negative interaction, low physician trust, and experiences of discrimination as predictors of worsened caregiver health. To measure social support, we measured received support (instrumental, emotional, and informational support) and satisfaction with support. In addition to demographics, social support, and adverse social experiences, we collected measures for depressive symptoms and mental and physical health quality of life were collected as outcome measures.

Depressive Symptoms

Depressive symptoms were measured using the 20-item Center for Epidemiological Studies – Depression (CES-D) (Radloff, 1977). This scale asks participants to rate the frequency with which they felt depressive symptoms such as loneliness, issues with appetite, and sleep dysregulation in the past week. For example, one statement participants are asked to rate states, “I thought my life had been a failure.” Participants rate this item on a scale from “Rarely or none of the time (0)” to “Most or all of the time (3).” Scores on the CES-D can range from 0 to 60, with higher scores representing more depressive symptoms (Radloff, 1977). The Cronbach’s alpha for this measure was .94, indicating acceptable reliability.

Quality of Life

The SF-36 was utilized to measure quality of life in caregivers (Ware Jr, 1999). The Mental Health Component Summary (MCS) and Physical Health Component Summary (PCS) will each be calculated separately to measure physical and mental health quality of life. The SF-36 asks participants to rate their physical and mental health using eight different subscales, each with a standardized score from 1 to 100. These subscales are physical function, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health. Cronbach’s alphas for each subscale that consisted of more than 3 items are given in Table 1. All subscales were considered reliable. Summary scores for the MCS and PCS are then calculated from these using the guidelines described by the developers of the scale (Ware et al., 1994; Ware Jr, 1999). Lower scores indicate worse health on each of these items.

Negative Interaction

Negative interaction was measured using the Negative Interaction portion of the Medical Outcomes Survey – Social Support (MOS-SS) (Krause, 1995). This scale asks participants to rate how often others have made too many demands on them, have been critical of them, have pried into their affairs, and have taken advantage of them in the past month with four total items, one addressing each of these negative interactions. Each item is rated on a scale of one to four, from “Never (1)” to “Very often (4).” Participants scores are calculated by adding up the ratings for each item. Scores for negative interaction have a potential range of 4 to 16. Higher scores indicate an individual experienced more negative interaction in the past month. The Cronbach’s alpha for this measure was .77, indicating acceptable reliability.

Low Physician Trust

Low physician trust was calculated using the Trust in Physician Scale (Anderson & Dedrick, 1990). This scale assesses a participant’s belief that their physician is capable of caring for them and can be trusted. It asks participants to rate how much they agree with statements about their physician and care. For example, participants are asked to rate the statement, “I sometimes distrust my doctor’s opinions and would like a second one.” eleven of these statements are rated from “Totally disagree (1)” to “Totally agree (5).” Scores are calculated by adding up scores for all items, with total scores ranging from 11 to 55 (Anderson & Dedrick, 1990). Lower scores on this measure indicate less trust in physicians. The Cronbach’s alpha for this measure was .88, indicating acceptable reliability.

Experiences of Discrimination

Discrimination was measured using a modified version o the Experiences of Discrimination (EOD) scale (Krieger et al., 2005), modified with appraisal ratings for the different settings included. This instrument measures the extent to which individuals have been exposed to discrimination in their daily life. The scale asks participants if events occurred (Yes or No), how often they occurred (coded as frequency), and how much the events affected them in different places and from various sources (coded as stressfulness) (stressfulness was not a part of the original scale but was added by Clay and colleagues later on, as it may better assess the importance of experiences of discrimination to individuals) (Williams et al., 2020). Participants are asked if they experienced discrimination at school, getting hired or getting a job, at work, getting housing, getting medical care, getting service in a store or restaurant, getting credit, bank loans or a mortgage, on the street or in a public setting, and/or from the police or in the courts. For frequency, participants rate one to three, with 1 for “Once,” 2 for “Two or Three Times,” and 3 for “Four or More Times.” For how upsetting the event was, participants rate from zero to four from “Not at all (0)” to “Extremely (4).” The EOD results in three scores, one for number of settings in which discrimination occurred (0 to 9), the frequency with which discrimination occurred (0 to 27), and the reported stressfulness of the discrimination (0 to 36) (Krieger et al., 2005). Higher scores on these subscales indicate a higher number of locations where discrimination occurred (EOD Sum), higher frequency of EOD (EOD Frequency), and more stress due to EOD (EOD stress).

Social Support

Social Support was measured using the MOS-SS (Krause, 1995). This survey measures social support as a multi-faceted resource. It includes an overall measure of social support, a measure of satisfaction, and three individual types of support (instrumental, emotional, and informational). The questionnaire asks participants to rate items related to the receipt of each type of support from Never (1) to Very often (4). For example, for instrumental support, participants are asked, “In the past month, how often have others helped you with housework, chores and yard work?” Instrumental support consisted of 3 items added together, and these items had a Cronbach’s alpha of .74, indicating acceptable reliability. For emotional support, participants are asked, “In the past month, how often have others listened to you talk about your private feelings?” Emotional support consisted of 4 items added together, and these items had a Cronbach’s alpha of .89, indicating acceptable reliability. For informational support, participants are asked, “In the past month, how often have others listened to you talk about your private feelings?”. Informational support consisted of 4 items added together, and these items had a Cronbach’s alpha of .86, indicating acceptable reliability (Krause, 1995; Sherbourne & Stewart, 1991).

Participants were also asked how satisfied they are with each of the three types of support. Participants rate satisfaction with each of the three items from Not at all (1) to Very (4). Satisfaction with support is calculated by adding up the three satisfaction items, with a range of 3 to 12. Each subscale is calculated individually by adding the rating for each item within the subscale. Satisfaction with support had a Cronbach’s alpha of .74, indicating acceptable reliability (Krause, 1995; Sherbourne & Stewart, 1991).

Due to the strong possibility of the COVID-19 pandemic leading to changes in individuals' social support, we also asked participants, "Compared to prior to the COVID-19 outbreak, would you say the support you receive from friends, family members, and other community members is?" Additionally, to assess changes in satisfaction with support we asked participants, "Compared to prior to the COVID-19 outbreak, how satisfied are you with the support you receive from friends, family members, and other community members?" Answers to these questions were set on an ordinal scale, and were as follows, "Much worse (1)," "Somewhat worse (2)," "About the same (3)," "Somewhat better (4)," and, "Much better (5)."

Data Analysis

Descriptive statistics, including means and frequencies, were first calculated and examined for the entire sample, then for each racial group. Racial groups were compared on study variables using independent samples t-tests and chi-squares, depending on whether the variables were dichotomous or continuous. Pearson's correlations were examined to test associations among continuous variables. These descriptive statistics were then further utilized to conduct tests of multicollinearity, normality, homogeneity, and linearity where applicable. The data was also examined for outliers and missing data, and the appropriate steps were taken to mitigate potential errors in the analyses. One participant left two questions related to stressfulness of experiences of discrimination unanswered. To avoid not counting this participants' answers to the rest of the survey instrument, their missing values were replaced with the average of their scores for the rest of the stressfulness items.

Age, gender, income difficulty, and race were included as covariates for all of the following analyses (except race, which was not used as a covariate in the first hypothesis, as it was the predictor variable). To test the first hypothesis, that social support satisfaction would be reported more by Black caregivers than White caregivers, we examined multiple linear regression models, with race as the independent variable, and received support and satisfaction with support as dependent variables. Additionally, measures of change in social support satisfaction and received support due to the COVID-19 pandemic were included post-hoc as an addition to these analyses. To test the second hypothesis, that adverse social experiences would predict more depressive symptoms and worse quality of life, we planned to employ univariate (one outcome), multiple linear regression with covariates and adverse social experiences as independent variables, and depressive symptoms, MCS, and PCS as outcome measures in separate models. Only those adverse social experiences that were associated (using Pearson's *r*) with the outcome measures, and only the outcome measures that were associated with adverse social experiences were analyzed in this way. To test the third hypothesis, that higher scores on social support measures would predict fewer depressive symptoms and better quality of life, we again employed a series of univariate, multiple linear regression models, with social support measures as independent variables and depressive symptoms, MCS, and PCS as dependent variables (again, analyses were only performed when Pearson's *r*'s between two variables were significant). To test the final hypothesis, that social support would buffer the effect of adverse social experiences on depressive symptoms and quality of life, we utilized multiple linear regression models testing the interaction effect of adverse social experiences and social support measures on depressive symptoms, MCS, and PCS. For these models, only those adverse social experiences that were associated with outcome variables, and vice-versa, were analyzed. Figure 1 is an example graphic to describe these potential moderation analyses.

RESULTS

At the time of data analysis, 431 attempts had been made to complete the survey. However, upon examination of the cases, it was determined that many individuals did not complete the survey, were screened out, provided fake information, or were "bots" that attempted to complete the survey for nefarious reasons. Bots are advanced algorithms designed to force their way through the end of the survey with the goal(s) of improving their ability to answer questions that require short answers (giving appropriate answers to questions rather than giving random data), completing the survey for the financial incentives, and possibly invalidating researchers' data. Of the 431 attempts, 264 (61.3%) entries were either incomplete or screened out. Another 107 (24.8%) entries were determined to be bots. Bots were not able to receive financial incentive or invalidate the data because they were not able to provide working contact information, which was necessary to pay participants. Sixty (13.9%) of the 431 attempts to complete the survey were human participants who completed the survey. Thus, the dataset was reduced to 60 individuals by creating a filter variable that separated valid cases into a new dataset. Four more participants were not included in the final analysis dataset, as they did not report their race as Black or White, which was important to the first hypothesis for the study. This left 56 individuals in the final sample used for data analysis.

All study variables were investigated for violations of assumptions of normality, homogeneity of variance, and multicollinearity where appropriate. Additionally, those same study variables were examined for outliers. Depressive symptoms and PCS both violated the assumption of normality. However, multiple linear regression is considered to be robust to violations of this assumption and capable of yielding valid conclusions (Schmidt & Finan, 2018). All received support measures, negative interaction and EOD measures were also not normally distributed. Additionally, income difficulty, hours spent caring, and length of time spent caring were not normally distributed. Cronbach's alphas were examined for all variables where appropriate. All variables examined this way were deemed reliable. Table 1 displays values for Shapiro-Wilk and Levene's for study variables.

In all, there were 56 participants that provided valid data and were a part of the included racial groups for analyses; 33 of whom reported their race as Black (58.9%). Fifty-one (91.1%) participants reported their sex as female at birth. Descriptive statistics for the entire sample, and separated by race, are provided in Table 2. On average, participants spent approximately 44 hours per week caring for their loved one. In response to the question about income difficulty, 9 (16.1%) participants answered that their income was not enough to make ends meet, 10 (17.9%) answered, "Gives you just enough to get by on," 19 (33.9%) answered, "Keeps you comfortable but permits no luxuries," and 18 (32.1%) answered, "Allows you to do more or less what you want." 3 (5.4%) participants reported that they had been providing care for 0 to 6 months, 7 (12.5%) reported providing care 6 months to 1 year, 12 (21.4%) reported providing care 1 to 2 years, 11 (19.6%) reported providing care 2 to 5 years, and 23 (41.1%) reported providing care for over 5 years. On average, participants reported 16.30 (bachelor's degree and higher) years of education. Ten participants were spouse partners to the care recipient, 28 were children or children-in-law, and 18 listed their relationship to the care recipient as other. Of the 56 participants, 28 were asked about their marital status. Of these, 18 (64.2%) answered that they were currently married.

Black and White caregivers did not differ in their reported age, sex at birth, income difficulty, education, relationship to the care recipient, hours spent caring, or length of time spent caring (all p's > .05). They also did not differ in any of the MOS-SS received support variables or satisfaction with support (all p's > .05). However, on average, Whites reported a more negative change in both received support ($t = -2.90$, $p < .01$) and satisfaction with support ($t = -2.92$, $p < .01$) due to the COVID-19 pandemic. There were no reported racial differences in negative interaction (all p's > .05). Whites reported significantly less trust in physicians than Blacks ($t = -2.45$, $p < .05$). Blacks reported experiencing discrimination in more locations ($t = -4.84$, $p < .01$) and more frequently ($t = -4.18$, $p < .01$) than Whites, and they reported more stress due to experiences of discrimination ($t = -4.79$, $p < .01$) than Whites. There were no reported racial differences in depressive symptoms, PCS, or MCS (all p's > .05).

Pearson's Correlations

Pearson's correlations (r) were conducted between continuous covariates and health outcomes, and between social support measures, adverse social experiences, and health outcomes. The results for these analyses are reported in Table 3 and Table 4, respectively. Hours spent caring and number of years having provided care were both unrelated to study variables, therefore they were not implemented as covariates in further analyses. Emotional support ($p < .01$) and satisfaction with support ($p < .05$) were both associated with having fewer depressive symptoms. Change for the worse in both received support ($p < .05$) and satisfaction with support ($p < .05$) due to the COVID-19 pandemic were associated with having more depressive symptoms, as was higher negative interaction ($p < .05$). None of the social support measures or adverse social experiences were associated with PCS (all *p*'s > .05). Emotional support ($p < .05$) and satisfaction with support ($p < .01$) were both associated with higher MCS scores. Change for the worse in both received support ($p < .01$) and satisfaction with support ($p < .01$) due to the COVID-19 pandemic were associated with having lower MCS scores.

Racial Differences in Adverse Social Experiences and Social Support Satisfaction

There were significant differences in all collected EOD measures between Blacks and Whites. EOD stress was the most strongly associated with health outcomes, and because it was the most representative of the stress caused by discrimination, we focused on this measure in our analyses. In line with our first hypothesis, when controlling for age, sex at birth, and income difficulty, Black racial identification significantly predicted experiencing more stress due to discrimination (EOD stress) ($\beta = .51$, $p < .01$). Black racial identification also significantly predicted having more trust in physicians ($\beta = .30$, $p < .05$), which was in contrast to our first hypothesis. Additionally, the independent samples t-test did not reveal a significant difference between Whites and Blacks on negative interaction, thus this association was not examined using multiple linear regression. Table 5 provides detailed statistics for these models and the included covariates. To follow up the finding that Blacks had more trust in physicians, Pearson's r was used to determine the associations between income difficulty and education with physician trust. More income difficulty (r = .04, p = .80) and lower education (r = .14, p = .29) were not significantly associated with having less trust in physicians.

The independent sample t-test did not reveal a significant difference between Black and White caregivers in social support satisfaction, thus the association was not examined using multiple linear regression. Due to the timing of data collection being in the midst of the COVID-19 pandemic, and because of the racial differences revealed by independent samples t-tests in change in received support and change in support satisfaction due to the COVID-19 pandemic, we ran two separate multiple linear regression models with each of these measures as outcomes and race as a predictor. When controlling for covariates, White racial identification significantly predicted more negative change in received social support due to the COVID-19 pandemic (β = .36, p < .01). In a separate linear regression model, when controlling for covariates, White racial identification also predicted more negative change in satisfaction with social support due to the COVID-19 pandemic (β = .34, p < .05). Table 6 provides more detailed statistics for these models and the included covariates.

Adverse Social Experiences and Health Outcomes

Pearson's correlations revealed that physician trust and all measures of EOD were not significantly associated with any of the health outcomes examined in this study. They were not included as predictors of depressive symptoms, PCS, or MCS. Negative interaction, however, was associated with depressive symptoms. When controlling for covariates, negative interaction was no longer a significant predictor of depressive symptoms ($\beta = .22$, $p > .05$). This would be considered a medium effect size (Acock, 2008). No measures of adverse social experiences significantly predicted any health outcome measures when controlling for covariates.

Social Support and Health Outcomes

Pearson's correlations revealed that having more emotional support and being more satisfied with social support were both associated with reporting fewer depressive symptoms. Thus, both measures were examined as predictors in separate linear regression models. In line with our third hypothesis, scoring higher in emotional support predicted reporting fewer depressive symptoms when controlling for covariates ($\beta = -.38$, $p < .01$). Also in line with our third hypothesis, scoring higher in satisfaction with social support also predicted reporting fewer depressive symptoms when controlling for covariates ($\beta = -.32$, $p < .05$).

Due to the timing of data collection being in the midst of the COVID-19 pandemic, and because of the associations revealed by Pearson's correlations between changes in support due to the COVID-19 pandemic and depressive symptoms, we conducted two additional analyses to determine if these changes would predict depressive symptoms. When controlling for covariates, changes in received support due to the COVID-19 pandemic trended towards significance in predicting depressive symptoms ($\beta = -.29$, $p < .10$). The effect size for this relationship would be considered medium (Acock, 2008). Changes in satisfaction with support due to the COVID-19 pandemic did not predict depressive symptoms when controlling for covariates ($\beta = -.20$, $p > .05$). If this effect were significant, it would have a weak-medium effect size (Acock, 2008).

Table 7 provides more detailed statistics for these models with depressive scores and the included covariates.

Pearson's correlations revealed having more emotional support and social support satisfaction were both associated with having a higher MCS score. Thus, they were examined as predictors using linear regression. When controlling for covariates, reporting more emotional support significantly predicted having a higher MCS score ($\beta = .44$, $p < .01$). Satisfaction with social support also significantly predicted having a higher MCS score ($\beta = .40$, $p < .01$). These findings were in line with our third hypothesis.

Pearson's correlations revealed negative changes in received support and satisfactions with support due to the COVID-19 pandemic were associated with lower MCS score. We conducted two additional analyses to determine if these changes would predict MCS score. When controlling for covariates, negative change in received support due to the COVID-19 pandemic significantly predicted having a lower MCS score ($\beta = .42$, $p < .01$). Negative change in satisfaction with support due to the COVID-19 pandemic also significantly predicted having a lower MCS score when controlling for covariates ($\beta = .33$, $p < .01$). Table 8 provides more detailed statistics for these models with MCS as the outcome and the included covariates.

Social Support Measures as Moderators of the Effects of Adverse Social Experiences on Health Outcomes

To determine whether social support serves as a buffer against the effects of adverse social experiences on health outcomes, we originally planned to test measures of social support as moderators in regression analyses with adverse social experiences as predictors and depressive symptoms, PCS, and MCS as outcome variables. Pearson's correlations revealed that the only significant association between adverse social experiences and health outcomes was that more negative interactions were associated with more depressive symptoms. Thus, the only moderation effects tested were those that involved negative interaction as the predictor and depressive symptoms as the outcome. None of the social support measures, including satisfaction with support, moderated the effect of negative interaction on depressive symptoms when controlling for covariates. There was no support for our fourth hypothesis. Additionally, changes in received support and satisfaction with support due to the COVID-19 pandemic were tested as moderators using similar linear regression models. When controlling for covariates, these moderation effects were not significant, either. Detailed results for these analyses involving moderation of the effect of negative interaction on depressive symptoms are provided in Table 9.

DISCUSSION

This study examined the differences between Black and White adult caregivers in adverse social experiences and social support. Bivariate analyses revealed no racial differences in received support or satisfaction with support. Bivariate analyses revealed significant differences between Blacks and Whites in EOD and physician trust. In covariate-adjusted models, these racial differences were still significant. However, Whites had less trust in physicians. Based on these results, the first hypothesis, that Blacks experience more adverse social experiences and are more satisfied with social support, was somewhat supported, but with several caveats.

The finding that, in covariate-adjusted models, there were significant racial differences in EOD, is a replication of findings from a large body of research (Banks et al., 2006; Canady et al., 2008; Choi et al., 2013; Huynh et al., 2012; Ong et al., 2009). In the United States, Blacks have experienced discrimination in a wide variety of forms throughout history. Thus, it is not surprising that discrimination would be found in Black adult caregivers. These experiences are somewhat unique to racial and ethnic minority caregivers, along with women and LGBTQ+ caregivers, as it is most frequently the majority population that is discriminating, knowingly or otherwise. This finding is novel in the sense that discrimination in caregivers is less studied than other potential risk factors. This discrimination may lead to a variety of health outcomes such as depression, anxiety, and worse mental health QOL, thus it was important to study in the context of caregiving (Banks et al., 2006; Canady et al., 2008; Choi et al., 2013; Huynh et al., 2012; Ong et al., 2009).

The difference between Blacks and Whites in physician trust was significant in covariate-adjusted models, but in the opposite direction of what is typically seen in Americans. One reason for this finding may be the educational status and income difficulty on average for the entire sample. As mentioned previously, the average level of education was quite high, and the average income difficulty was quite low. This did not differ by race, which is not reflective of the American population at large, or more specifically, American caregivers. On average, Blacks are more likely to have a lower income and educational status, which may be responsible for less health education and receiving worse care (due to poor health insurance, poor access to healthcare, and other factors related to systemic racism and disparities in care quality) historically, and in turn, lower physician trust (Bloome, 2014; Doescher et al., 2000). This may not have been the case in our sample for the reasons outlined above. Education level and income difficulty were not associated with physician trust in this sample; thus, more work is needed to determine if this is, in fact, the case, or if other factors are responsible for the unusual differences in physician trust.

The finding that negative interaction did not differ by race in bivariate analyses contrasts with a growing body of literature that has found Blacks to experience more negative interaction (Browning et al., 2020). There are many possible reasons for this finding, some of which will be discussed as limitations to this study. In this sample, measures of social support also did not differ between Blacks and Whites, which may help to explain why negative interaction did not differ, but more work is needed to explore this potential connection.

One potential cause for lack of racial differences in both negative interaction and social support satisfaction in bivariate analyses is the fact that data collection occurred in the midst of the COVID-19 pandemic. This pandemic altered many individuals’ entire social networks during the time of data collection, and this may have led to less interactions for both racial groups altogether, thus leading to less differences in the amount of negative interaction and social support satisfaction. Blacks were less likely than Whites to experience negative changes in their social support due to the COVID-19 pandemic, and this may have also helped to protect against negative interaction. Differences in social support are not consistent across previous samples, and this may also explain why no differences were found in this sample, either.

This study also examined the role of adverse social experiences in the context of a caregiving stress process model. Reporting more negative interaction predicted having more depressive symptoms when controlling for covariates. Bivariate analyses revealed EOD (all subscales) and physician trust were not significantly associated with health outcomes. The second hypothesis, that adverse social experiences would predict health outcomes, was partially supported.

The finding that negative interaction predicts more depressive symptoms in covariate-adjusted analyses is one that has been previously reported in the literature (Browning et al., 2020; Clay et al., 2013; Krause, 1995). In previous studies examining just caregivers, negative interaction is negatively associated with several measures of health outcomes (Clay et al., 2013). Research in other fields, such as diabetes care, has revealed that individuals who experience more negative interaction may have less self-efficacy when caring for themselves, and have worse outcomes related to their disease in particular (Tang et al., 2008). This may be due to an internalization of the negative interaction, which may lead to less self-worth and worsened overall self-care, which are both associated with depressive symptoms. Despite negative interaction not being associated with other health outcomes in bivariate analyses, it is an important factor to study in caregivers, and more work is needed to determine its role in the stress process model.

The finding that all EOD measures were unrelated to health outcomes is in contrast to a wide body of literature that suggests that EOD is associated with worsened mental health (Banks et al., 2006; Canady et al., 2008; Choi et al., 2013; Huynh et al., 2012; Williams et al., 2020). A potential reason for this finding may be that this study was cross-sectional, and experiences of discrimination may take time to lead to depressive symptoms and worsened mental health QoL. Additionally, these experiences, while stressful, may not have lasting effects on caregivers, who regularly experience intense stressors. Their coping mechanisms for dealing with this type of stress may be more conducive to preventing worsened mental health outcomes. However, this is less studied in the literature, and more work is needed to understand the role of experiences of discrimination in the context of mental health in caregivers. It is not that surprising that EOD would be unrelated to physical health QoL, as there is minimal research to suggest this association, but researchers should not discount EOD as a potential concern in regard to worsened physical health. The finding that physician trust being unrelated to depressive symptoms and both PCS and MCS is not necessarily in contrast to the literature that already exists but having low physician trust may be related to other health measures, such as self-care and self-care efficacy (Lee & Lin, 2009; Piette et al., 2005; White et al., 2013). It may be important to continue to look at this adverse social experience in that context.

This study also aimed to confirm the relationship of social support to health outcomes in the context of a caregiving stress process model. Emotional support and satisfaction with support predicted fewer depressive symptoms and having a higher MCS score when controlling for covariates. Instrumental support and informational support were unassociated with health outcomes in this sample. None of the social support measures were associated with PCS, as revealed by Pearson’s correlations. The third hypothesis, that social support measures would predict health outcomes, was partially supported.

Social support measures do not often predict physical health outcomes, as those who need more social support often have more health problems. Particularly, receiving some forms of support are sometimes associated with having worse physical health (Browning et al., 2020). The finding that emotional support and satisfaction with support predict fewer depressive symptoms and better MCS scores helps to confirm findings from previous studies that have found similar results. Social support satisfaction and emotional support have been revealed as important predictors of fewer depressive symptoms and better mental health QoL (Brand et al., 2016; Cohen & Wills, 1985; Kaufman et al., 2010; Leung, 2005; Liu et al., 2016; Nightingale et al., 2016; Peirce et al., 2000; Tang et al., 2008). Social support is an integral element of coping with mental health problems and stressors that arise across a variety of contexts, but particularly in caregiving. Because social support serves as a buffer against caregiver burden, and caregiver burden is associated with worse mental health outcomes, it stands to reason being more satisfied with one's support and reporting receiving more emotional support would indirectly lead to better mental health outcomes. While this is something that has been tested in caregivers previously, it was important to confirm that these findings would remain significant in a sample that included equal or greater numbers of Black caregivers compared to Whites, as many caregiver studies have been conducted with samples that are predominately White.

Finally, this study hypothesized that social support would buffer the effects of adverse social experiences on health outcomes (depressive symptoms, PCS, MCS). The fourth hypothesis was not supported, as none of the regression models utilized to examine this hypothesis revealed significant moderation effects when controlling for covariates.

As this hypothesis was largely exploratory, this finding is not in disagreement with previous literature on this subject. Tertiary stressors are the least studied factors involved in the stress process model, and the importance of social support as buffers against tertiary stressors has also been studied minimally in this context. Additionally, adverse social experiences are a novel concept to this study. Adverse social experiences may have other effects on caregivers, but these were outside the scope of this study.

Limitations

This study provided a novel examination of racial differences in social support and adverse social experiences, and the effects of these factors in health outcomes for caregivers. That said, multiple limitations weaken the strength of this study to detect differences between racial groups in these factors and the ability to understand relationships among the factors studied here. Some of these limitations leave room to improve future studies on this topic, while some may help to guide future researchers to ask more informed questions in the context of the caregiver stress process model.

A major limitation of this study is the sample size. To answer questions about racial differences between Blacks and Whites in background factors, social support, and adverse social experiences, it would have been beneficial to include a much larger sample from a broader range of locations and contexts. Additionally, a larger sample size would have improved our ability to detect effects of adverse social experiences on health outcomes, and the ability of social support to buffer against these effects. While there were no significant interaction effects among these study measures, it is likely that some of the effects are unable to be detected with such a small sample of caregivers.

Another limitation is that the study did not examine a nationally representative sample of caregivers. We inadvertently recruited far more Black participants in comparison to White participants than expected, and this may have given us data that was not representative of the population as a whole. There were also not enough caregivers of other racial groups to detect associations among social support measures, adverse social experiences, and health outcomes in a truly racially diverse sample.

Our sample also contained an exceptionally small group of male caregivers. While female caregivers do outnumber male caregivers in the general population, this sample only contained five men. Having such a small number of men contributed to having an unrepresentative sample altogether. This also made comparisons between sexes impossible. The responses from the small number of men in this study also cannot be generalized to the entire male population.

This sample was also highly educated compared to the general population of caregivers. Caregivers in our study had at least a bachelor's degree on average. Better educated caregivers are likely to have better caregiving resources than less educated caregivers. In particular, better educated caregivers are likely to have less income difficulty than caregivers with less education, and that was the case for caregivers in this study. Typically, Black caregivers have less education and more income difficulty than White caregivers, but that was also not the case in this study (Clay et al., 2013; Clay et al., 2008; Kaufman et al., 2010; Roth et al., 2001). This may have affected results involving adverse social experiences, as these are less likely to be experienced by individuals with higher income and education status (Halanych et al., 2011).

Other issues with the sample of caregivers examined in this study may have had unintended effects on the findings. This sample had an unusually high number of years spent caring compared to the national average. In fact, these caregivers gave approximately double the amount of care per week to the typical American caregiver (Caregiving, 2020). Thus, they may have more intense caregiver burden than the population. There was an extremely high amount of variability for hours spent caring as well, which may have affected our ability to detect effects of social support and adverse social experiences on caregiver health outcomes. A larger sample may have a more typical number of hours spent caring.

Marital status was supposed to be collected as a part of this study, but programming issues with the survey instrument caused this measure to not be collected for half of the sample. This may have provided important information, particularly about the participants' social networks. Marital status is a strong predictor of social support, depression, and mental health QoL, but this information was not accessible for a large portion of our participants (Inaba et al., 2005; Sherbourne & Hays, 1990). Marital status could have been an important covariate in our regression analyses. Future iterations of this study should include this information to better describe the sample, and to better understand differences among participants in social support, adverse social experiences, and adverse social experiences.

This study was conducted online, and cross-sectionally. While research conducted completely online is typically considered acceptable, there could be issues where participants would have preferred to take the survey in-person, which may have affected our sample. Many bots attacked the survey by repeatedly trying to complete it. While our procedures for eliminating these bots were detailed and intensive, it is possible that a bot may have been capable of completing the survey and creating data that should not have been possible. That said, it is unlikely that a bot made it into the final dataset, as individuals had to talk to a researcher on the phone to be paid for completion of the survey. In-person and in-home surveys may have also been able to better access the portion of our intended population that would prefer to not complete the survey online. Additionally, some survey items may have been better asked in-person. This study was limited by funding in this regard, but a more inclusive study may be able to take these issues into account.

Another issue with this data is that all measures were self-reported. Issues with self-report data are well-studied. Participants may misinterpret directions. They may also become distracted by outside information. If participants were to complete the survey in front of others, this may have also affected answers. Self-report data are often inaccurate compared to more objective measures. This can cause issues with validity of these self-report data. Thus, any self-reported data should be interpreted with caution (Baranowski, 1985).

As mentioned previously, this study was conducted in the midst of a global pandemic. This undoubtedly had effects on caregivers' social networks, mental health, and potentially physical health. It is likely that this may have also affected caregivers' responses to our questionnaires. While we were able to ask about participants' change in social support due to the COVID-19 pandemic, this was outside the scope of our original aims. Therefore, our measures of changes due to the pandemic are rudimentary at best. A more detailed study of these changes, including those to mental health, physical health, and social networks, may provide better information about caregivers during this extraordinary moment in human history.

Implications

These findings have implications that may affect the social support networks, physicians, nurses, and mental healthcare workers of family caregivers, and the caregivers themselves. While this study did not reveal much in the way of racial differences between Black and White caregivers, the finding that Black caregivers within the sample experienced more discrimination and stress due to discrimination, even when they experience the same income difficulty and are equally educated compared to White caregivers, is an important replication of previous findings. It is important for clinicians to be mindful of preventing their own biases against Black care recipients and caregivers in healthcare. It is also interesting that White caregivers had less trust in physicians than Black caregivers in this sample. It may be useful for researchers to further examine this racial difference in a more typical sample and control for background characteristics such as income difficulty and education level or determine if education modifies the relationship between race and physician trust.

Social support satisfaction and emotional support predicting mental health outcomes is another finding that may be a point of emphasis for mental health professionals who deal with family caregivers. These factors being associated with better mental health outcomes may help guide family counselors to help caregivers who are dealing with issues with depression and other mental health issues. It may also help to meet with the families and friends of caregivers to help them better support these caregivers in times of stress and emotional need. Caregivers have unique emotional stressors that social support networks may be best in assisting. This finding may also help to inform caregivers where they may need to ask for more assistance, even when that assistance is not an instrumental support, such as providing transportation or helping with housework.

The finding that negative interaction was the adverse social experience most strongly associated with mental health outcomes is one that may have important implications for the families and friends of caregivers, not to mention caregivers' counselors and other mental health professionals. Working to limit these negative interactions may help to lessen the burden that caregivers feel when dealing with their care recipients. It also may be important to take these negative interactions into account when providing counseling to caregivers and their loved ones. More work is needed to understand the role of these negative interactions in the context of family caregiving.

Future Directions

By far, the biggest limitation to this study was the small sample size. A continuation of this research will include far more participants. This will allow for repetition of the analyses reported here with far greater power to detect differences between participants. Additionally, a larger sample should be more representative of the general caregiving population. More detailed analyses examining racial group differences and other group differences (sex differences, caregiver-recipient differences, and differences among different reasons for caregiving) would be possible with a much larger sample size.

The differences between Whites and Blacks on adverse social experiences point to a need to further examine the role of race in caregiving research. While this study focused on adverse social experiences, other potential tertiary stressors may be discussed, to further elaborate on the caregiver stress process model. The adverse social experiences examined in this study should also continue to be studied, due to limitations with the study. There may be additional associations not revealed by our analyses, and in a more representative sample of caregivers in the United States, the differences between Whites and Blacks in these factors may not be the same.

The associations of emotional support and satisfaction with mental health outcomes reiterate the importance of examining individual social support factors as important buffers of caregiver burden. The post-hoc examination of changes in received support and satisfaction with support due to the COVID-19 pandemic and their associations with mental health outcomes also provide invaluable information to researchers as we discover the implications of this tragedy and unique time in human history, especially in relation to caregiver-care recipient relationships. The examination of these changes in social support may also help to elaborate on other aspects of the caregiver role during a pandemic and other times of extreme stress. More work is needed to understand how changes due in social support due to the pandemic may have affected the mental health of caregivers in the present and moving forward.

In this study, social support was not revealed as a buffer against the effects of adverse social experiences on health outcomes. Much of this is likely due to the lack of effects on health outcomes by adverse social experiences. That said, a larger sample with similar measures of adverse social experiences may reveal more and stronger associations between these types of experiences and health outcomes. The association between negative interaction with mental health outcomes is also an important finding that may help to guide further study on this subject. It may also be beneficial to consider additional adverse social experiences and how they interact with social support in caregivers. Future work must be done to further examine these factors in the context of the caregiver stress process model.

Conclusions

This study aimed to examine race, social support, and adverse social experiences in caregivers. Some limitations to the sample size and time period of data collection, along with limitations to online cross-sectional data may have affected results. The study did provide some evidence for the importance of these factors in predicting health outcomes and examining additional factors in the caregiver stress process model. Future studies may further examine these factors and their important roles in caregiver health. Additionally, more work will be conducted to determine how changes in social support due to the COVID-19 pandemic affected caregiver mental health.

REFERENCES

Acock, A. C. (2008). *A gentle introduction to Stata*. Stata press.

Anderson, C. S., Linto, J., & Stewart-Wynne, E. G. (1995, May). A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke, 26*(5), 843-849. https://doi.org/10.1161/01.str.26.5.843

Anderson, L. A., & Dedrick, R. F. (1990, Dec). Development of the Trust in Physician scale: a measure to assess interpersonal trust in patient-physician relationships. *Psychol Rep, 67*(3 Pt 2), 1091-1100. https://doi.org/10.2466/pr0.1990.67.3f.1091

Antonio, M. C., Ahn, H. J., Ing, C. T., Dillard, A., Cassel, K., Kekauoha, B. P., & Kaholokula, J. K. a. (2016). Self-reported experiences of discrimination and depression in Native Hawaiians. *Hawai'i Journal of Medicine & Public Health, 75*(9), 266.

Banks, K. H., Kohn-Wood, L. P., & Spencer, M. (2006). An examination of the African American experience of everyday discrimination and symptoms of psychological distress. *Community mental health journal, 42*(6), 555-570.

Baranowski, T. (1985). Methodologic issues in self-report of health behavior. *Journal of School Health, 55*(5), 179-182.

Barnes, L. L., De Leon, C. F. M., Lewis, T. T., Bienias, J. L., Wilson, R. S., & Evans, D. A. (2008). Perceived discrimination and mortality in a population-based study of older adults. *American Journal of Public Health, 98*(7), 1241-1247.

Bloome, D. (2014). Racial inequality trends and the intergenerational persistence of income and family structure. *American sociological review, 79*(6), 1196-1225.

Borrell, L. N., Roux, A. V. D., Jacobs Jr, D. R., Shea, S., Jackson, S. A., Shrager, S., & Blumenthal, R. S. (2010). Perceived racial/ethnic discrimination, smoking and alcohol consumption in the Multi-Ethnic Study of Atherosclerosis (MESA). *Preventive medicine, 51*(3-4), 307-312.

Brand, C., Barry, L., & Gallagher, S. (2016). Social support mediates the association between benefit finding and quality of life in caregivers. *Journal of health psychology, 21*(6), 1126-1136.

Brody, G. H., Lei, M. K., Chae, D. H., Yu, T., Kogan, S. M., & Beach, S. R. (2014). Perceived Discrimination Among A frican A merican Adolescents and Allostatic Load: A Longitudinal Analysis With Buffering Effects. Child development, 85(3), 989-1002.

Browning, W. R., Clay, O. J., Bowen, P. G., Pouncey, J., & Crowe, M. G. (2020). Negative interaction mediates the disparity in diabetes distress between older Black and White adults. *Manuscript submitted for publication.*

Canady, R. B., Bullen, B. L., Holzman, C., Broman, C., & Tian, Y. (2008). Discrimination and symptoms of depression in pregnancy among African American and White women. *Women's Health Issues, 18*(4), 292-300.

NAC: National Alliance for Caregiving/AARP (2015). Caregiving in the United States 2015.

NAC: National Alliance for Caregiving/AARP (2020). Caregiving in the United States 2020.

Choi, K.-H., Paul, J., Ayala, G., Boylan, R., & Gregorich, S. E. (2013). Experiences of discrimination and their impact on the mental health among African American, Asian and Pacific Islander, and Latino men who have sex with men. *American Journal of Public Health, 103*(5), 868-874.

Clay, O. J., Grant, J. S., Wadley, V. G., Perkins, M. M., Haley, W. E., & Roth, D. L. (2013, Feb). Correlates of health-related quality of life in African American and Caucasian stroke caregivers. *Rehabil Psychol, 58*(1), 28-35. https://doi.org/10.1037/a0031726

Clay, O. J., Roth, D. L., Wadley, V. G., & Haley, W. E. (2008, Aug). Changes in social support and their impact on psychosocial outcome over a 5-year period for African American and White dementia caregivers. *Int J Geriatr Psychiatry, 23*(8), 857-862. https://doi.org/10.1002/gps.1996

Cobb, S. (1976, Sep-Oct). Presidential Address-1976. Social support as a moderator of life stress. *Psychosom Med, 38*(5), 300-314. https://doi.org/10.1097/00006842-197609000-00003

Cohen, S., & Wills, T. A. (1985, Sep). Stress, social support, and the buffering hypothesis. *Psychol Bull, 98*(2), 310-357. https://www.ncbi.nlm.nih.gov/pubmed/3901065

Doescher, M. P., Saver, B. G., Franks, P., & Fiscella, K. (2000). Racial and ethnic disparities in perceptions of physician style and trust.

Dolezsar, C. M., McGrath, J. J., Herzig, A. J., & Miller, S. B. (2014). Perceived racial discrimination and hypertension: a comprehensive systematic review. *Health Psychology, 33*(1), 20.

Geng, H.-m., Chuang, D.-m., Yang, F., Yang, Y., Liu, W.-m., Liu, L.-h., & Tian, H.-m. (2018). Prevalence and determinants of depression in caregivers of cancer patients: A systematic review and meta-analysis. *Medicine, 97*(39).

Gonyea, J. G., O'Connor, M., Carruth, A., & Boyle, P. A. (2005, Sep-Oct). Subjective appraisal of Alzheimer's disease caregiving: the role of self-efficacy and depressive symptoms in the experience of burden. *Am J Alzheimers Dis Other Demen, 20*(5), 273-280. https://doi.org/10.1177/153331750502000505

Goode, K. T., Haley, W. E., Roth, D. L., & Ford, G. R. (1998, Mar). Predicting longitudinal changes in caregiver physical and mental health: a stress process model. *Health Psychol, 17*(2), 190-198. https://doi.org/10.1037//0278-6133.17.2.190

Halanych, J. H., Safford, M. M., Shikany, J. M., Cuffee, Y., Person, S. D., Scarinci, I. C., Kiefe, C. I., & Allison, J. J. (2011). The association between income, education, and experiences of discrimination in older African American and European American patients. *Ethnicity & disease, 21*(2), 223.

Haley, W. E., Levine, E. G., Brown, S. L., & Bartolucci, A. A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and aging, 2*(4), 323.

Haley, W. E., Roth, D. L., Hovater, M., & Clay, O. J. (2015, Mar 31). Long-term impact of stroke on family caregiver well-being: a population-based case-control study. *Neurology, 84*(13), 1323-1329. https://doi.org/10.1212/WNL.0000000000001418

House, J. S., Landis, K. R., & Umberson, D. (1988, Jul 29). Social relationships and health. *Science, 241*(4865), 540-545. https://doi.org/10.1126/science.3399889

Howard, V. J., Cushman, M., Pulley, L., Gomez, C. R., Go, R. C., Prineas, R. J., Graham, A., Moy, C. S., & Howard, G. (2005). The reasons for geographic and racial differences in stroke study: objectives and design. *Neuroepidemiology, 25*(3), 135-143.

Huynh, Q. L., Devos, T., & Dunbar, C. M. (2012, Jan). The psychological costs of painless but recurring experiences of racial discrimination. *Cultur Divers Ethnic Minor Psychol, 18*(1), 26-34. https://doi.org/10.1037/a0026601

Inaba, A., Thoits, P. A., Ueno, K., Gove, W. R., Evenson, R. J., & Sloan, M. (2005). Depression in the United States and Japan: gender, marital status, and SES patterns. *Social science & medicine, 61*(11), 2280-2292.

Kaufman, A. V., Kosberg, J. I., Leeper, J. D., & Tang, M. (2010). Social support, caregiver burden, and life satisfaction in a sample of rural African American and

White caregivers of older persons with dementia. *Journal of Gerontological Social Work, 53*(3), 251-269.

Krause, N. (1995, Mar). Negative interaction and satisfaction with social support among older adults. *J Gerontol B Psychol Sci Soc Sci, 50*(2), P59-73. https://doi.org/10.1093/geronb/50b.2.p59

Krieger, N., Smith, K., Naishadham, D., Hartman, C., & Barbeau, E. M. (2005, Oct). Experiences of discrimination: validity and reliability of a self-report measure for population health research on racism and health. *Soc Sci Med, 61*(7), 1576-1596. https://doi.org/10.1016/j.socscimed.2005.03.006

Lee, Y.-Y., & Lin, J. L. (2009). The effects of trust in physician on self-efficacy, adherence and diabetes outcomes. *Social science & medicine, 68*(6), 1060-1068.

Leung, L. L., P. S. (2005). Multiple determinants of life quality: The roles of Internet activities, use of new media, social support, and leisure activities. *Telematics and Informatics, 22*(3), 161-180.

Lewis, T. T., Kravitz, H. M., Janssen, I., & Powell, L. H. (2011). Self-reported experiences of discrimination and visceral fat in middle-aged African-American and Caucasian women. *American journal of epidemiology, 173*(11), 1223-1231.

Litzelman, K., Kent, E. E., Mollica, M., & Rowland, J. H. (2016). How does caregiver well-being relate to perceived quality of care in patients with cancer? Exploring associations and pathways. *Journal of Clinical Oncology, 34*(29), 3554.

Liu, L., Gou, Z., & Zuo, J. (2016). Social support mediates loneliness and depression in elderly people. *Journal of health psychology, 21*(5), 750-758.

Manns-James, L., Anthony, M. K., & Neal-Barnett, A. (2020). Racial Discrimination, Racial Identity, and Obesity in Collegiate African American Women. *Journal of Racial and Ethnic Health Disparities*, 1-15.

Marsh, N. V., Kersel, D. A., Havill, J. H., & Sleigh, J. W. (2002). Caregiver burden during the year following severe traumatic brain injury. *Journal of clinical and experimental neuropsychology, 24*(4), 434-447.

Nightingale, C. L., Curbow, B. A., Wingard, J. R., Pereira, D. B., & Carnaby, G. D. (2016, Sep). Burden, quality of life, and social support in caregivers of patients undergoing radiotherapy for head and neck cancer: A pilot study. *Chronic Illn, 12*(3), 236-245. https://doi.org/10.1177/1742395316644305

Ong, A. D., Fuller-Rowell, T., & Burrow, A. L. (2009). Racial discrimination and the stress process. *Journal of personality and social psychology, 96*(6), 1259.

Park, E. O., Yates, B. C., Meza, J., Kosloski, K., & Pullen, C. (2016). Spousal caregivers of coronary artery bypass surgery patients: Differences between caregivers with low vs. high caregiving demands. *Rehabilitation Nursing, 41*(5), 260-269.

Pearlin, L. I., Lieberman, M. A., Menaghan, E. G., & Mullan, J. T. (1981, Dec). The stress process. *J Health Soc Behav, 22*(4), 337-356. https://www.ncbi.nlm.nih.gov/pubmed/7320473

Pearlin, L. I., Schieman, S., Fazio, E. M., & Meersman, S. C. (2005). Stress, health, and the life course: Some conceptual perspectives. *Journal of health and Social Behavior, 46*(2), 205-219.

Peirce, R. S., Frone, M. R., Russell, M., Cooper, M. L., & Mudar, P. (2000). A longitudinal model of social contact, social support, depression, and alcohol use. *Health Psychology, 19*(1), 28.

Piette, J. D., Heisler, M., Krein, S., & Kerr, E. A. (2005). The role of patient-physician trust in moderating medication nonadherence due to cost pressures. *Archives of internal medicine, 165*(15), 1749-1755.

Pinquart, M., & Sorensen, S. (2005, Feb). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *Gerontologist, 45*(1), 90-106. https://doi.org/10.1093/geront/45.1.90

Pinquart, M., & Sorensen, S. (2007, Mar). Correlates of physical health of informal caregivers: a meta-analysis. *J Gerontol B Psychol Sci Soc Sci, 62*(2), P126-137. https://doi.org/10.1093/geronb/62.2.p126

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied psychological measurement, 1*(3), 385-401.

Reinhard, S. C., Feinberg, L. F., Houser, A., Choula, R., & Evans, M. (2019). Valuing the Invaluable: 2019 Update – Charting a Path Forward.

Roth, D. L., Haley, W. E., Owen, J. E., Clay, O. J., & Goode, K. T. (2001, Sep). Latent growth models of the longitudinal effects of dementia caregiving: a comparison of African American and White family caregivers. *Psychol Aging, 16*(3), 427-436. https://www.ncbi.nlm.nih.gov/pubmed/11554521

Roth, D. L., Mittelman, M. S., Clay, O. J., Madan, A., & Haley, W. E. (2005, Dec). Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychol Aging, 20*(4), 634-644. https://doi.org/10.1037/0882-7974.20.4.634

Roth, D. L., Perkins, M., Wadley, V. G., Temple, E. M., & Haley, W. E. (2009, Aug). Family caregiving and emotional strain: associations with quality of life in a large national sample of middle-aged and older adults. *Qual Life Res, 18*(6), 679-688. https://doi.org/10.1007/s11136-009-9482-2

Russo, J., & Vitaliano, P. P. (1995, Jul-Sep). Life events as correlates of burden in spouse caregivers of persons with Alzheimer's disease. *Exp Aging Res, 21*(3), 273-294. https://doi.org/10.1080/03610739508253985

Sawatzky, J., & Fowler-Kerry, S. (2003). Impact of caregiving: Listening to the voice of informal caregivers. *Journal of Psychiatric and Mental Health Nursing, 10*(3), 277-286.

Schmidt, A. F., & Finan, C. (2018, Jun). Linear regression and the normality assumption. *J Clin Epidemiol, 98*, 146-151. https://doi.org/10.1016/j.jclinepi.2017.12.006

Sherbourne, C. D., & Hays, R. D. (1990). Marital status, social support, and health transitions in chronic disease patients. *Journal of health and Social Behavior*, 328-343.

Sherbourne, C. D., & Stewart, A. L. (1991). The MOS social support survey. *Social science & medicine, 32*(6), 705-714.

Slopen, N., & Williams, D. R. (2014). Discrimination, other psychosocial stressors, and self-reported sleep duration and difficulties. *Sleep, 37*(1), 147-156.

Son, J., Erno, A., Shea, D. G., Femia, E. E., Zarit, S. H., & Parris Stephens, M. A. (2007). The caregiver stress process and health outcomes. *Journal of aging and health, 19*(6), 871-887.

Sorensen, S., & Conwell, Y. (2011, Jun). Issues in dementia caregiving: effects on mental and physical health, intervention strategies, and research needs. *Am J Geriatr Psychiatry, 19*(6), 491-496. https://doi.org/10.1097/JGP.0b013e31821c0e6e

Stanfors, M., Jacobs, J. C., & Neilson, J. (2019). Caregiving time costs and trade-offs: Gender differences in Sweden, the UK, and Canada. *SSM-population health, 9*, 100501.

Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-oncology, 19*(10), 1013-1025.

Tang, T. S., Brown, M. B., Funnell, M. M., & Anderson, R. M. (2008). Social support, quality of life, and self-care behaviors among African Americans with type 2 diabetes. *The diabetes educator, 34*(2), 266-276.

Ware, J. E., Keller, S. D., & Kosinski, M. (1994). *SF-36: Physical and mental health summary scales: A user's manual*. Health Assessment Lab.

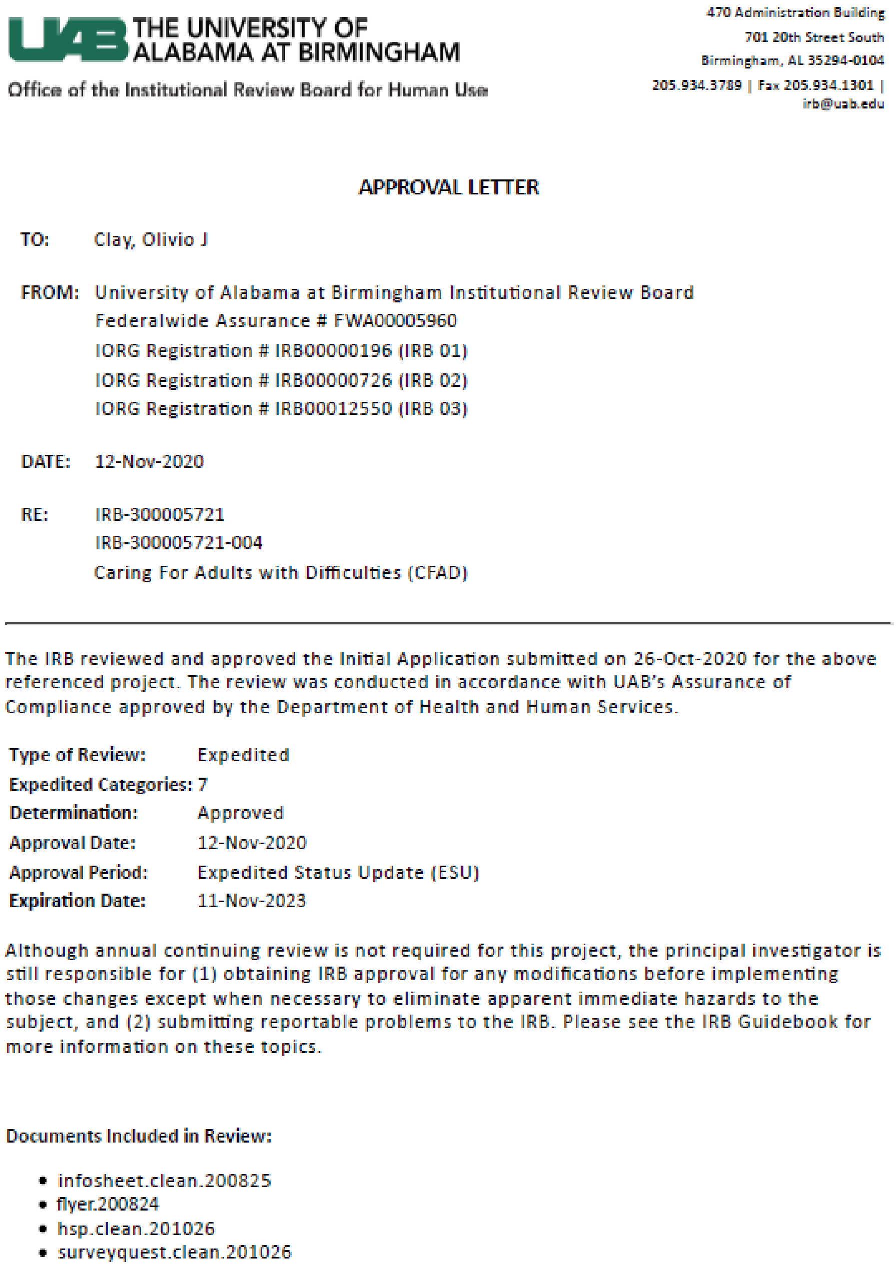
Ware Jr, J. E. (1999). SF-36 health survey.

White, R. O., Osborn, C. Y., Gebretsadik, T., Kripalani, S., & Rothman, R. L. (2013). Health literacy, physician trust, and diabetes-related self-care activities in Hispanics with limited resources. *Journal of health care for the poor and underserved, 24*(4), 1756.

Williams, I. C., Clay, O. J., Ovalle, F., Atkinson, D., & Crowe, M. (2020, Jan). The Role of Perceived Discrimination and Other Psychosocial Factors in Explaining Diabetes Distress Among Older African American and White Adults. *J Appl Gerontol, 39*(1), 99-104. https://doi.org/10.1177/0733464817750273

APPENDIX A

IRB Approval Letter



THE UNIVERSITY OF
ALABAMA AT BIRMINGHAM
Office of the Institutional Review Board for Human Use

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APPROVAL LETTER

TO: Clay, Olivio J

FROM: University of Alabama at Birmingham Institutional Review Board
Federalwide Assurance # FWA00005960
IORG Registration # IRB00000196 (IRB 01)
IORG Registration # IRB00000726 (IRB 02)
IORG Registration # IRB00012550 (IRB 03)

DATE: 12-Nov-2020

RE: IRB-300005721
IRB-300005721-004
Caring For Adults with Difficulties (CFAD)

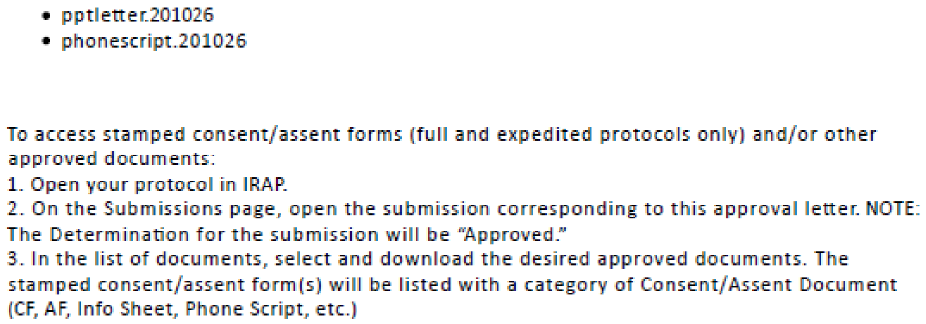
The IRB reviewed and approved the Initial Application submitted on 26-Oct-2020 for the above referenced project. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services.

Type of Review: Expedited
Expedited Categories: 7
Determination: Approved
Approval Date: 12-Nov-2020
Approval Period: Expedited Status Update (ESU)
Expiration Date: 11-Nov-2023

Although annual continuing review is not required for this project, the principal investigator is still responsible for (1) obtaining IRB approval for any modifications before implementing those changes except when necessary to eliminate apparent immediate hazards to the subject, and (2) submitting reportable problems to the IRB. Please see the IRB Guidebook for more information on these topics.

Documents Included in Review:

- infosheet.clean.200825
- flyer.200824
- hsp.clean.201026
- surveyquest.clean.201026



- pptletter.201026
- phonescript.201026

To access stamped consent/assent forms (full and expedited protocols only) and/or other approved documents:
1. Open your protocol in IRAP.
2. On the Submissions page, open the submission corresponding to this approval letter. NOTE: The Determination for the submission will be "Approved."
3. In the list of documents, select and download the desired approved documents. The stamped consent/assent form(s) will be listed with a category of Consent/Assent Document (CF, AF, Info Sheet, Phone Script, etc.)

Table 1. *Tests of Assumptions*

Variable	Normality (Shapiro - Wilk) (*p*)	Homogeneity of Variances (Levene's *p*)	Assumption Violation
Age	.42	.16	
Income Difficulty	<.01	.16	Positively Skewed
Hours Spent Caring	<.01	.51	Positively Skewed
Length of Care	<.01	.63	Negatively Skewed
Instrumental Support	<.01	.18	Positively Skewed
Emotional Support	<.01	.56	Positively Skewed
Informational Support	<.05	.61	Positively Skewed
Satisfaction with Support	.09	.99	
Received Support Change	<.01	.49	
Support Satisfaction Change	<.01	.30	
Negative Interaction	<.01	.70	Positively Skewed
Physician Trust	.07	.14	
EOD Sum	<.01	<.01	Positively Skewed
EOD Frequency	<.01	<.05	Positively Skewed
EOD Stress	<.01	<.01	Positively Skewed
Depressive Symptoms	<.05	.71	Positively Skewed
PCS	<.01	.85	Negatively Skewed
MCS	.31	.32	
Physical Function			
Role Physical			
General Health			
Vitality			
Role Emotional			

Table 2. *Sample Descriptive Statistics by Race*

Variable	All (N=56) Mean (std)/ n(%)	White (n=23) Mean (std)/ n(%)	Black (n=33) Mean (std)/ n(%)	t or (χ^2)	p
Age	50.35 (12.96)	49.09 (14.21)	51.12 (11.96)	-.58	.57
Female Gender[a]	51 (91.1%)	20 (87.0%)	31 (93.9%)	.81	.39
Education	16.30 (2.74)	15.96 (2.76)	16.55 (2.75)	-.79	.43
Income Difficulty	2.85 (1.04)	2.70 (.93)	2.91 (1.16)	-.74	.47
Hours Spent Caring	44.07 (43.35)	39.35 (36.41)	47.24 (47.26)	-.67	.50
Length of Care	3.76 (1.26)	3.87 (1.36)	3.73 (1.21)	.41	.68
Instrumental Support	5.07 (2.06)	4.57 (1.75)	5.36 (2.22)	-1.44	.16
Emotional Support	10.45 (3.26)	10.22 (3.18)	10.45 (3.45)	-.26	.80
Informational Support	7.93 (2.75)	7.48 (2.47)	8.21 (2.90)	-.99	.33
Satisfaction with Support	8.00 (2.25)	7.87 (2.82)	7.97 (2.34)	-.16	.87
Received Support Change	2.91 (.793)	2.57 (.66)	3.15 (.80)	-2.90**	<.01
Support Satisfaction Change	2.93 (.828)	2.57 (.79)	3.18 (.77)	-2.92**	<.01

Note: * $p < .05$, ** $p < .01$, *a* significance given is for Fisher's exact test due to cell sizes < 5

Table 2. *Sample Descriptive Statistics by Race Continued*

Variable	All (N=56) Mean (std)/ n(%)	White (n=23) Mean (std)/ n(%)	Black (n=33) Mean (std)/ n(%)	*t or* (χ^2)	*p*
Negative Interaction	7.45 (2.39)	7.57 (2.25)	7.39 (2.47)	.26	.79
Physician Trust	40.42 (7.64)	37.70 (8.60)	42.58 (6.30)	-2.45*	.02
EOD Sum	1.73 (1.97)	.43 (.99)	2.85 (2.24)	-4.84**	<.01
EOD Frequency	4.88 (6.11)	1.46 (3.85)	8.26 (8.12)	-4.18**	<.01
EOD Stress	4.86 (6.16)	1.22 (2.83)	7.40 (6.60)	-4.79**	<.01
Depressive Symptoms	17.00 (10.67)	19.13 (10.57)	16.30 (11.52)	.93	.35
PCS	45.92 (6.96)	45.51 (8.49)	46.34 (5.69)	-.44	.66
MCS	43.10 (7.24)	40.78 (6.30)	44.28 (7.90)	-1.77	.08

Note: * $p < .05$, ** $p < .01$, *a* significance given is for Fisher's exact test due to cell sizes < 5

Table 3. *Correlation Matrix of Covariates and Health Outcomes*

Variable	1	2	3	4	5	6	7
1. Age	1						
2. Income Difficulty	.10	1					
3. Hours Spent Caring	.34*	.15	1				
4. Length of Care	.25	.22	.28*	1			
5. Depressive Symptoms	-.14	-.27*	-.01	.06	1		
6. PCS	.04	-.02	.08	.09	-.27*	1	
7. MCS	.19	.14	.19	-.00	-.71**	-.02	1

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

Table 4. *Correlation Matrix of Support Measures, Adverse Social Experiences, and Health Outcomes*

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Instrumental Support	1													
2. Emotional Support	.30*	1												
3. Informational Support	.44**	.68**	1											
4. Support Satisfaction	.43**	.70**	.57**	1										
5. Received Support Change	.22	.28*	.20	.16	1									
6. Support Satisfaction Change	.24	.27*	.20	.19	.85**	1								
7. Negative Interaction	.39**	.09	.29*	.03	-.02	-.05	1							
8. Physician Trust	.05	-.08	-.02	.03	.24	.13	-.08	1						
9. EOD Sum	.18	-.03	.08	.09	-.13	-.07	.22	.27*	1					
10. EOD Frequency	-.00	-.03	-.01	.03	-.17	-.13	.10	.21	.91	1				
11. EOD Stress	.24	-.07	.07	.02	-.12	-.06	.31*	.28*	.94**	.86*	1			
12. Depressive Symptoms	-.03	-.40**	-.08	-.32*	-.34*	-.26	.29*	-.04	.13	.10	.20	1		
13. PCS	-.18	-.15	-.11	-.08	-.17	-.07	-.16	.01	.03	.06	.03	-.27*	1	
14. MCS	.13	.45*	.23	.38**	.46**	.40**	-.19	.01	-.05	-.05	-.10	-.71**	-.02	1

Note: * *p* < .05, ** *p* < .01

Table 5. *Linear Regression Models with Race as a Predictor of Adverse Social Experiences*

	Physician Trust			Stressfulness of Discrimination		
Variable	*b*	*SE b*	*β*	*b*	*SE b*	*β*
Age	.10	.08	.18	-.03	.06	-.06
Female Gender	.37	3.51	.01	2.59	2.53	.12
Income Difficulty	-.10	.95	.01	-1.07	2.53	.12
Black Race	4.66	2.04	.30*	6.29	1.48	.51***

Notes: b = unstandardized beta, *β* = standardized beta.
* $p < .05$, ** $p < .01$, *** $p < .001$

Table 6. *Linear Regression Models with Race as a Predictor of Social Support Change due to the COVID-19 Pandemic*

	Change in Received Support			Change in Support Satisfaction		
Variable	*b*	*SE b*	*β*	*b*	*SE b*	*β*
Age	.01	.01	.20	.01	.01	.18
Female Gender	-.49	.34	-.18	.20	.37	.07
Income Difficulty	.13	.09	.17	.09	.10	.12
Black Race	.57	.20	.36**	.56	.21	.34*

Notes: b = unstandardized beta, *β* = standardized beta. * *p* < .05, ** *p* < .01, *** *p* <.001

Table 7. *Individual Linear Regression Models with Relevant Social Support Variables and Negative Interaction as Predictors of Depressive Symptoms*

	Depressive Symptoms		
Variable	*b*	*SE b*	*β*
Emotional Support	-1.26	.42	-.38**
Social Support Satisfaction	-1.53	.63	-.32*
Change in Received Support	-4.09	2.08	-.29^{+}
Change in Support Satisfaction	-2.62	1.98	-.20
Negative Interaction	1.05	.65	.22

Notes: b = unstandardized beta, *β* = standardized beta. Each model represented here was a separate univariate linear regression model with the variable in the left column as a predictor and depressive symptoms as the outcome. $^{+}$ p <.1, * *p* < .05, ** *p* < .01, *** *p* <.001

Table 8. *Individual Linear Regression Models with Relevant Social Support Variables as Predictors of Mental Component Summary*

	Mental Component Summary		
Variable	*b*	*SE b*	*β*
Emotional Support	.979	.27	.44**
Social Support Satisfaction	1.30	.41	.40**
Change in Received Support	3.89	1.33	.42**
Change in Support Satisfaction	-2.94	1.28	.33*

Notes: b = unstandardized beta, *β* = standardized beta. Each model represented here was a separate univariate linear regression model with the variable in the left column as a predictor and MCS as the outcome. * $p < .05$, ** $p < .01$, *** $p < .001$

Table 9. *Individual Linear Regression Models with Social Support Variables Moderating the Effect of Negative Interaction on Depressive Symptoms*

	Depressive Symptoms		
Variable	*b*	*SE b*	*β*
Instrumental Support	2.89	1.67	.26
Emotional Support	.13	1.34	.01
Informational Support	2.16	1.48	.20
Social Support Satisfaction	2.12	1.75	.16
Change in Received Support	.89	1.34	.09
Change in Support Satisfaction	2.25	1.57	.20

Notes: b = unstandardized beta, *β* = standardized beta. Each model represented here was a separate univariate linear regression model with the variable in the left column as an interaction effect with negative interaction and depressive symptoms as the outcome. Predictors, moderators, and covariates were all standardized to have a mean of 0 and standard deviation of 1 as they were on different scales. * $p < .05$, ** $p < .01$, *** $p <.001$

Figure 1. *Diagram of Moderation Analyses*