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Coping, Well-Being, and Depression among Caregivers of Young Adults with Developmental Disabilities

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Abstract:	This ten-year-long longitudinal study included 134 caregivers of young adults with autism and intellectual and developmental disabilities (IDDs). The effects of caregivers' coping strategies, as well as sociodemographic features (e.g. race) and symptomatology of their young adults (e.g. externalizing behaviors, autism symptom severity), were explored to predict changes in caregiver well-being and depression. Lower caregiver education and higher young adult externalizing behaviors both predicted lower well-being and higher depression among caregivers, while caregivers of color experienced higher depression than white caregivers over time. All five of the caregiver coping strategies investigated predicted changes in caregiver well-being and/or depression, and some effects were moderated by young adult externalizing behaviors and other sociodemographic features. Notably, higher use of positive coping among caregivers of adults with high externalizing behaviors predicted higher caregiver well-being and lower depression. Results illustrate the potential strength of certain coping strategies to aid caregiver well-being and mental health.

Caregivers and Coping: Well-being, Depression, and Coping Strategies Among Caregivers of Young Adults with Developmental Disabilities

Abstract

This ten-year-long longitudinal study included 134 caregivers of young adults with autism and intellectual and developmental disabilities (IDDs). The effects of caregivers' coping strategies, as well as sociodemographic features (e.g. race) and symptomatology of their young adults (e.g. externalizing behaviors, autism symptom severity), were explored to predict changes in caregiver well-being and depression. Lower caregiver education and higher young adult externalizing behaviors both predicted lower well-being and higher depression among caregivers, while caregivers of color experienced higher depression than white caregivers over time. All five of the caregiver coping strategies investigated predicted changes in caregiver well-being and/or depression, and some effects were moderated by young adult externalizing behaviors and other sociodemographic features. Notably, higher use of positive coping among caregivers of adults with high externalizing behaviors predicted higher caregiver well-being and lower depression. Results illustrate the potential strength of certain coping strategies to aid caregiver well-being and mental health.

Caregivers and Coping

Autism spectrum disorder (ASD) and other intellectual and developmental disabilities (IDDs) are enduring conditions; as such, caregiving for a child with ASD and/or IDD is often a lifelong role. While research has long documented the higher rates of objective obstacles, stress, and depression caregivers of IDD face compared to the general population, caregiving also encompasses benefits which may affect the psychological well-being of caregivers (Marsack-Topolewski et al., 2021; Band-Winterstein & Avieli, 2017). Caregiver well-being has cascading effects on family functioning (Browne et al., 2015; Marsack-Topolewski & Wilson, 2021), and family functioning is thought to play a key role in the well-being of individuals with ASD and/or IDD (Smith et al., 2012). Therefore, from a family systems perspective, it is important to understand predictors of well-being in this population of caregivers, not only for the benefit of caregivers themselves, but for their loved ones with autism or IDD (Smith et al., 2012). Further, in order to consider caregivers’ strengths and resilience in addition to their challenges, improved understanding of potential adaptive predictors, such as coping strategies, is also needed (Bekhet et al., 2012). Many factors may predict lower well-being of caregivers of individuals with IDD, including lower socioeconomic status (Lindsey & Barry, 2018), autism symptomatology (Smith et al., 2008), lower access to services (Harper et al., 2013), and maladaptive coping strategies (Wong et al., 2020). However, with notable exceptions from Mailick-Seltzer and Greenberg (see Mailick Seltzer et al., 2011; Namkung et al., 2018), as well as cross-sectional work byMarsack-Topolewski and colleagues (Marsack-Topolewski & Wilson, 2021), much of this research focuses on caregiver well-being shortly after the affected child’s diagnosis. Additional longitudinal work is needed to understand the well-being of caregivers later in the life course.

Well-being likely evolves as caregivers age alongside their children. The first decade of the individual with IDD's adulthood presents a particularly important period for understanding changes in caregiver well-being (Pellicano et al., 2022). This decade includes the transition out of school, sometimes termed the "services cliff" (Shattuck et al., 2012), when many individuals with IDDs experience changes in (and often drastic losses of) supports and services (McKenzie et al., 2017; Smith et al., 2012**)**. A body of longitudinal research has reported on the still-present rates of autism symptoms and maladaptive behaviors among autistic adolescents and adults after exiting high school (Taylor & Seltzer 2010), and on improvements in maternal well-being when their adult son or daughter had declining behavioral difficulties (Lounds et al., 2007). Notably, many studies have pointed to child behavioral symptoms (e.g. aggression), rather than intellectual disability or autism symptoms, as a bigger driver of poorer well-being among caregivers of people with DDs (Chan et al., 2017; Hastings et al., 2005; Rattaz et al., 2017; Smith et al., 2008; Wong et al., 2020). Nevertheless, longitudinal research on changes in the well-being of caregivers of adults with ASD and other DDs remains sparse which limits understanding of temporal changes within caregivers, especially after key adulthood transitions into adulthood.

Further, existing research in this population often operationalizes "well-being" with negative constructs of psychopathology, most often depression (e.g. Chan et al., 2017; Piazza et al., 2014). A recent meta-analysis by Schnabel and colleagues revealed that across 28 studies investigating depression, approximately 31% of caregivers of autistic people met criteria for clinical depression -- a substantial elevation compared to the estimated 4.4% global clinical depression prevalence in the general population (Schnabel et al., 2020). Studies have also consistently highlighted higher levels of depression among caregivers of children with autism compared to mothers of children with other IDDs such as Down syndrome or intellectual disabilities alone (Abbeduto et al., 2004; Ekas & Whitman, 2010).

Positively framed well-being, in contrast, includes constructs such as purpose in life, self-acceptance, and perceptions of personal growth (Deci & Ryan, 2008; Ryff, 1989). Emphasizing positive elements of caregiver well-being aligns with an on-going shift in autism research to prioritize strengths-based approaches (Urbanowicz et al., 2019). Studying depression alongside these positive constructs provides a more holistic view of caregivers' experiences. The notable longitudinal work of Mailick, Greenberg and colleagues has utilized this holistic dual conceptualization of caregiver psychological health outcomes, and indicates caregivers of adults with IDD experience reduced well-being and increased depression over time, particularly as caregivers enter their 70's, and compared to age-matched peers without disabled children or with other disabilities (Mailick Seltzer et al., 2011; Namkung et al. 2018). Strengths-based approaches strive to highlight resiliencies in autistic and IDD individuals and their families, alongside areas of need (Bekhet et al., 2012; Szatmari et al., 2021).

Consistent with this strengths-based perspective is the construct of coping. Coping refers to a set of mechanisms, thoughts, and behaviors that are employed to manage situational or global stressors. One's patterns of coping can either promote or hinder psychological well-being over time (Carver & Scheier, 1994; Mayordomo-Rodríguez et al., 2015). Coping strategies can be behavioral or psychological (e.g., talking to a friend or reframing negative thoughts) and productive or unproductive (e.g., meditating to relieve stress or punching a wall). Among mothers of children with ASD, optimism and cognitive reframing-based coping are linked to greater ratings of happiness and hopefulness (Wong et al., 2020). Problem-focused coping has been found to predict longitudinal declines in depression among mothers of adults with intellectual disability (Kim et al., 2003) and higher well-being among mothers of toddlers and adolescents with ASD (Smith et al., 2008). In contrast, increased use of distraction to cope has been linked to increased caregiver distress among mothers of autistic children (Benson, 2014).

To date, little work has examined the impacts of coping styles for caregivers of adults with IDDs, and even less work has leveraged longitudinal methods to examine these constructs in this age group (see Kim et al., 2003 for an exception). Previous cross-sectional work among caregivers of adults with autism and IDD ages 18 and older showed that problem-focused coping (including spirituality and social support) and acceptance predicted positive perceived outcomes for parents, while disengagement and distraction coping predicted greater burden (Marsack-Topolewski & Wilson, 2021; Piazza et al., 2014).

Foundational coping theory suggests that one's coping strategies may be generally stable over time, and past research has corroborated this (Carver & Scheier, 1994; Godor et al., 2022; Powers et al., 2002). However, some types of coping, like active coping and acceptance, may be more malleable to change amongst caregivers (Godor et al., 2022), and could therefore serve as possible targets for interventions that leverage beneficial strategies. Longitudinal approaches allow us to understand the implications of coping strategies for well-being and mental health as caregivers age alongside their adult children. Furthermore, research suggests that different coping strategies may differentially predict caregiver well-being and mental health based on characteristics of the individual with ASD (Benson, 2014; Smith et al., 2008). More work is needed to understand person-level predictors and longitudinal links between older caregivers' well-being, mental health, and coping.

Study Aims

Aim 1: Predictors of caregiver well-being

Aim 1a. Characterize positive dimensions of well-being in caregivers over a ten-year period, when their young adults with autism and/or IDD were 18 to 28 years old, and investigate effects of demographic (race, parental education, and young adult biological sex) and young adult person-level characteristics (ASD symptomatology, externalizing behaviors, and intellectual disability of the young adult) on change in caregiver well-being.

Aim 1b. Leverage a strengths-based approach to examine the impact of coping strategies on patterns of caregiver well-being over a ten-year period, and investigate whether the impact of coping strategies on caregiver well-being was moderated by caregiver demographic and young adult personal characteristics.

Aim 2: Predictors of caregiver depression

Aim 2a. Investigate potential effects of demographic and young adult person-level characteristics on declines in caregiver depression, as a secondary measure of caregiver well-being, over the time their young adults were roughly ages 18 to 28 years.

Aim 2b. Investigate the impact of coping strategies on caregiver depression declines over the same period, examining whether caregiver demographic and young adult personal characteristics moderate impacts of coping strategies on caregiver depression.

Hypotheses

Aim 1a. In line with prior work (e.g., Hastings et al., 2005), we hypothesized that young adult externalizing behaviors, but not intellectual disability or autism severity, would predict lower positive well-being and/or declines in positive well-being over the study period compared to caregivers of young adults with fewer externalizing behaviors.

Aim 1b. Although coping strategies are a robust cross-sectional correlate of caregiver happiness, distress, and quality of life, limited work has examined longitudinal effects of coping strategies on well-being among caregivers of individuals with autism and/or IDD, particularly in adulthood (Benson 2010, 2014; Kim et al., 2003). In line with existing cross-sectional work (Piazza et al., 2014), we hypothesized that caregiver use of problem-focused and positive coping strategies would be associated with increased positive well-being, regardless of caregiver demographic or young adult personal characteristics, while use of denial coping and active avoidance coping would predict decreased well-being.

Aim 2a. As past studies highlight higher depression among caregivers of children with autism compared to other IDDs (e.g. Ekas & Whitman, 2010), we expected that lower young adult autism severity would predict lower caregiver depression in our sample. We also expected that higher externalizing behaviors of the young adult would predict higher caregiver depression over time, in line with the body of literature which points to the detrimental and compounding impacts of behaviors that challenge on caregiver psychological functioning (e.g. Smith et al., 2008; Wong et al., 2020).

Aim 2b. Considering the longitudinal findings by Kim et al. (2003), we hypothesized that problem-focused coping would predict longitudinal declines in depression among caregivers of adults with IDD, especially among caregivers of adults with more externalizing symptoms. We also hypothesized that positive coping would predict lower caregiver depression, as it encompasses constructs like positive reinterpretation, which may direct respond to the negative emotions and interpretations associated with depressive symptoms (Lambert et al., 2012).

Method

Participants

The current sample draws from an overall longitudinal cohort of 253 individuals referred for autism evaluations and their families. Data for this study was collected when the young adults with autism and/or IDD were 18 to 28 years old. The overall cohort was recruited from three sites in the United States: North Carolina, the greater Chicago area, and Michigan. Families from Chicago and North Carolina (n = 213) were originally referred to clinics for possible ASD or non-ASD developmental delays when their children were under 3 years old. Families from Michigan (n = 40) subsequently joined the study when their children were referred to clinics for evaluations of autism or DD at 9 years old; all had previous diagnoses made under age 5. The present analyses included 134 caregivers (*M*age = 48.1 years, SD = 6.04 years at the beginning of the study period; *M*age = 58.19 years, SD = 9.22 years by end of study) who completed the Scales of Psychological Well-Being questionnaire (Ryff, 1989) and the Beck Depression Inventory (Beck et al., 1996) at least once when their young adult was between 18 to 28 years old. Of the 119 participants from the larger longitudinal cohort excluded from the present analyses, 79 were lost due to attrition before their young adults turned 18, while 40 were lost due to not completing any well-being or depression measures. No major differences were found between those with missing and included data amongst any major predictor variables (all $p >$ .05). In the current study, “caregiver” was operationalized as the primary caregiver of each young adult participant; this included 118 mothers, 11 fathers, 3 grandmothers, and 2 aunts. No caregivers within the sample were related to each other. Out of the 134 included caregivers, 113 still lived in the same home with their young adult at the time of initial data collection. A majority of caregivers were white (82%), non-Hispanic (98%), completed a college degree (65%), and had a male young adult (79%). While 105 of the young adults had diagnoses of ASD (with or without co-occurring ID), 29 young adults had diagnoses of a non-autism IDD: intellectual disability (ID), learning disability (LD), Down Syndrome, and often multiples of these diagnoses co-occurring. Differences between participants in the current subsample and the total longitudinal cohort are reported in Table 1. Analyses revealed race, caregiver education, and young adult CSS scores differed significantly between the current subsample and total sample (all $p < .001$). Race, caregiver education, and CSS were therefore treated as covariates in all analyses.

Procedure

All procedures were approved by relevant institutional review board(s); guardians, and individuals with IDD over 18 who were their own legal guardians, gave written consent as required by the relevant IRBs prior to visits. The main outcome measures, the Scales of Psychological Well-Being (Ryff, 1989) and the Beck Depression Inventory (Beck et al., 1996), were mailed to caregivers at six study timepoints: when the adults with IDD were approximately 18, 20, 22, 24, 26, and 28 years old. All other measures, including the Brief COPE (Carver, 1997) and the Child Behavior Checklist (CBCL, Achenbach & Rescorla, 2001), were collected once at the beginning of the study period, when the adults were approximately age 18. Clinicians blinded to diagnosis conducted face-to-face testing on the adults when they were approximately 18, including the Autism Diagnostic Interview-Revised (ADI-R, Le Couteur et al., 2003), Autism Diagnostic Observation Schedule (ADOS-2; Lord et al., 2012), the Vineland Adaptive Behavior Scales (VABS-2; Sparrow et al., 1985, 2005), and standardized developmentally appropriate IQ tests (see Anderson et al., 2014).

Measures

Well-being

Caregivers (N = 134) completed a modified version of the Scales of Psychological Well-Being (SPWB; Ryff, 1989) at the six study timepoints listed above (*mean* = 3.88 completed timepoints per caregiver; 66 to 92 participants responded at each given timepoint). The reliability and validity of the 84-item version of the SPWB (14 items within six subscales: purpose in life, personal growth, self-acceptance, autonomy, environmental mastery, and positive relations with others) is well-documented across age groups and contexts, including longitudinal studies (Abbott et al., 2010; Ryff, 2014). Consistent with SPWB author recommendations to reduce participant burden (Ryff, 1989; Ryff, 2014), and with permission from the authors, an abbreviated 42-item version was created for the present study, including half of the 84-item version's six subscales: self-acceptance (14 items e.g., "In general, I feel confident and positive about myself"), personal growth (14 items e.g., "I enjoy seeing how my views have changed and matured over the years"), and purpose in life (14 items e.g., "I feel good when I think of what I've done in the past and what I hope to do in the future"). Caregivers rated the 42 items on a 6-point Likert scale. All 42 items were summed to calculate a total well-being score for each caregiver who completed the measure at each timepoint.

Depression

As a secondary measure to well-being, caregivers (n = 132) completed the Beck Depressive Inventory, 2nd edition (BDI-II; Beck, Steer, & Brown, 1996) at least once when their adults were approximately 18, 20, 22, 24, 25, 26, and 27 years old (*mean* = 3.76 completed timepoints per caregiver, mode = 6 completed per caregiver). The BDI–II is a 21-item self-report questionnaire including items related to emotions associated with depression, physical/somatic symptoms, and shifts in lifestyle. Each item rated in terms of severity in the past two weeks on a 0 to 3 scale. Research has highlighted strong internal consistency and convergent validity of the BDI-II (Dozois et al., 1998).

Coping

Caregivers (*n* = 99) completed the Brief Coping Orientation to Problems Experienced Inventory (Brief COPE; Carver, 1997) when their young adults were approximately 18 years old. The Brief COPE is generally reliable across a variety of populations, including caregivers, and offers several strengths, including ease of completion and measurement of a range of coping responses (Kato, 2015; Muniandy et al., 2021). The situational format of the Brief COPE consists of 28 items rated on a 4-point Likert scale that describe strategies used in response to a specific stressor or set of stressors (e.g., "I've been saying to myself ‘this isn't real’"). In the current study, caregivers were instructed, “These items ask what you've been doing to cope with the challenges you may encounter raising a child on the autism spectrum.”

Brief COPE subscales were based on empirically-derived factors from a prior study of caregivers of children with ASD (Hastings et al.; 2005). Rated as a high-quality study by a systematic review of Brief COPE factor structures (Solberg et al., 2022), the Hastings et al., factors have been utilized in other studies to determine coping strategies (e.g., Lai et al., 2014; Agha 2021). For the sake of interpretability and clarity, the “religious/denial coping” subscale from Hastings et al. was scored as two separate subscales in the current study (i.e., religious and denial), producing a total of five coping dimensions: **active avoidance** (9 items, α = .662, describing attempts to “avoid” the stressor); **problem-focused** (7 items, α = .845, capturing attempts to directly confront the stressor to modify or eliminate its effects); **positive** (6 items, α = .734, depicting use of humor, positive reframing, acceptance, and one item of emotional social support); **religious** (2 items, α = .797, including praying or meditation and/or seeking comfort in religion), and **denial** (2 items, α = .555, describing attempts to tell oneself the situation is not real).

Young Adult Externalizing Behaviors

Caregivers completed the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001) when their young adults were approximately 18 years old (n = 111). When data at age 18 were missing, we supplemented CBCL data from the timepoint most proximal to age 18. Containing 118 items on a 3-point Likert scale, the CBCL has evidence for validity among individuals with ASD (Schiltz & Magnus, 2021). Based on previous studies illuminating how challenging behaviors predict caregiver outcomes (Smith et al., 2008), the current study used externalizing domain scores, which include CBCL's rule-breaking behavior and aggressive behavior subscales.

Young Adult IQ

Cognitive abilities of the adults with ASD and/or IDD were measured at approximately age 18 via face-to-face assessments selected from a standardized hierarchy (n = 117). Ratio IQs were calculated from age equivalents when raw scores fell outside deviation score ranges. See Anderson et al. (2014) for a detailed description of IQ testing in this sample.

Young Adult Diagnoses and Autism Symptomology

Clinicians made blinded diagnoses of ASD or other neurodevelopmental disabilities at each in-person visit for all study participants (N = 134). In this sample, 105 individuals had diagnoses of ASD, and 29 had diagnoses of other IDD, as described earlier. Given considerable overlap in challenges faced during young adulthood for all individuals with developmental disabilities and their caregivers (Lord et al., 2020), all participants with or without ASD were retained in the current analyses. Autism symptomology of every young adult, regardless of diagnosis, was measured using calibrated severity scores (CSS) from the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012) at approximately 18 years old (n = 107), and when unavailable, from the next closest assessment. CSS scores range from 1 to 10, with higher scores reflecting more autism symptoms.

Young Adult Daily Living Skills

Clinicians administered the Vineland Adaptive Behavior Scales, 2nd edition (VABS-II, Sparrow et al., 2005) to caregivers when their adults with IDD were approximately 18 years old (n = 133). The VABS-II is a standardized and well-validated structured interview assessing communication, daily living skills (DLS), and socialization, in comparison to other same-aged individuals. As the current study only sought to examine the role of daily living skills, only VABS-II DLS age equivalence (AE) scores were used in the current analyses.

Data Analysis

Multilevel Modeling

Multilevel modeling via the mixed procedure in Stata 17.0 was used to investigate changes in caregiver well-being over the 10-year study period, as well as the impact of demographic characteristics and coping strategies on the intercept of parent well-being and changes in well-being over time (i.e., cross level interactions with age). Time (i.e., age) was centered at the young adult's age 18 for ease of interpretation. A multilevel modeling approach was selected to account for the nested structure of data across time and non-independence of assessment observations, and to evaluate the inclusion of random effects across participants on well-being estimates. Additionally, multilevel modeling in Stata uses full maximum likelihood (FIML). Thus, missing data are handled by estimating the model using all available information. We used an alpha level of .05 for null hypothesis significance testing. Use of multilevel modeling among sample sizes similar to that of the current study is supported by previous simulation studies (Lee & Hong, 2021; McNeish & Stapleton, 2016). A total of 113 participants in the sample had well-being data at a minimum of two time points. Analyses revealed that, within the study sample, those with missing data on CBCL externalizing scores did not differ significantly from those with completed CBCL externalizing scores across all major study variables, nor did those with missing Brief COPE scores differ from those with included Brief COPE scores ($p > .05$ for all).

Aim 1a & 2a models: Impacts of Demographic and Young Adult Characteristics on Caregiver Well-Being and Depression. First, the effects of demographic covariates (i.e., caregiver education, race) and young adult-level factors (i.e., IQ, externalizing behavior, daily living skills) on caregiver well-being or depression were modeled independent of coping strategies. Effects of demographic and young adult-level factors were tested as main effects and as interactions with time. Separate models were run predicting caregiver well-being and depression.

Aim 1b & 2b models: Associations Between Coping and Caregiver Well-Being and Depression. Models examining effects of each coping strategy on caregiver well-being or depression were constructed and analyzed separately. By examining each coping strategy separately, we aimed to gain a fine-grained understanding of the independent effects of each coping strategy on caregiver well-being. This approach also allowed us to avoid issues with multicollinearity. Models were constructed using a three-step approach. The first and simplest model for each coping strategy included fixed effects for time, coping strategy, time x coping strategy interaction terms, and a random effect for time. Next, demographic (e.g., race, urbanicity, caregiver education) and young adult covariates (e.g., participant IQ, externalizing behavior CBCL scores, CSS, and DLS-AE) were added simultaneously to models as fixed effects. Non-significant effects were then removed. Finally, for significant covariates, covariate x coping strategy, covariate x time, and covariate x coping strategy x time interaction terms were added. Non-significant covariates and interaction terms identified at this stage were removed from the final models.

Results

Aim 1 Results: Predictors of Caregiver Well-being

Aim 1a. Demographic and Young Adult Characteristics on Caregiver Well-Being

The first model examined change in caregiver well-being, without accounting for variance explained by coping strategy (Table 2). There was no significant fixed effect of time on caregiver well-being, indicating stability in well-being on average across the ten years. Random effects for participant and time were significant (both $p < .05$), indicating average well-being scores and change in well-being over time differed across individual caregivers, respectively. There were no significant effects of race, young adult biological sex, IQ, DLS, ADOS CSS, urbanicity, and recruitment site (all $p > .05$). These covariates were dropped from the final well-being model. There were significant main effects of caregiver education (b = 16.612, $p = .001$), and young adult externalizing symptoms (b = -0.683, $p = .002$). Before accounting for caregivers' use of coping strategies, on average, caregivers with less than a college degree and caregivers of individuals with high externalizing symptoms reported lower well-being. There were no significant interaction terms between significant covariates. In other words, the degree of change in caregiver well-being over time was not impacted by demographic factors.

Aim 1b: Effects of Caregiver Coping on Well-Being

Table 4 displays the effects of coping strategies on caregiver reported well-being over time.

Positive coping and well-being. The main effects and interaction between time x positive coping were not significant (b = -1.045, $p = .152$; Table 4). There was, however, a significant three-way externalizing x positive coping x time interaction (b = 0.039, *p* = .001) on caregiver well-being. The effect of positive coping on change in well-being differed based on externalizing behaviors of the caregiver's young adult. Positive coping appeared more beneficial (i.e., related to larger, positive differences in well-being) for caregivers of individuals with higher (versus lower) levels of externalizing symptoms at age 18 (Figure 1).

Active avoidance coping and well-being. Although the main effect of active avoidance coping on well-being was not significant, there was a significant two-way interaction between active avoidance coping x time (b = 2.097, *p* = .004) on caregiver well-being. Caregivers who reported higher active avoidance coping at the beginning of the study demonstrated increasing well-being over time, while caregivers who reported lower active avoidance coping demonstrated consistent well-being over time.

Problem-focused coping and well-being. There was a main effect of problem-focused coping (b = -47.608, *p* = .009) and a significant time x problem-focused coping interaction (b = 2.369, *p* = .028) on caregiver well-being. There was also a significant two-way interaction between young adult externalizing x problem-focused coping (b = 0.788, *p* = .022) and a significant three-way interaction between race x problem-focused coping x time (b = -3.479, *p* = .003). High problem-focused coping was more strongly related to well-being collapsed over time for caregivers of adults with high externalizing symptoms than those with low externalizing symptoms. The effect of problem-focused coping on parent well-being differed by race, such that caregivers of color (predominantly Black in the current study) who engaged in lower problem-focused coping appeared to report increasing well-being over time, whereas caregivers of color who reported high problem-focused coping appeared to report decreasing well-being over time.

This trend was not observed for white caregivers, for whom higher and lower and problem-focused coping predicted relatively steady well-being over time (Figure 2).

Religious coping and well-being. There was a significant main effect of religious coping (b = 4.857, *p* = .046) and a significant religious coping x time interaction on caregiver well-being (b = -0.991, *p* = .001; Table 4). Caregivers who reported low religious coping at the beginning of the study had lower well-being than those who reported high religious coping, but by the end of the study period, low religious copers reported greater well-being than those who used more religious coping.

Denial coping and well-being. There was no main effect of denial coping (b = -10.815, *p* = .126), but there was a significant interaction between time and denial coping on caregiver well-being (b = 2.348, *p* = .001). Caregivers who reported engaging in higher denial coping reported increasing well-being over time. Caregivers who reported low denial coping, on the other hand, reported consistent well-being over time.

Aim 2 Results: Predictors of Caregiver Depression

Aim 2a. Demographic and Young Adult Characteristics on Caregiver Well-Being

In the model of caregiver depression that did not yet include coping variables, there were no significant effects of young adult biological sex, IQ, DLS, ADOS CSS, urbanicity, or recruitment site on caregiver depression (all *p* > .05; Table 3). These covariates were therefore dropped from the final model. There were significant main effects of caregiver education (b= -5.247, *p* < .001), young adult externalizing symptoms (b=0 .269, *p* < .001), and race (b= 3.786, *p* = .026). These main effects were further characterized by significant two-way interactions with time including education x time (b = 0.772, *p* < .001) externalizing x time (b = -0.037, *p* < .001), and race x time (b = 0.137, *p* < .001. On average, caregivers with less than a four-year college degree and caregivers of individuals with relatively high externalizing symptoms reported increasing depression scores over the study period. Black caregivers reported increasing depression scores over the study period, and white caregivers reported decreasing depression scores over the study period.

Aim 2b: Effects of Caregiver Coping on Depression

Table 5 displays all the effects of coping strategies on caregiver reported depression over time.

Positive coping and depression. There was a significant effect of time (b = 1.188, *p* = .002) on caregiver depression, but not of positive coping (b = 0.098, *p* = .935) nor positive coping x time (b= 0.123, *p* = .567). The three-way interaction between externalizing behaviors x positive coping x time (b = -0.014, *p* = .001) on caregiver depressive symptoms was significant (Figure 3). Similar to its effect on caregiver well-being, the effect of positive coping on change in depression over time differed based on the externalizing behaviors of the young adult such that caregivers who had an adult with high externalizing symptoms and who reported engagement in higher positive coping at the beginning of the study predicted relatively steeper declines in depression over time.

Active avoidance coping and depression. Significant main effects of active avoidance coping (b = 6.261, *p* = .009), time (b = 1.254, *p* = .006), and the two-way interaction between active avoidance coping x time (b = -1.241, p < .001) emerged on caregiver depressive symptoms. These were further characterized by significant three-way interactions between study site x time x active avoidance coping (b = 2.467, *p* < .001) and between caregiver education x time x active avoidance coping (b = .356, *p* < .001) on caregiver depressive symptoms. For study site, caregivers in Illinois and Michigan reported relatively steady depression levels when they reported higher active avoidance coping, with slightly declining depression when reporting lower active-avoidance coping; meanwhile, caregivers in North Carolina reported declining depression levels when they reported higher active avoidance coping. For education, while caregivers with less than a college degree tended to report higher depression overall, the reported use of high active avoidance coping predicted higher depression at the beginning of the study period, but declining depression over time (Figure 4).

Problem-focused coping and depression. Although the main effect of problem-focused coping was not significant (b = -0.120, *p* = .916), there was a significant main effect of time (b = 1.070, *p* = .040) and a two-way interaction between problem-focused coping x time, as well as a three-way interaction between caregiver education x problem-focused coping x time (b = .586, *p* = .018) on caregiver depressive symptoms. The effects of problem-focused coping on the trajectory of caregiver depression differed based on levels of the caregiver's education (Figure 5). For those with less than a college degree, higher problem-focused coping predicted declines in depression over time, whereas for those with a college degree or above, declines in caregiver depression were predicted by lower problem-focused coping.

Religious coping and depression. There were no significant effects of time (*p* = .412), religious coping (*p* = .306), or religious coping x time (*p* = .918) on caregiver depression. There were only significant main effects of caregiver education (b = -5.132, *p* = .000) and adult externalizing symptoms (b = .200, *p* = .002) in the final depression and religious coping model.

Denial coping and depression. While there was a significant effect of time (1.422, *p* = .009), there were no significant main effects of denial coping (*p* = .880) or denial coping x time (*p* = .547), on caregiver depressive symptoms. The two-way interaction between adult externalizing x time (b = -.028, *p* = .002) was significant in the final depression and denial coping model.

Discussion

Caregiver well-being affects many aspects of family functioning (Browne et al., 2015; Smith et al., 2012). Despite the many changes and obstacles caregivers of adults with IDDs face as their loved ones enter adulthood, little is known about stability and change in caregivers' well-being during this crucial period. The current study used a strengths-based approach— examining an autonomous avenue of psychological functioning (coping), and positive aspects of psychological health (positive well-being, supplemented by declines in depression) — to address this gap. By examining effects of adaptive *and* maladaptive caregiver coping strategies on well-being and depression, we sought to highlight the resilience of this population and capture the experiences of older caregivers with nuance and dignity.

Aim 1a and 2a: Effects of Sociodemographic and Young Adult Characteristics on Caregiver Well-Being and Depression

When not considering coping strategies, we identified that, compared to caregivers with less than a college degree or caregivers with young adults with high externalizing symptoms, higher caregiver education and lower young adult externalizing symptoms predicted higher well-being and lower depression overall, and decreasing depression over time. Lower caregiver education is often associated with greater economic insecurity (Hill & King, 1995), and such economic stressors have been found to place psychological strain on parents (Gard et al., 2020). The detriments of financial strain may be compounded for caregivers of children with IDD, for whom lower SES can exacerbate parenting stress and structural barriers to meeting their family's needs (e.g. service needs, costs of living, transportation; Pickard & Ingersoll, 2016)**.** Consistent with previous literature, our results also suggest that the effects of externalizing behaviors -- which included physical and verbal aggression and rule-breaking -- may have a more pronounced impact on caregivers' overall well-being than other young adult individual differences (Hastings et al., 2005; Rattaz et al., 2017; Wong et al., 2020). Specifically, IQ, autism symptoms, and daily living skills did not predict caregiver well-being or depression, and there were no significant differences in well-being or depression outcomes between caregivers of adults with IDD and caregivers of adults with autism with or without intellectual disability. These null effects are striking given the range of symptoms and abilities in our sample, and does not replicate earlier studies that have found that caregivers of autistic individuals have higher levels of depression than caregivers of individuals with other types of IDDs (e.g. Abbeduto et al., 2004). However, in line with our findings, other studies have found that caregivers of children with ASD and caregivers of other IDD report comparable experiences of stigma and mental health challenges (Mitter et al., 2019; Scherer et al., 2019). Moreover, adults with autism and adults with other IDD experience similar difficulties attaining normative outcomes, such as employment and living independently (Clarke et al., 2021; Lord et al., 2020). Clinicians may leverage these findings to prioritize targeting young adult externalizing behaviors above other psychological characteristics when working with adults with IDD, particularly when seeking to promote family and caregiver functioning.

Aim 1b and 2b: Effects of Caregiver Coping on Well-Being and Depression

Lower engagement in problem-focused coping among caregivers when their adults were approximately 18 years old predicted both higher well-being and lower depression over the ten-year period. Similarly, higher active avoidance coping at age 18 predicted initially higher but decreasing depression over time, and increasing well-being over time. Religious and denial coping both predicted caregiver well-being (but not depression) over time.

Young adult externalizing behaviors and certain sociodemographic features modified the effects of coping strategies on caregiver well-being and depression. For example, caregivers whose adult children exhibited high externalizing behaviors, greater use of positive coping predicted both increasing caregiver well-being and decreasing depression over time. These findings are discussed further in clinical implications. For another example, caregiver race, caregiver education, and young adult externalizing interacted with the effects of problem-focused coping. For caregivers of color, higher problem-focused coping was associated with slightly higher well-being intercepts at the first timepoint but appeared to predict declining well-being (but not depression) over time, while for caregivers with less than a college degree, high problem-focused coping predicted initially similar but significantly declining depression (but not increasing well-being) compared to caregivers with less than a college degree who reported low problem-focused coping. Individuals with neurodevelopmental disorders and their families lose access to school-based services in the years surrounding the transition to adulthood (McKenzie et al., 2017). This loss of services is associated with declines in daily living skills and slowing improvements in social communication (Clarke et al., 2021; Taylor & Seltzer, 2010). For certain caregivers who frequently engage in problem-focused coping, which includes active efforts to modify or address problems such as through seeking professional support or modifying behaviors, the dwindling availability of supports and lack of adult services may make the first decade of adulthood an especially frustrating time. Additional work in separate samples is needed to replicate these findings and further explore the roles of sociodemographic features.

Counterintuitively, we found both denial and active avoidance coping were related to improved caregiver well-being over time. These coping strategies are typically considered “maladaptive,” and have been found to predict poorer outcomes for caregivers of children with IDD (Benson 2010). While it might be tempting to speculate how denial and active avoidance coping could be adaptive in some ways, it is more likely that this improvement in well-being over the decade-long study period may relate to caregivers using more maladaptive coping strategies around the time their adult was 18 (when coping was measured), which then may have changed, leaving room for improved well-being as the adolescents became adults. In other words, caregivers might have learned to use more adaptive and less maladaptive coping strategies over time. Various authors have concluded that parents learn to cope more effectively over years of practice in responding to the challenges linked to raising a child or adolescent with IDD (Gray, 2002; Smith et al. 2008). While the transition after adolescence presents a new set of challenges and stressors for families, caregivers may initially find themselves resorting to maladaptive coping strategies to deal with the daunting and unknown. Over years of navigating these new adulthood challenges, however, caregivers may learn to cope and adapt just as they learned to cope and adapt to childhood and adolescent challenges. This is speculation, however, as the present study only measured coping at age 18. More research is needed to explore differences in coping strategies over time and their associations with well-being.

Clinical Implications

Intervention literature on caregivers of individuals with autism and other IDDs often focuses on supporting younger caregivers immediately following their child’s diagnosis. These interventions are not designed to support caregiver well-being over many years (Prata et al., 2018). Considering the high rates of mental health concern among caregivers of people with intellectual disabilities and autism (Gogoi et al., 2017; Scherer et al., 2019), there is a clear need to support caregivers' psychological functioning in the years following diagnosis. Given that higher reports of positive coping predicted greater well-being and declining depression for caregivers of adults with high externalizing behaviors in the present study, interventions leveraging aspects of positive coping might be useful for this population. The positive coping construct generally described caregivers' attempts to cope via modes of positive reframing, acceptance, humor, and emotional social support-seeking, with items such as, "I've been trying to see it in a different light, to make it seem more positive." Though more work is needed to understand the relationship between positive coping and well-being among this population of adult caregivers, it is possible that therapies like Acceptance and Commitment Therapy (ACT) and Cognitive Behavioral Therapy (CBT), which emphasize accepting difficult thoughts and emotions or using positive reframing techniques, could be a fruitful approach for caregivers of adults with behaviors that challenge. Indeed, recent work of ACT and CBT has been promising for their helpfulness among caregivers of autistic children (Corti et al., 2018; Onyishi et al., 2023). While we are hopeful that therapeutic strategies can offer ways of adaptively responding to caregiving challenges, it is also critical to highlight that truly addressing the many caregiving stressors in this population starts at a systemic level of government-provided resources that offer adequate supports to address families' needs (Smith et al., 2012).

Limitations

Despite the strengths of this study, including its longitudinal design, representation of young adults across a range of cognitive and autism/IDD symptomatology, and use of multilevel modeling technique, this work is not without limitations. Although theory suggests one's coping strategies are relatively consistent across time (Carver & Scheier, 1994), this study measured caregiver coping strategies at only one time point. Further, a unique and relatively small group of families comprise this study. Caregivers in this sample sought help for their children early in childhood and during the 1990s, an era in which knowledge about autism and IDD was far less widespread than today. This sample's participants may therefore differ meaningfully from caregivers of individuals diagnosed in more recent decades and/or later in development. Finally, though the current sample remains more racially and socioeconomically representative than many other samples in autism research (Steinbrenner et al., 2022), the sample includes almost no Hispanic, Asian, or Native families, and we have experienced more attrition amongst Black families and families with lower caregiver education over the years this cohort has been studied.

Future Directions

Two coping strategies generally considered maladaptive, active avoidance and denial, were associated with increased well-being and/or decreased depression over time; this could suggest that families may learn or adopt more adaptive strategies over time to achieve greater well-being. However, because the current study measured coping strategies only when caregivers' young adults were roughly age 18, it could not examine possible changes in coping strategies over time, and these changes' possible effects on caregiver depression and well-being. Future work should attempt to replicate and understand these associations with continued measurement of coping over time. Future work could also investigate other possible factors, like access to formal services, co-residence of the young adult, and young adult symptom regression or improvements, to explore the mechanisms behind unexpected coping findings, like those for denial and active avoidance coping. Finally, coping strategies present potential targets for tailored interventions. Future intervention studies in caregivers of adults with IDD could promote the use of certain coping strategies tailored to family and child/adult characteristics at different later stages of life.

By focusing on the benefits of coping and positive constructs of well-being and decreased depression, the current analyses leveraged a strengths-based approach to understand outcomes for caregivers of adults with autism and other IDDs. There have been recent calls for an increase in strengths-based investigations in autistic individuals (Szatmari et al., 2021); we strongly believe more strengths-focused studies at the family systems level are needed as well. Many caregivers show lifelong resilience in the face of these chronic challenges. Families often report caring for an individual with IDD is a source of great meaning and joy in addition to stress. Future work should strive to capture these complexities and support caregivers' inherent capacities for resilience.

Conclusion

The life course impacts of a DD or ASD diagnosis are felt not only by diagnosed individuals, but by their caregivers and families. This study characterizes stability and change in the well-being and depression of caregivers of young adults with autism and other IDDs, and sheds light on the interactive effects of coping strategies, family demographic characteristics, and young adult characteristics on caregiver well-being and depression during this unique developmental period. Caregivers with less than a college degree reported lower well-being, highlighting the continued need for support for families with access to fewer resources. Caregivers of adults with greater externalizing behaviors also reported lower well-being, but those who used positive and problem-focused coping appeared to benefit. As caregivers and their young adults with ASD or IDD age and as channels of formal support become increasingly limited, identifying internal resources that support caregiver well-being—like coping strategies—becomes increasingly pivotal.

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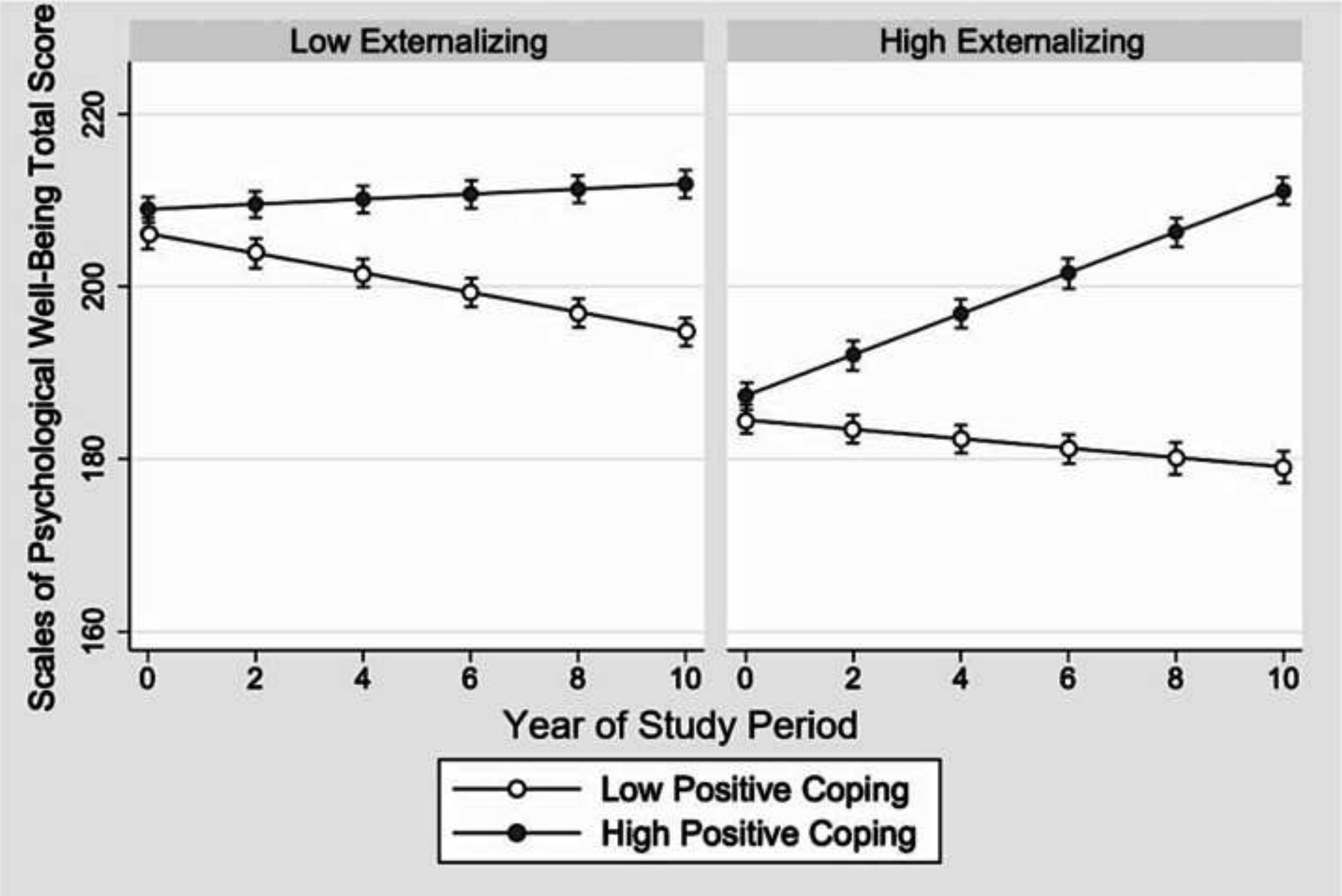
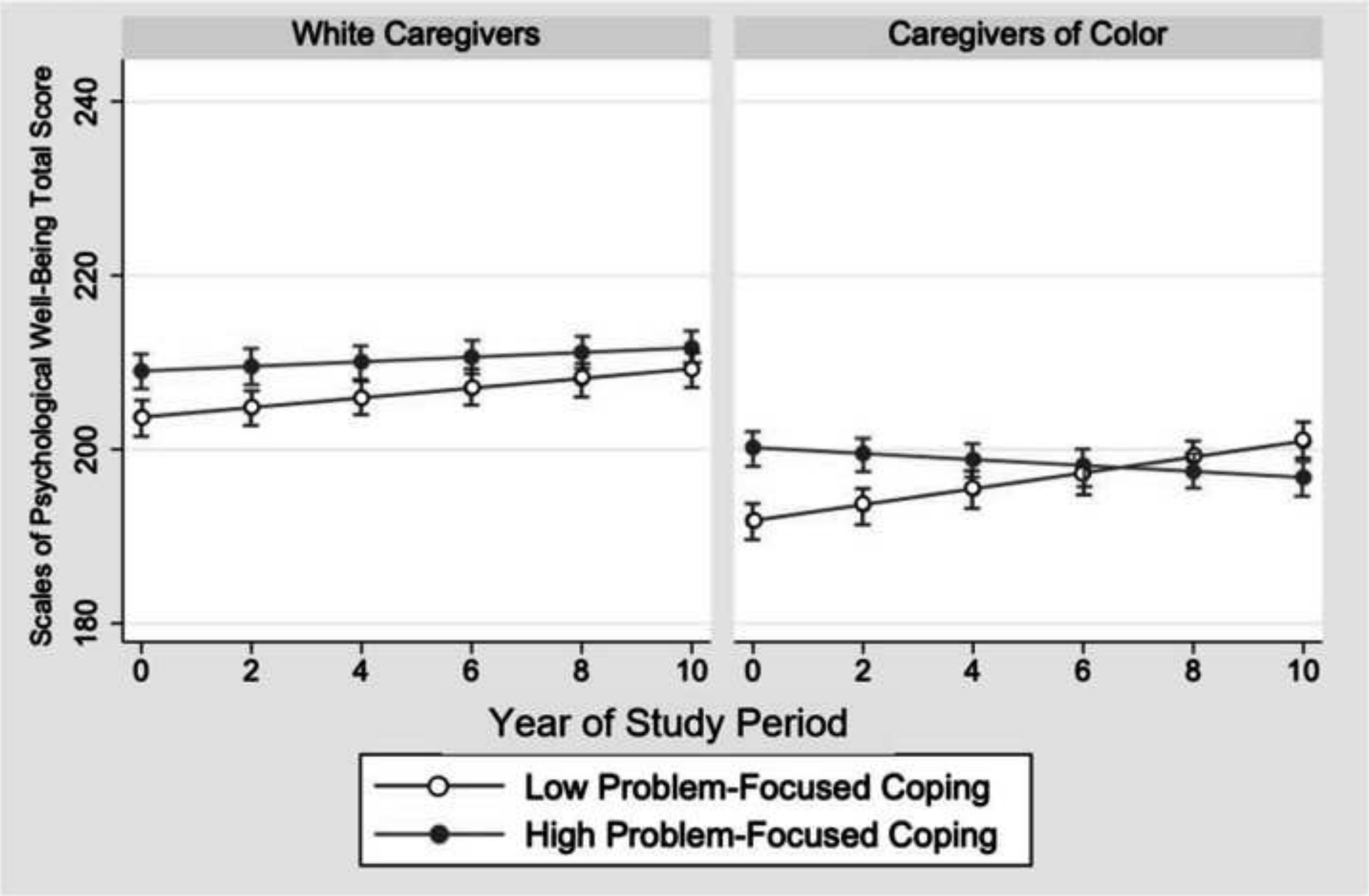
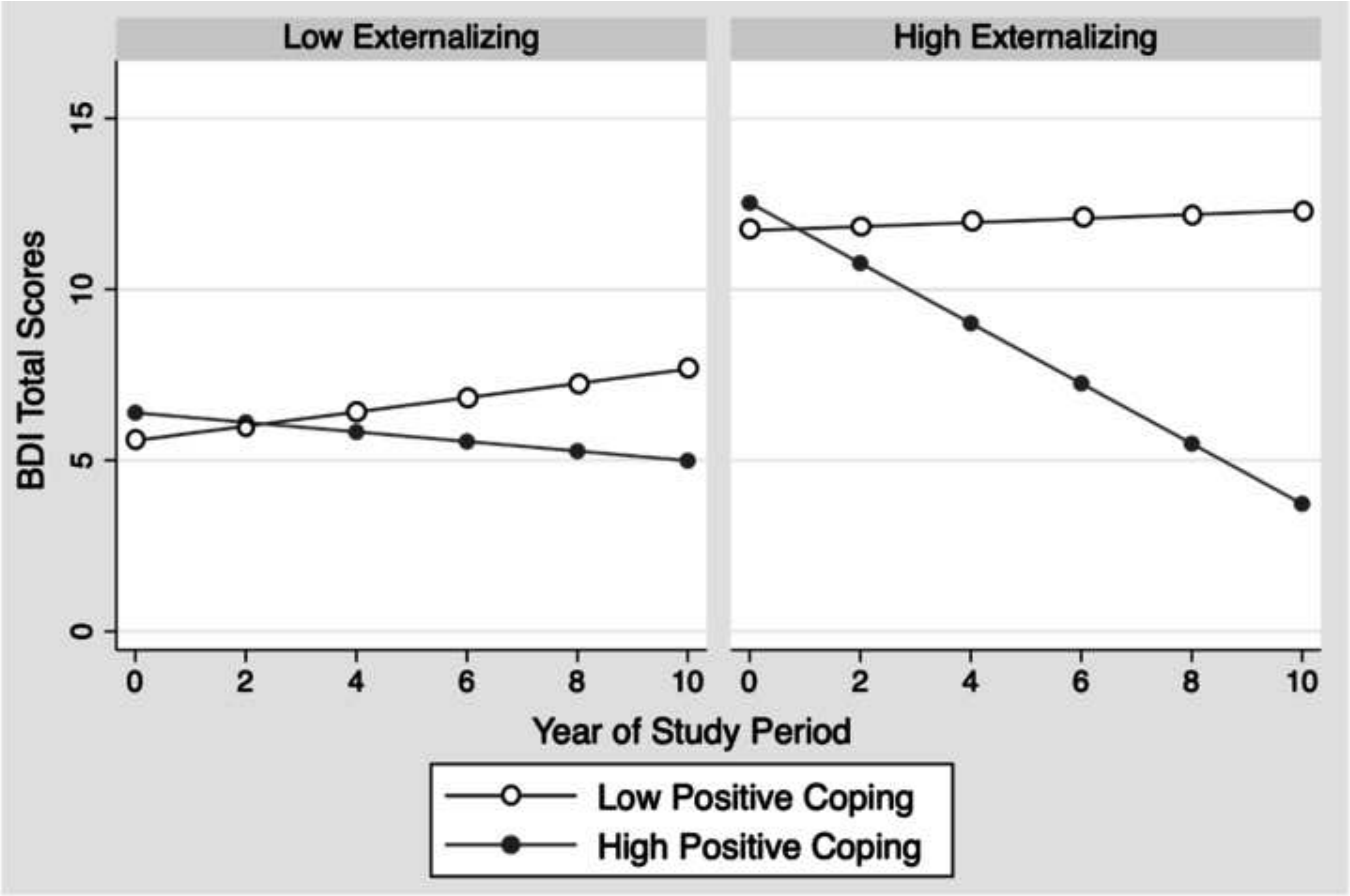
Effect of Positive Coping on Caregiver Well-Being by Young Adult Externalizing



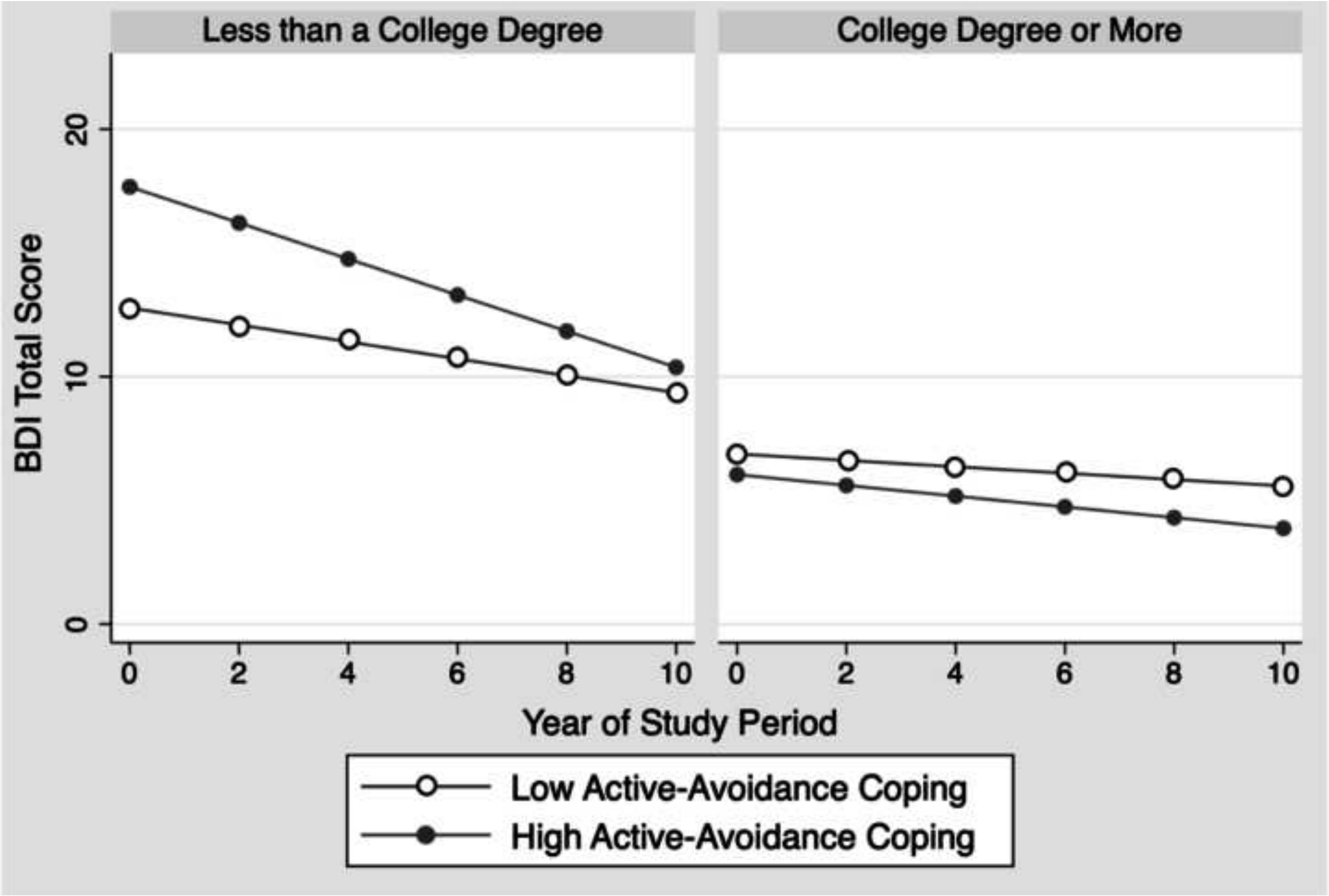
Effect of Problem-Focused Coping on Caregiver Well-Being by Caregiver Race



Effect of Positive Coping on Caregiver Depression by Young Adult Externalizing



Effect of Active Avoidance Coping on Caregiver Depression by Caregiver Education



Effect of Problem-Focused Coping on Caregiver Depression by Caregiver Education

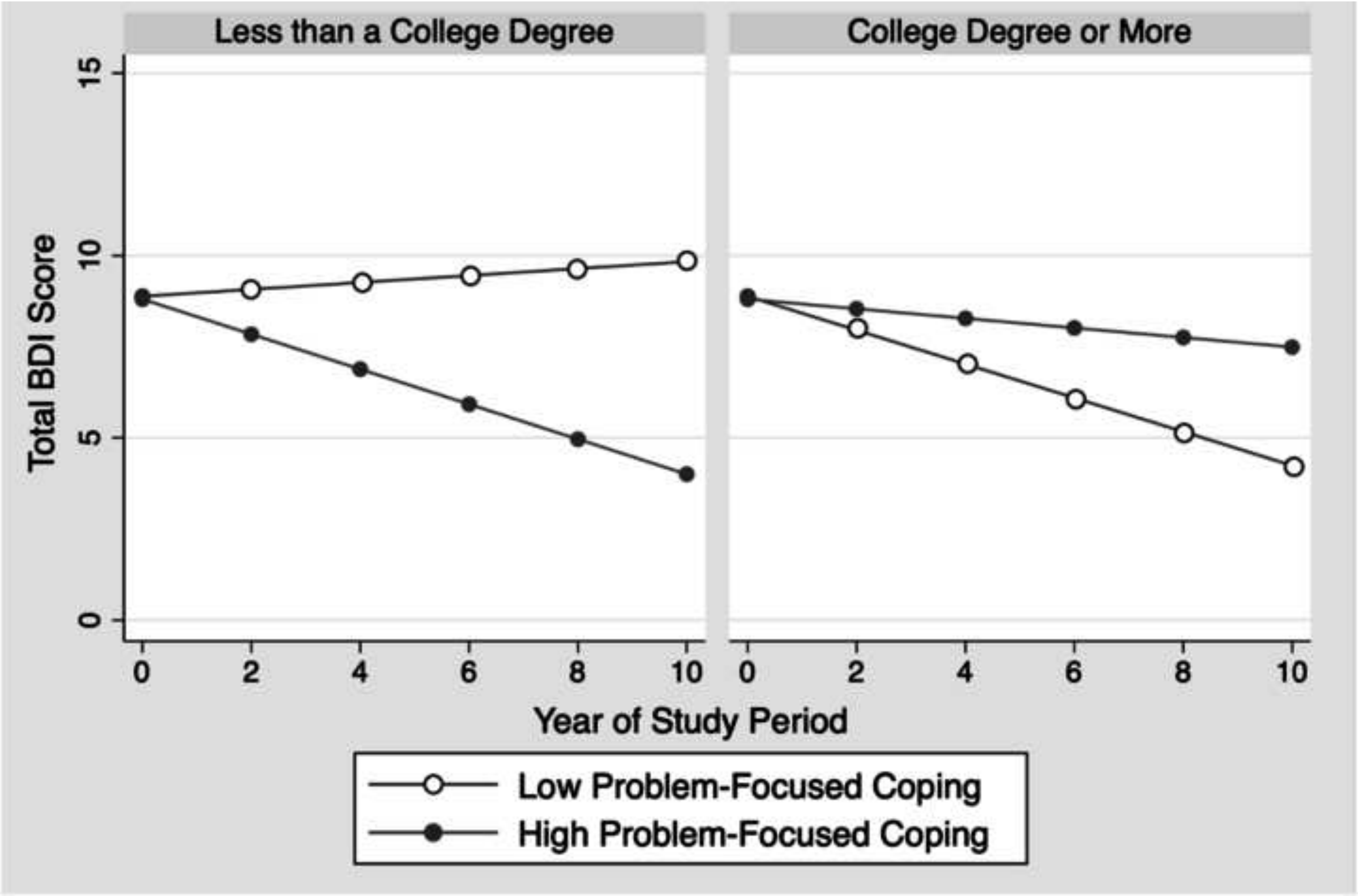


Table 1

Demographic Characteristics of the Current Subsample and Overall Longitudinal Cohort

		Study subsample count	Total cohort count	
Race	Person of color	25	74	$X^2(1) = 15.446$; *p* = < .001
	White	109	179	
Young Adult Biological Sex	Male	106	203	$X^2(1) = .230$; *p* = .631
	Female	28	50	
Caregiver Education	Some college or less	46	114	$X^2(1) = 48.894$; *p* = < .001
	College degree or more	88	139	
Diagnostic Status	ASD	105	196	$X^2(1) = 129$; *p* = .720
	Other DD	29	57	
Urbanicity	Rural	42	88	$X^2(1) = 1.220$; *p* = .269
	Urban	87	158	
		Study subsample mean score	Total cohort mean score	Two-sided *p*
Nonverbal IQ		64.36	63.23	*p* = .807
CBCL Externalizing Score		50.19	48.50	*p* = .651
CSS score		5.14	6.83	*p* < .001
Vineland DLS AE		10.573	10.358	*p* = .838

Table 2

Effects of Demographic and Young Adult Characteristics on Caregiver Well-being

Caregiver Total Well-being (SPWB) Scores				
Main Effects	**Coefficient**	**SE**	**95% CI**	
Caregiver Education	16.612**	4.625	7.545	25.678
Race	--	--	--	--
Urbanicity	--	--	--	--
Young Adult Biological Sex	--	--	--	--
Site	--	--	--	--
Young Adult Externalizing (CBCL)	-0.683**	0.223	-1.121	-0.245
Young Adult Non-Verbal IQ	--	--	--	--
Autism Symptoms (CSS)	--	--	--	--
Daily Living Skills (VABS-2)	--	--	--	--
Time	0.231	0.299	-0.356	0.818
Random Effects	**Coefficient**	**SE**	**95% CI**	
Time	29.509	17.614	9.159	95.071
Individual Caregiver	460.504	73.607	336.648	629.929

Note. Table 2 displays multilevel output of impacts of demographic and young adult person-level characteristics on trajectories of caregiver well-being. Non-significant covariate main effects were identified and omitted before testing interaction terms. Non-significant covariate interaction terms were removed from final well-being models.

**Significant at .01.

Table 3

Effects of Demographic and Young Adult Characteristics on Caregiver Depression

Caregiver Total Depression (BDI-II) Scores				
Main Effects	**Coefficient**	**SE**	**95% CI**	
Caregiver Education	-5.799**	.737	-7.244	-4.354
Race	2.559**	.968	.661	4.456
Urbanicity	--	--	--	--
Young Adult Biological Sex	--	--	--	--
Site	--	--	--	--
Young Adult Externalizing (CBCL)	.267**	.033	.202	.333
Young Adult Non-Verbal IQ	--	--	--	--
Autism Symptoms (CSS)	--	--	--	--
Daily Living Skills (VABS-2)	--	--	--	--
Time	.528	.346	-.151	1.208
Race x time	-.371*	.165	-.694	-.047
Caregiver education x time	.772**	.125	.526	1.017
Adult externalizing x time	-.037**	.005	-.048	-.026
Random Effects	**Coefficient**	**SE**	**95% CI**	
Time	.000	.000	0	0
Individual Caregiver	2.87	1.088	1.370	6.038

Note. Table 3 displays multilevel output of impacts of demographic and young adult person-level characteristics on trajectories of caregiver depression. Non-significant covariate main effects were identified and omitted before testing interaction terms. Non-significant covariate interaction terms were removed from final depression models.

* Significant at .05. **Significant at .01.

Table 4

Effects of Caregiver Coping Strategies on Caregiver Well-being over Time

	Positive Coping				Active Avoidance Coping				Problem-Focused Coping				Religious Coping				Denial Coping			
	Co-efficient	SE	95% CI		Co-efficient	SE	95% CI		Co-efficient	SE	95% CI		Co-efficient	SE	95% CI		Co-efficient	SE	95% CI	
Coping Strategy	7.785	4.083	-0.218	15.789	-12.804	6.990	-26.505	0.896	-47.608**	18.288	-83.453	-11.764	4.857*	2.430	0.938	9.620	-10.815	7.071	-24.675	3.045
Caregiver Education	--	--	--		14.522**	5.022	4.679	24.366	--	--	--		14.519**	4.991	4.736	24.302	14.738**	4.965	5.007	24.470
Race	-11.658	6.082	-23.580	0.262	--	--	--		-64.775**	24.063	-111.938	-17.612	--	--	--		--	--	--	
CBCL Externalizing	-1.233**	0.250	-1.725	-0.742	-0.781**	0.249	-1.271	-0.292	-3.047**	0.930	-4.871	-1.223	-0.774**	0.241	-1.248	-0.301	-0.780**	0.244	-1.260	-0.300
Time	-1.953	1.258	-4.419	0.513	-2.824*	1.127	-5.034	-0.613	-4.659	2.451	-9.463	0.144	2.697**	0.740	1.246	4.148	-2.456**	0.86	-4.142	-0.769
Coping Strategy x Time	-1.045	0.728	-2.473	0.383	2.097**	.735	.656	3.539	2.369*	1.077	0.257	4.481	-0.991**	0.273	-1.526	-0.455	2.348**	0.699	0.978	3.719
Race x Time	--	--	--		--	--	--		7.834**	2.785	2.375	13.293	--	--	--		--	--	--	
Race x Coping Strategy	--	--	--		--	--	--		22.544*	9.514	3.897	41.191	--	--	--		--	--	--	
CBCL Ext. x Coping Strategy	--	--	--		--	--	--		0.788*	0.343	0.115	1.462	--	--	--		--	--	--	
Race x Time x Coping Strategy	--	--	--		--	--	--		-3.479**	1.180	-5.793	-1.165	--	--	--		--	--	--	
CBCL Ext. x Time x Coping Strategy	0.039**	0.011	0.017	0.060	--	--	--		--	--	--		--	--	--		--	--	--	

	Positive Coping				Active Avoidance Coping				Problem-Focused Coping				Religious Coping				Denial Coping			
	Co-efficient	SE	95% CI		Co-efficient	SE	95% CI		Co-efficient	SE	95% CI		Co-efficient	SE	95% CI		Co-efficient	SE	95% CI	
Time	27.493*	17.369	7.970	94.842	35.219*	19.984	11.582	107.096	27.912*	18.102	7.829	99.501	21.430*	16.826	4.599	99.856	21.496*	17.692	4.283	107.879
Individual Caregiver	455.876*	78.190	325.726	638.031	457.654*	79.010	326.275	641.935	427.826*	74.009	304.801	600.505	471.419*	80.112	337.874	657.748	462.274*	78.966	330.747	646.104

Note. For length, only covariates with significant main effects and/or interaction terms in a coping model are reported in Table 4. For all coping models, non-significant main effects were identified and omitted before testing interaction terms; non-significant interaction terms were removed from final coping models.

*Significant at .05. **Significant at .01.

Table 5

Effects of Caregiver Coping Strategies on Caregiver Depression over Time

	Positive Coping				**Active Avoidance Coping**				**Problem-Focused Coping**				**Religious Coping**				**Denial Coping**			
	Co-efficient	SE	95% CI		Co-efficient	SE	95% CI		Co-efficient	SE	95% CI		Co-efficient	SE	95% CI		Co-efficient	SE	95% CI	
Coping Strategy	0.098	1.218	-2.289	2.487	6.261**	2.404	1.548	10.974	-0.120	1.133	-2.340	2.100	-.0738	0.721	-2.152	0.674	0.495	3.286	-5.946	6.938
Caregiver Education	--	--	--		--	--	--		--	--	--		-5.132**	1.423	-7.922	-2.341	--	--	--	
CBCL Externalizing	0.394**	0.074	0.249	0.539	--	--	--		0.252**	0.068	.118	0.385	0.200**	0.065	0.071	0.329	0.367**	0.078	0.212	0.521
Time	1.188**	3.765	0.451	1.926	1.254**	0.457	0.357	2.152	1.070*	0.521	0.047	2.093	-0.198	0.242	-.0674	0.276	1.422**	0.542	0.358	2.486
Coping Strategy x Time	0.123	0.216	-0.299	0.547	-1.241**	0.317	-1.864	-0.618	-0.516*	0.204	-0.916	-0.116	-0.009	0.088	-0.183	0.164	-0.205	0.341	-0.876	0.464
CBCL Ext. x Time	--	--	--		--	--	--		--	--	--		--	--	--		-0.028**	0.009	-0.046	-0.010
Education x Time	--	--	--		--	--	--		-1.488*	0.652	-2.768	-0.209	--	--	--		--	--	--	
Site 2 x Time	--	--	--		-1.600*	7.407	-3.131	-0.220	--	--	--		--	--	--		--	--	--	
Site 3 x Time	--	--	--		-3.499**	1.010	-5.479	-1.519	--	--	--		--	--	--		--	--	--	
Education x Coping Strategy	--	--	--		-5.796**	1.178	-0.106	-3.486	--	--	--		--	--	--		--	--	--	
Education x Time x Coping Strategy	--	--	--		.356**	0.133	0.094	0.619	0.586*	0.247	0.100	1.071	--	--	--		--	--	--	
CBCL Ext. x Time x Coping Strategy	-0.014**	0.003	-0.02	-0.007	--	--	--		--	--	--		--	--	--		--	--	--	
Site 3 x Time x Coping Strategy	--	--	--		2.467**	0.785	1.884	3.852	--	--	--		--	--	--		--	--	--	

	Positive Coping				**Active Avoidance Coping**				**Problem-Focused Coping**				**Religious Coping**				**Denial Coping**			
	Co-efficient	SE	95% CI		Co-efficient	SE	95% CI		Co-efficient	SE	95% CI		Co-efficient	SE	95% CI		Co-efficient	SE	95% CI	
Time	0.000	0.000	0.000	0.000	0.000	0.000	0	.	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0	.
Individual Caregiver	36.22	6.315	25.735	50.975	46.460	8.071	33.053	65.387	38.703	6.871	27.329	54.812	33.811	5.976	23.911	47.809	39.748	6.858	28.342	55.744

Note. For length, only covariates with significant main effects and/or interaction terms in a coping model are reported in Table 5. For all coping models, non-significant main effects were identified and omitted before testing interaction terms; non-significant interaction terms were removed from final coping models.

*Significant at .05. **Significant at .01.