Outcomes among caregivers of toddlers with ASD concerns following implementation of Screen-Refer-Treat, a novel service delivery model for early ASD detection and intervention

Trent DesChamps

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Reading Committee:
Wendy Stone, Chair
Shannon Dorsey
Katherine Foster

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Abstract

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Trent DesChamps

Chair of the Supervisory Committee:
Wendy Stone
Department of Psychology

The American Academy of Pediatrics recommends early ASD screening in primary care settings (Hyman et al., 2020) and evidence demonstrates that specialized early interventions lead to more optimal outcomes among children with ASD (Landa, 2018). However, rates of early ASD screening in the community remain low and many families face barriers to getting an ASD diagnostic evaluation and access to specialized intervention services. As such, caregivers report that the pre-diagnosis period is marked by uncertainty and overwhelming worry (Mulligan, MacCulloch, Good, & Nicholas, 2012), and previous research suggests a link between caregiver wellbeing and the quality of care services for children with ASD (Parker & Killian, 2020). To address these challenges, ongoing implementation efforts are aimed at increasing ASD screening and evidence-based early interventions in the community (Broder Fingert et al., 2019). Aligned with these efforts, a novel service delivery model, Screen-Refer-Treat (SRT; Ibañez et al, 2019), was developed and implmemented in 4 Washington State counties to increase use of the M-CHAT-R/F (Robins et al., 2014) at 18-month well-child primary care visits and expedite delivery of ASD early intervention (i.e., Reciprocal Imitation Training; Ingersoll, 2010) within Part C early intervention (EI) programs for toddlers who screen at-risk for ASD, but who have not yet received a formal ASD diagnostic evaluation. To implement SRT, primary care providers and EI providers received training on SRT components. Two separate cohorts of families were recruited - one before providers received SRT training and one following SRT training - to assess family outcomes before and after SRT was implemented. Families either had a child with ASD concerns (ASD-C), non-ASD developmental concerns (e.g., motor delays, DEV-C), or no developmental concerns (NO-C). The present study compared caregiver quality of life, parenting stress, parenting self-efficacy, and family-centered care between ASD-C, DEV-C, and NO-C caregivers who were either exposed (i.e., post-SRT cohort) or not exposed to SRT (i.e., pre-SRT cohort). Parenting self-efficacy and family-centered care did not differ between the three groups of caregivers or between the pre-SRT and post-SRT cohorts. Consistent with previous work (DesChamps, Ibañez, Edmunds, Dick, & Stone, 2020), results revealed that ASD-C caregivers in both cohorts reported higher levels of parenting stress compared to DEV-C and NO-C caregivers. Within the pre-SRT cohort, ASD-C caregivers reported lower quality of life compared to DEV-C and NO-C caregivers. However, quality of life was higher among ASD-C caregivers in the post-SRT cohort such that there was no longer a difference in quality of life among ASD-C, DEV-C, and NO-C caregivers following SRT implementation. This study provides preliminary evidence that implementation of the SRT service delivery model may have a positive impact on the wellbeing of caregivers of young children with ASD concerns. Results and limitations are further discussed.

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition marked by social communication challenges and restricted and repetitive behaviors or interests (American Psychiatric Association, 2013). The most recent report from the Centers for Disease Control and Prevention (CDC) estimated that approximately 1 in 54 children in the United States has an ASD diagnosis (Maenner et al., 2020). According to the CDC report, prevalence rates are similar among non-Hispanic white, non-Hispanic Black, and Asian/Pacific Islander, but are lower for Hispanic children. ASD is more prevalent among males compared to females (4.3:1). The median age of diagnosis is estimated to be 51 months, which is similar for males and females and across racial and ethnic groups with the exception that Black children with lower cognitive ability are diagnosed later than white children with lower cognitive ability. Additionally, Black children are less likely than white children to have an initial ASD evaluation by 36 months.

Specialized early interventions for ASD lead to better outcomes for young children with ASD as well as those presenting with prodromal ASD symptoms (Landa, 2018; Zwaigenbaum, Bauman, Choueiri, et al., 2015) because early intervention (EI) capitalizes on experience-dependent neuroplasticity during a critical period in child development (Kolb & Gibb, 2011). Given the importance of specialized EI, ongoing efforts aim to increase early detection of infants and toddlers at risk for ASD to facilitate a timely diagnosis and receipt of specialized services (Zwaigenbaum, Bauman, Choueiri, et al., 2015; Zwaigenbaum & Maguire, 2019).

In line with these efforts, the American Academy of Pediatrics (AAP) recommends universal ASD screening and surveillance at 18 and 24 month well-child visits in primary care (Hyman, Levy, & Myers, 2020; Zwaigenbaum et al., 2015). To aid in early detection, validated ASD screening tools have been developed to screen infants and toddlers in primary care settings that can identify children at risk for ASD (Levy et al., 2020). When a child is identified as showing “red flags” for ASD, the AAP guidelines state that the child should receive prompt referrals for both an ASD diagnostic evaluation and general EI services (Hyman et al., 2020).

Children ages 3 and younger who present with signs of developmental disorders or delays are entitled to state-funded EI services at no cost under Part C of the Individuals with Disabilities Education Act (IDEA, 2004). Part C EI programs offer intervention services (e.g. occupational, speech, or physical therapy) that can benefit at-risk children prior to receiving an ASD diagnostic evaluation. Additionally, EI programs are another setting through which ASD screening and surveillance can occur to identify at-risk children and refer them for a diagnostic evaluation (Hyman et al., 2020). Once a formal ASD diagnosis is obtained, children become eligible to receive specialized ASD interventions. Unlike general EI services, specialized ASD interventions such as applied behavioral analysis (ABA) or “Naturalistic Behavioral Developmental Interventions” (NDBIs) are designed to address ASD symptoms directly and are efficacious for improving developmental outcomes for children with ASD (Landa, 2018; Schreibman et al., 2015; Zwaigenbaum et al., 2015)

Despite recommended standards of care, the process described above by which universal ASD screening and surveillance leads to early diagnosis and access to specialized EI services has not been realized in community practice. ASD screening rates in primary care settings continue to be low (Rea, Armstrong-Brine, Ramirez, & Stancin, 2019; Siu, 2016), and screening rates are lower for racial and ethnic minorities (Carbone et al., 2020; Zeleke, Hughes, & Drozda, 2019). Even in the few studies that have reported higher ASD screening rates, routine screening did not translate to recommended referral practices (Carbone et al., 2020; Monteiro, Dempsey, Berry, Voigt, & Goin-Kochel, 2019). For example, a recent study found that the majority of primary care practices that were studied conducted routine ASD screening at 18 and 24 months; however, only 31% of children who screened at-risk for ASD were referred for an ASD diagnostic evaluation (Monteiro et al., 2019).

Additionally, many caregivers become concerned about their child's development between 15 and 19 months of age (Chawarska et al., 2007; Coonrod & Stone, 2004; De Giacomo & Fombonne, 1998; Karp, Ibañez, Warren, & Stone, 2017) and the majority of caregivers begin discussing their concerns with the child's primary care provider (PCP) soon after the child's second birthday (De Giacomo & Fombonne, 1998; Zuckerman, Lindly, & Sinche, 2015). However, caregivers commonly report that PCPs give them reassuring, passive, and sometimes dismissive responses when they raise initial concerns about their child (Boshoff, Gibbs, Phillips, Wiles, & Porter, 2019; Legg & Tickle, 2019). For example, many caregivers of children with ASD recall PCPs telling them that they were being overly worried (Carbone et al., 2010; Crais et al., 2020; Lappé et al., 2018; Locke et al., 2020) and often recommended a "wait and see" approach (Ferguson & Vigil, 2019; Locke et al., 2020; Moodie-Dyer et al., 2014; Singh, 2016; Stahmer et al., 2019; Zuckerman et al., 2014). These types of provider responses significantly increase the odds of a delayed diagnosis (Barnard-Brak et al., 2017; Zuckerman et al., 2015), which partially explain the multi-year gap between initial concerns (i.e., ~15-19 months) and diagnosis (i.e. median = 51 months).

As a result of low screening rates in primary care and a lack of proactive provider responsiveness to caregiver concerns, many children miss out on access to specialized ASD services during a critical period in early development. Although PCPs often refer toddlers who are later diagnosed with ASD to general EI services because of associated developmental concerns such as language or motor delays (Monteiro et al., 2016), many toddlers who are at risk for ASD remain unidentified while in EI because EI providers do not regularly conduct ASD screening (Tomlin, Koch, Raches, Minshawi, & Swiezy, 2013) and often feel unprepared to discuss ASD concerns with families (Stone et al., 2019). Moreover, even when toddlers are identified early, many “age out” (i.e., turn 3 years old) of Part C services before becoming eligible for specialized services due to long wait times for ASD diagnostic services (Barton, Dumont-Mathieu, & Fein, 2012; Crais et al., 2020; Lappe et al., 2018; Locke et al., 2020). Additionally, many EI programs have low capacity for providing specialized ASD interventions (Wise, Little, Holliman, Wise, & Wang, 2010).

In light of many provider- and system- level barriers to an early ASD diagnosis and access to specialized services, caregivers report that the pre-diagnosis period is marked by confusion, uncertainty, and overwhelming worry (Mulligan, MacCulloch, Good, & Nicholas, 2012). However, much of the work on caregiver wellbeing in the context of ASD has focused on caregiver outcomes following an ASD diagnosis. This work demonstrates that ASD caregivers experience higher levels of caregiver stress compared to caregivers of children with other developmental disorders and caregivers of children with typical development (Hayes and Watson); lower psychological, physical, and social quality of life (quality of life) compared to the general population (Vasilopoulou & Nisbet, 2016; Yirmiya & Shaked, 2005); and lower self-reported efficacy in the caregiving role compared to caregivers of children with other disorders (Smart, 2016). Although these outcomes are commonly associated with child factors such as challenging behaviors (Chan, Lam, Law, & Cheung, 2018; Estes et al., 2009; Neece, Green, & Baker, 2012), recent work demonstrates that the quality of care services (e.g., family-centered care) impacts the wellbeing of caregivers of children with ASD (Braddock & Twyman, 2014; Hodgetts, McConnell, Zwaigenbaum, & Nicholas, 2017; Moh & Magiati, 2012; Parker &

Killian, 2020) and efforts to improve care services may reduce caregiver burden (Parker, Diamond, & Del Guercio, 2020).

Although caring for a child with an ASD diagnosis clearly affects the wellbeing of caregivers, the reported challenges families face during the pre-diagnosis period suggest that caregivers start experiencing reduced wellbeing long before diagnosis. To test this, members of our research group examined longitudinal patterns of parenting stress among caregivers of toddlers with early ASD concerns (DesChamps, Ibañez, Edmunds, Dick, & Stone, 2020). Compared to caregivers of toddlers with other developmental concerns (e.g., motor delay) and toddlers with no concerns, ASD-concerned caregivers reported higher levels of parenting stress consistently across a 6-month period, suggesting that ASD-concerned caregivers face unique stressors during the pre-diagnostic period. Additionally, ASD-concerned caregivers also reported lower psychological and social quality of life and lower parenting self-efficacy compared to caregivers in the other two groups. DesChamps and colleagues did not examine ratings of family-centered care received from providers; however, retrospective reports from ASD caregivers suggest that negative interactions with providers and service systems during the pre-diagnostic period are associated with increased stress and less satisfaction with the diagnostic process (Boshoff et al., 2019; Legg & Tickle, 2019).

Given the incongruity between recommended standards of care and community practice, and the negative impact of diagnostic delays on child and caregiver outcomes, burgeoning efforts are focused on implementing innovative models of service delivery to improve access to early screening, diagnosis, and ASD treatment (Broder Fingert et al., 2019). This work is influenced by advances in implementation science aimed at identifying strategies to foster community stakeholder engagement and facilitate adoption of evidence-based practices in clinical settings

(Powell et al., 2015). Central to this work is the importance of collaborating with stakeholders to identify barriers and solutions to implementation (Goodman & Sanders Thompson, 2017). As ASD stakeholders, caregivers of children with ASD, PCPs, and EI providers all agree that a lack of provider preparedness to identify early signs of ASD, use validated screening tools, and make appropriate referrals for diagnostic evaluation and EI services are barriers to recommended ASD screening and referral practices (Crais et al., 2020; Crais et al., 2014; Fenikilé, Ellerbeck, Filippi, & Daley, 2015; Lappe et al., 2018; Locke et al., 2020; Mazurek et al., 2020; Self, Parham, & Rajagopalan, 2015; Tomlin et al., 2013). As such caregivers and providers often cite the need for more training (Fenikilé et al., 2015; Locke et al., 2020; Self et al., 2015), and evidence suggests that provider training is associated with increased confidence in recognizing early ASD signs and higher rates of ASD screening (Self et al., 2015).

An innovative service delivery model that incorporates stakeholder perspectives, community partnerships, and provider trainings is “Screen-Refer-Treat” (SRT, Ibañez et al., 2019). The SRT model was designed to increase universal ASD screening in primary care, improve referral practices, and expedite access to specialized ASD interventions for at-risk children before they receive a formal diagnostic evaluation. To do so, PCP and Part C EI providers within the same community are trained on the components of the SRT model. Specifically, PCPs receive training in universal ASD screening practices that includes the use of an online version of the M-CHAT-R/F (Robins et al., 2014), a validated Stage 1 screening tool. When results from the M-CHAT-R/F indicate ASD risk, PCPs are encouraged to make immediate referrals to participating community EI agencies. Community EI providers receive training in Reciprocal Imitation Training (RIT, Ingersoll, 2010), an inexpensive and easily-administered evidence-based ASD intervention, and the Screening Tool for Autism in Toddlers

(STAT; Stone, Coonrod, Turner, & Pozdol, 2004; Stone, McMahon, & Henderson, 2008), an interactive, validated Stage 2 screening procedure. Such trainings are intended to facilitate Stage 1 ASD screening at 18-month well-child visits in primary care (i.e., “Screen”), immediate referral to EI (i.e., “Refer”), and delivery of ASD intervention in EI for children verified as at-risk (i.e., “Treat”) following a positive Stage 2 screening (Figure 1).

Importantly, whereas current service delivery models require an official medical diagnosis before ASD-specific interventions are accessible, SRT provides at-risk children with access to early ASD-specialized intervention by training Part C EI providers to deliver RIT (Ibañez et al., 2019). Moreover, SRT is focused on building community capacity for screening and specialized ASD services within existing primary care and Part C EI systems that are easily accessible for families. As such, SRT is envisioned as a scalable solution for improving ASD detection and intervention service delivery. Beyond the goal of improving child outcomes, SRT also aims to improve outcomes for caregivers who interact with these systems, particularly since families of toddlers with ASD concerns are burdened with myriad stressors during the pre-diagnostic period.

Present Study

The present study was a preliminary investigation of the potential impact of SRT on caregivers of toddlers with ASD concerns who were exposed to the SRT model through PCP and EI providers who received SRT training (described below). Specifically, the present study examined caregiver quality of life (i.e., psychological, social, physical, and environmental indicators of overall quality of life), parenting stress (i.e., stress specific to the role of caregiving), parenting self-efficacy (i.e., self-perceived efficacy in caring for a child), and family-centered care (e.g., extent of respectful and supportive care) among caregivers of children with ASD concerns who were either exposed or not exposed to SRT. This work is critical for evaluating the effectiveness of the SRT model for improving family-level outcomes during the ASD pre-diagnostic period and informing continued efforts to develop innovative approaches to ASD service delivery.

As described above, caregivers of children with ASD concerns experience high levels of parenting stress, low levels of quality of life, low levels of parenting self-efficacy, and negative health care interactions that are associated with stress and low satisfaction with care. Additionally, recent work suggests that efforts to improve ASD service delivery may have a positive impact on these outcomes. For example, increased quality of ASD-related health care has been shown to reduce negative outcomes among caregivers of children with an ASD diagnosis (Parker & Killian, 2020). Given that SRT implementation into community primary care and Part C EI service systems was designed to increase evidence-based ASD screening and intervention practices that could lead to better outcomes for children and families, it was hypothesized that caregivers of children with ASD concerns whose child received care from an SRT-trained provider (i.e., following SRT implementation) would report more optimal outcomes compared to caregivers who worked with the same providers before those providers received SRT training (i.e., prior to SRT implementation). Specifically, it was hypothesized that caregivers of children with ASD concerns who were exposed to the SRT model via their child's PCP or EI provider would report higher levels of quality of life, lower levels of parenting stress, higher levels of parenting self-efficacy, and higher levels of family-centered care received from their child's provider compared to caregivers of children with ASD concerns who were not exposed to SRT. Additionally, since SRT was specifically designed to improve service delivery for families of children with ASD concerns, it was hypothesized that differences in outcomes among caregivers who were exposed to SRT versus those who were not exposed to SRT would be greater (and more optimal) for caregivers of children with ASD concerns compared to caregivers of children with other developmental concerns and children with no developmental concerns (see Method section for descriptions of each group).

Support for these hypotheses would provide preliminary evidence that the SRT model may be effective for improving family-level outcomes in the community and necessitate future work to examine specific mechanisms through which SRT contributes to more optimal outcomes for caregivers of children with ASD concerns. Additionally, this study contributes to the growing literature investigating associations between ASD service delivery and caregiver satisfaction and wellbeing. As such, this work provides critical information for researchers, policy makers, clinicians, and families as ongoing collaborative efforts among ASD stakeholders seek to translate evidence-based ASD practices into community settings and provide better care for children and families.

Method

Recently, a 5-year pragmatic stepped-wedge trial (Figure 2) was conducted to test the effectiveness of SRT for improving both system-level and family-level outcomes within 4 diverse Washington State counties (Lewis, Skagit, Spokane, and Yakima; Ibañez et al., 2019). Unlike explanatory models that test how an intervention works under optimal conditions, pragmatic trials are designed to evaluate the effectiveness of an intervention under conditions of routine community practice (Patsopoulos, 2011). Thus, participants in the full SRT trial were community PCP and Part C EI providers who received SRT training, as well as families who were receiving services from those participating PCP and EI providers.

Participants

The present study analyzed data from 510 caregivers of children ages 16 to 36 months old who participated in the SRT trial. As part of the SRT trial, two separate cohorts of families, one Pre-SRT (*n* = 314) and one Post-SRT (*n* = 196), were recruited to compare family outcomes before and after SRT implementation. Caregiver-child dyads (i.e. families) were recruited through either the child's PCP or EI provider who was also participating (i.e., providers who received SRT training as part of the pragmatic trial). Families recruited through their child's PCP were eligible for the study if their child was between 16 and 20 months old at the time of enrollment in order to assess family experiences with PCPs during their 18-month well child visit. Families recruited through their child's EI provider were eligible if their child was between 16 and 36 months old at the time of enrollment in order to assess family experiences with EI services. Participating families had a child with either ASD concerns (Pre-SRT: *n* = 63; Post-SRT: *n* = 69), other non-ASD developmental concerns (Pre-SRT: *n* = 69; Post-SRT: *n* = 39), or no developmental concerns (Pre-SRT: *n* = 182; Post-SRT: *n* = 88). See Table 1 for participant characteristics and Figure 3 for a visual description of the nested structure of the SRT pragmatic trial.

Compared to the Pre-SRT cohort, children were older in the Post-SRT cohort at the time of enrollment, $t(504) = -3.23$, $p = .001$. The Post-SRT cohort also had a higher proportion of caregivers who identified as Latinx/Hispanic, X^2 (1, $N = 498$) = 7.08, $p<.01$, and a higher proportion of families recruited from EI providers, X^2 (1, $N = 510$) = 21.51, $p < .001$, compared to the Pre-SRT cohort. The two SRT cohorts did not differ on any other demographic variables (*ps* > .05).

Procedure

All procedures were approved by the University of Washington institutional review board and all participants consented to all study procedures upon enrollment in the study.

Caregivers who were interested in participating in the SRT trial completed a “permission to contact” form and were contacted by trained research staff to determine their eligibility. The research staff conducted a structured interview to identify caregivers’ concerns about their child’s development. Specifically, caregivers were asked if they had explicit concerns about ASD or social development as well as any other concerns such as language, motor, sensory, and behavioral challenges.

Algorithms were developed and used to assign caregiver-child dyads to the appropriate “concerns” group based on the types of concerns caregivers endorsed. Specifically, families were assigned to the ASD Concerns (ASD-C) group if the caregiver endorsed explicit concerns about ASD or reported concerns about social interaction combined with the presence of at least one of the following behaviors: unusual use of language or vocalization (e.g. unusual intonation), language delay, unusual use of toys or objects (e.g. lining up toys), unusual body movements (e.g., hand flapping), and/or hyper- or hypo-sensitivity to sensory experiences. Additionally, if caregivers reported the child had an ASD diagnosis, the family was assigned to ASD-C. Families were assigned to the Non-ASD Developmental Concerns (DEV-C) group if they endorsed concerns related to language, motor, sensory, social, and/or behavioral problems, but did not endorse a combination of concerns that met criteria for the ASD concerns group described above. Finally, parents were assigned to the No Concerns (NO-C) group if they did not endorse any developmental concerns for their child. All families were unaware of the study design and were not informed of group or cohort status.

SRT Implementation

To implement SRT, participating PCPs, Part C EI providers, and clinic support staff received training and technical assistance on SRT components. In-person training workshops were conducted at each practice site (e.g., an EI agency where participating EI providers practiced). Counties were randomly assigned to 1 of 4 staggered implementation periods (i.e., stepped-wedge) when PCP and EI providers within the same county received training in SRT components (described below). Within each county, the PCP and EI trainings were conducted over a 3-month period.

ASD Screening and Referral Training for PCPs. Trainings for PCPs comprised a 2-hour office-based workshop that covered the rationale and processes for early detection of ASD symptoms, conducting universal screening 18 month well-child visits using an online version of the M-CHAT-R/F, and how to discuss positive screens and referrals with caregivers. Tablets and Wifi "hotspots" were provided to each practice for administration of the online M-CHAT-R/F and a second training visit focused on providing office staff with technical assistance for the online M-CHAT-R/F and developing an optimal workflow to facilitate implementation of the M-CHAT-R/F. Additionally, all practices could request further technical assistance from the research team to address any technical issues or barriers to implementation.

ASD Screening and ASD Intervention Training for EI Providers. EI providers received training through 2 full-day workshops that involved didactics and "hands on" practice. During one workshop, EI providers were taught to administer the STAT screening and a caregiver interview to assess ASD risk. Information for discussing ASD with caregivers was also provided. During the other workshop, EI providers received training on implementing RIT for toddlers for whom they had ASD concerns and also on coaching parents to use RIT with their child. EI programs could also request additional support from the research team including ongoing performance feedback on STAT and RIT administration or any concerns with implementation.

Family Outcome Measures

Caregivers in both the Pre-SRT and Post-SRT cohorts were sent the same battery of questionnaires every three months (i.e. repeated measures), starting at the time of enrollment and ending once their child reached 36 months of age. Questionnaires were completed online using a REDCap interface (Harris et al., 2009), and were also available in paper versions upon request. All questionnaires were available in both English and Spanish. The present study analyzed questionnaire data that assessed caregiver quality of life, parenting stress, parenting self-efficacy, and family-centered care received from the child's provider.

World Health Organization Quality of Life Assessment-BREF. The World Health Organization Quality of Life Assessment-BREF (WHOQOL-BREF; WHOQOL Group, 1998) is a widely used 26-item survey that assesses self-reported quality of life across four domains: psychological, physical, social, and environmental. All items are rated on a 1 to 5 scale. The WHOQOL-BREF of life has been validated across different populations, including parents of children with ASD (Dardas & Ahmad, 2014) and demonstrates high discriminant and content validity as well as adequate internal consistency (α range: .66 - .80; WHOQOL Group., 1998). Subscales were summed and total scores (Range: 26 - 130) were used in primary analyses. Higher scores indicate greater quality of life.

Parenting Stress Index-Short Form. The Parenting Stress Index-Short Form (PSI-SF; Abidin, 1995), a widely used measure of caregiving stress, is a 36-item self-report measure that assesses stress arising from characteristics of the parent, child, and parent-child relationship. All items are rated on a 1 (Strongly Agree) to 5 (Strongly Disagree) scale. The PSI-SF comprises 3 subscales: parent distress, difficult child, and parent-child dysfunctional interaction. While the PSI-SF has been widely used to assess parenting stress in the context of ASD (Hayes & Watson, 2013) and has strong psychometric properties (Abidin, 2012), some items from individual subscales may not clearly discriminate parents across a range of stress severity (Zaidman-Zait et al., 2010) and some studies support a two factor structure instead of the original three factor structure (Haskett, Ahern, Ward, & Allaire, 2006). Therefore, the present study analyzed PSI-SF total stress scores (Range: 36 - 180). Higher scores indicate greater parenting stress.

Parenting Efficacy Scale. The Parenting Efficacy Scale (PES; Teti & Gelfand, 1991) is a 10-item questionnaire that assesses self-perceived parenting efficacy across various domains of parenting a young child (e.g., soothing the child when the child is upset, getting the child to pay attention to the parent, knowing what the child enjoys). All items are rated on a 1 (Not Good At All) to 4 (Very Good) scale. The PES has strong internal consistency ($\alpha = .86$), good internal and concurrent validity (Teti & Gelfand, 1991), and has been used previously to assess self-reported parenting efficacy among caregivers of children with ASD (Kuhn & Carter, 2006). Total scores (Range: 10 – 40) were used in primary analyses. Higher scores indicate greater parenting self-efficacy.

Measure of Processes of Care. The Measures of Processes of Care (MPOC-20; King, King, & Rosenbaum, 2004) is a 20-item self-report tool assessing the extent to which families experience 5 aspects of family-centered care: enabling and partnership, coordinated and comprehensive care, respectful and supportive care, providing general Information, and providing specific information. This measure has been used extensively with families of children with special healthcare needs, including ASD (Carbone et al., 2013; Hodgetts et al., 2013), and has strong internal consistency (α range: .83 - .90) and construct validity (King et al., 2004). Items describing specific provider behaviors are rated on a 7-point Likert scale ranging from “Never” to “To a Very Great Extent,” to indicate the degree to which families experienced different aspects of family-centered care during the previous 3-month period. Families completed the MPOC-20 to rate family-centered care for either the child’s PCP or EI provider, depending on the provider who recruited the family to participate in the study. Subscales were summed and total scores (Range: 20 - 140) were used in primary analyses. Higher scores indicate greater family-centered care.

Parent Interview for Autism-Clinical Version. The Parent Interview for Autism–Clinical Version (PIA-CV; Stone et al., 2003) is a parent-report questionnaire developed to assess ASD symptom severity in young children. It comprises 11 behavioral domains, and has been used previously with children under 24 months (Carter et al., 2011). Domain scores on the PIA-CV have demonstrated differences between diagnostic groups, sensitivity to change over time, and intervention effects (Carter et al., 2011; Ibanez et al., 2018; Stone et al., 2003). Four domains of social communication behavior were collected for the SRT trial: social relating, imitation, language understanding, and nonverbal communication. These 4 domains show high internal consistency (α range: .73 - .88; Stone et al., 2003) and make up total of 41 items rated on a 1 to 5 scale. Subscales were summed and timepoint 1 totals scores (Range: 41 - 205) were entered into primary analyses to adjust for variation in child social communication.

Demographics Questionnaire. Caregivers completed a brief questionnaire to collect relevant family demographic variables such as age, race, ethnicity, caregiver level of education, and household income. Demographic variables were entered as covariates in all primary analyses to adjust for variation in those variables.

Analytic Approach

Missing Data

For all outcome measures, a small amount of item-level missingness within outcome questionnaires (< 5% across repeated measures of all outcomes) appeared to be missing completely at random and was addressed using mean imputation. To avoid listwise deletion of cases that were missing data for one or more predictor (which would reduce power) and ensure that all predictor variables were represented by equal sample sizes within all models, missing predictor data were imputed using a random forests (Breiman, 2001) procedure. Specifically, a random forests algorithm within the *missRanger* R package (Mayer, 2019) was used. Random forests imputation has an advantage over other imputation methods (e.g., multiple imputation) for handling mixed data types (e.g. continuous and categorical) such as those used in present study. For the present study, ten trees were used to impute missing data and imputations from random forest were combined with predictive mean matching, which generates realistic values within the data (e.g., the procedure provides values such as 0 or 1 for categorical variables).

Primary Analyses

A series of multi-level mixed models with random effects at the caregiver and county levels were used to estimate the difference from Pre-SRT to Post-SRT for all caregiver outcomes. Specifically, all models estimated the ‘time-averaged difference’ such that all Pre-SRT timepoints were coded as 0 and all Post-SRT timepoints were coded as 1. Within repeated measure designs, the time-average difference is as a powerful way to test for an overall intervention effect (Liu & Wu, 2005), and in the present study this approach was taken to test the hypothesis that caregiver outcomes in the Post-SRT cohort were more optimal compared to those in the Pre-SRT cohort. To test for group differences, the ASD-C, DEV-C, and NO-C groups were dummy coded such that the ASD-C group was the reference group (i.e., ASD-C = 0). To test the specific hypothesis that SRT was associated with more optimal outcomes for ASD-C caregivers in particular, 2-way SRT(Pre, Post) x Group(ASD-C, DEV-C, NO-C) interactions were entered into all primary outcome models. Post hoc analyses were used to confirm and further describe significant interactions. Specifically, for any significant interaction, subgroup analyses for each group were conducted to examine any differences between cohorts for each group. Additionally, analyses were conducted to examine group differences within each cohort.

All caregiver outcomes were analyzed separately. Additionally, family-centered care provided by PCPs and EI providers were modelled independently since families were exposed to either a PCP or EI provider who was participating in the SRT trial, depending on which type provider recruited the family to participate in the study. In other words, the model for PCP family-centered care only included data from caregivers who were recruited through their child's PCP. Likewise, the model for EI provider family-centered care only included data from those caregivers who were recruited through their child's EI provider.

To adjust for variation in other variables that could affect caregiver outcomes, including demographic variables that differed between the SRT cohorts, all models included the following covariates: caregiver sex, caregiver age, caregiver race and ethnicity, caregiver educational level, household income, presence of another child in the family with an ASD diagnosis, child sex, child age, child social communication functioning, and recruitment source. Categorical predictors were dichotomized as follows: Caregiver and child sex, male = 0, female = 1; caregiver race, white = 0, BIPOC = 1; caregiver ethnicity, non-Latinx/non-Hispanic = 0, Latinx/Hispanic = 1; caregiver educational level, > 4-year college degree = 0, ≤ 4-year college degree = 1; household income, > $20,000 = 0, ≤ $20,000 = 1; presence of another child in the family with ASD (i.e., the target child in the study was a high risk younger sibling), not high risk

= 0, high risk = 1; recruitment source, PCP = 0, EI = 1. Continuous predictors (i.e., caregiver and child age, child social communication) were centered at the grand mean of each predictor.

Exploratory Analyses

Since the cross-sectional design of the present study does not allow for causal inferences or an analytic approach for examining mechanisms of change, exploratory analyses were used to inform future work aimed at examining potential mechanisms through which SRT might impact ASD-C caregiver outcomes. Thus, if an outcome that was comprised of subscales significantly differed between the Pre-SRT and Post-SRT cohorts for the ASD-C group, subgroup analyses modeled the difference between Pre-SRT and Post-SRT on each subscale of the outcome for the ASD-C group. These analyses were intended to examine how each domain of the outcome differed between ASD-C caregivers in the Pre-SRT cohort and ASD-C caregivers in the Post-SRT cohort, which could inform hypotheses for future work.

Additionally, the primary analyses did not examine any associations between caregiver outcomes since the aim of the present study was to compare each outcome before and after SRT implementation. However, previous work demonstrates relationships between caregiver quality of life, parenting stress, parenting self-efficacy, and family-centered care, as well as associations between child social communication and measures of caregiver wellbeing (e.g., DesChamps et al., 2020; Parker & Killian, 2020). Therefore, to inform hypotheses for future work, Pearson correlations were conducted to describe associations between these variables in the present sample.

Results

Primary Analyses

Full model results for caregiver quality of life, parenting stress, parenting self-efficacy, EI provider family-centered care, and PCP family-centered care are displayed in Table 2. Below, fixed effects of SRT, concerns group, and the interaction between these two factors (i.e., effects of interest) are reported. Covariate effects were not interpreted since an individual effect of a covariate only provides an estimate of that covariate when all other parameters in the model are fixed to zero (i.e., the estimated effect for participants belonging to the reference group for all other variables) and is not an estimate of a general effect across the entire sample. However, as shown in Table 2, all covariates were retained within final models regardless of their level of significance in order to describe and interpret effects of interest after adjusting for variation in all covariates. All reported coefficients are unstandardized beta values to allow for scale-based interpretation of the results.

Caregiver Quality of Life

Caregiver quality of life was higher within the Post-SRT cohort compared to the Pre-SRT cohort ($b = 7.11$, $SE = 2.26$, $p = .002$). Fixed effects of concerns group (ASD-C vs DEV-C, ASD-C vs NO-C) indicated that the ASD-C group reported lower quality of life compared to both the DEV-C group ($b = 4.79$, $SE = 2.39$, $p = .05$) and the NO-C group ($b = 7.58$, $SE = 2.50$, $p = .003$). As illustrated in Figure 4, a significant SRT(Pre, Post) by group (ASD-C, NO-C) interaction indicated that the effect of SRT on caregiver quality of life differed between the ASD-C and NO-C groups such that the difference (i.e. increase) in quality of life between the Pre-SRT cohort and Post-SRT cohort was greater for the ASD-C group compared to the NO-C group ($b = -5.75$, $SE = 2.76$, $p = .037$). The same comparison between the ASD-C and DEV-C group was not significant ($b = -54.92$, $SE = 3.32$, $p = .13$).

To confirm the significant SRT(Pre, Post) by group (ASD-C, NO-C) interaction reported above, *post hoc* analyses were used to model the effect of SRT for each group separately. As described in Table 3, these analyses revealed that the ASD-C group in the Post-SRT cohort reported significantly higher quality of life compared to the Pre-SRT cohort ($b = 4.69$, $SE = 2.00$, $p = .02$). However, the levels of reported caregiver quality of life did not differ between cohorts for both the DEV-C group ($b = 2.80$, $SE = 2.62$, $p = .29$) and the NO-C group ($b = 0.61$, $SE = 1.32$, $p = .67$). Additional analyses were then used to examine group differences within each cohort separately (see Table 4). Results from theses analyses revealed that ASD-C caregivers reported lower quality of life compared NO-C caregivers in the Pre-SRT ($b = 6.52$, $SE = 2.82$, $p = .02$), but quality of life did not differ between ASD-C and NO-C caregivers in the Post-SRT cohort ($p > .05$). There were no group differences between ASD-C and DEV-C caregivers in either SRT cohort ($ps > .05$).

Parenting Stress

The ASD-C group reported significantly higher parenting stress compared to both the DEV-C group ($b = -12.83$, $SE = 3.77$, $p < .001$) and the NO-C group ($b = -13.06$, $SE = 3.96$, $p = .001$). There was not a significant SRT by concerns group interaction for parenting stress.

Parenting Self-Efficacy

No significant differences between SRT cohorts or between concerns groups were observed for parenting self-efficacy ($ps > .05$). However, parenting-self efficacy between the ASD-C and NO-C groups approached significance ($b = 1.21$, $SE = .63$, $p = .054$) suggesting ASD-C caregivers reported relatively lower parenting self-efficacy compared to NO-C caregivers.

Family-Centered Care

EI Provider Family-centered Care. No significant effects of SRT or concerns group were observed for EI family-centered care (*ps* > .05).

PCP Provider Family-centered Care. No significant effects of SRT or concerns group were observed for PCP family-centered care (*ps* > .05).

Exploratory Analyses

Exploratory analyses were proposed *a priori* to explore any observed effects of SRT for the ASD-C group in particular. Since the primary results above indicated that quality of life for ASD-C caregivers was higher in the Post-SRT cohort compared to the Pre-SRT cohort, exploratory analyses were focused on quality of life within the ASD-C group only.

To explore differences between cohorts for the individual domains of quality of life, the four domains of quality of life (psychological, social, physical, and environmental) were modeled separately for the ASD-C group. As described in Table 5 and illustrated in Figure 6, results revealed that the psychological (b = 1.90, SE = 0.84, p = .024), social (b = 1.05, SE = .053, p = .046) and physical (b = 1.69, SE = 0.74, p = .023) domains were significantly higher in the Post-SRT cohort compared to the Pre-SRT cohort. There was not an observed difference between cohorts for the environmental domain of quality of life (b = 1.46, SE = 1.04, p = 0.16).

Since the primary analyses did not model possible associations between caregiver outcomes, Pearson correlations were used to determine the strength of association between quality of life and other outcomes. Quality of life was correlated with parenting stress (r = -.67, p < .001), parenting self-efficacy (r = .53, p < .001), EI family-centered care (r = .27, p = .001), and PCP family-centered care (r = .13, p= .003). Additionally, given known associations between caregiver wellbeing and child social communication behaviors, associations between caregiver outcomes and child social communication were examined and found to be significant for quality of life ($r = .34, p < .001$), parenting stress ($r = -.58, p < .001$), and parenting self-efficacy ($r = .65, p < .001$).

Discussion

This study aimed to investigate the effects of a community implementation of the SRT service delivery model on outcomes among caregivers of young children with ASD concerns. Below, results are discussed in detail with a focus on developing hypotheses for future studies aimed at investigating possible mechanisms through which SRT could lead to better outcomes for ASD-C caregivers. Although many limitations of the present study will also be discussed, this study provides critical information for ongoing efforts to improve ASD service delivery for families of young children presenting with ASD concerns in early development.

Caregiver Quality of Life

ASD-C caregivers reported lower quality of life compared to DEV-C and NO-C caregivers, which is consistent with previous work (DesChamps et al., 2020). However, caregiver quality of life was higher in the Post-SRT cohort compared to the Pre-SRT cohort, and a significant SRT(Pre, Post) by Group(ASD-C, NO-C) interaction indicated that this difference was greater for the ASD-C group compared to the NO-C group. This interaction was further confirmed by subgroup analyses that modeled the effect of SRT on each group separately; specifically, the ASD-C group in the Post-SRT cohort reported higher quality of life than the ASD-C group in the Pre-SRT cohort, but there was not a difference in levels of caregiver quality of life between cohorts for the DEV-C and NO-C groups. Importantly, additional analyses revealed no group differences in the Post-SRT cohort suggesting that quality of life among ASD-C caregivers who were exposed to SRT was similar to that of both DEV-C and NO-C caregivers.

Although the finding that quality of life among ASD-C caregivers was higher in the Post-SRT cohort than the Pre-SRT cohort must be interpreted in light of the cross-sectional design of the study (see limitations section below), it provides preliminary evidence that exposure to the SRT service delivery model may have a positive effect on certain aspects of ASD-C caregiver wellbeing. As such, additional work is needed to investigate mechanisms through which SRT might improve quality of life for ASD-C caregivers. Such an investigation was beyond the proposed aims of the present study, and would require an appropriate study design and analytical approach for making causal inferences. For example, one approach would be to conduct a longitudinal mediation analysis within the Post-SRT cohort to test the hypothesis that individual differences in provider use of SRT practices predicts caregiver quality of life (or specific dimensions of quality of life), and test mediators (and moderators) of that effect. While such a study was beyond the scope of the present work, exploratory analyses were conducted to generate hypotheses for future studies aimed at identifying pathways through which SRT could positively impact ASD-C caregiver quality of life.

Quality of life is a multidimensional construct that cuts across the psychological, social, physical, and environmental dimensions of a person's life (WHOQOL Group, 1998). As such, if SRT did directly or indirectly improve ASD-C caregiver quality of life, these effects could have been stronger for some dimensions and weaker or nonexistent for other dimensions. To explore this further, subgroup analyses within the ASD-C group estimated the effect of SRT on the four dimensions of quality of life. Results revealed that SRT was associated with significantly higher levels of psychological, social, and physical quality of life. These dimensions are operationally defined by items on the WHOQOL-BREF that assess the extent to which an individual subjectively experiences certain indicators of each dimension. The psychological subscale assesses the extent to which an individual experiences negative emotions such as depression or anxiety, the degree to which the individual feels that their life is meaningful, and level of self-esteem. The social subscale measures an individual's subjective ratings of satisfaction with personal relationships and social support. The physical subscale is an index of self-perceived physical health and the individual's ability to physically engage with daily activities (e.g., work). There was no observed difference between the Pre-SRT and Post-SRT cohorts for the environmental quality of life subscale, which is comprised of items assessing contextual factors such as personal safety, financial security, and satisfaction with living accommodations.

In terms of what may have predicted differences in the psychological, social, and physical subscales following SRT, a robust literature demonstrates the deleterious effects of parenting stress on the psychological, social, and physical wellbeing of caregivers of children with an ASD diagnosis (Dardas & Ahmad, 2014; Giallo, Wood, Jellett, & Porter, 2013; Hartley et al., 2010; Hayes & Watson, 2013; Khanna et al., 2011; Phetrasuwan & Shandor Miles, 2009; Vasilopoulou & Nisbet, 2016). Additionally, there is growing evidence that negative experiences with service providers predict lower levels of psychological and physical health among ASD caregivers (Hodgetts et al., 2017; Parker & Killian, 2020), and that certain aspects of family-centered care (e.g., shared decision making between caregiver and provider) mediate the impact of challenging ASD behaviors on caregiver psychological and physical wellbeing (Parker and Killian 2020). Although the current study did not detect significant differences in parenting stress or family-centered care between SRT cohorts, these previous findings suggest that SRT could have affected specific dimensions of quality of life through subtle decreases in parenting stress and/or increases in family-centered care. In the present study, all outcomes were modeled separately in accordance with the proposed aim of investigating the effect of the SRT model on each caregiver outcome. Thus, outcomes were not examined as predictors of one another. However, exploratory analyses revealed correlations between ASD-C caregiver quality of life and parenting stress, parenting self-efficacy, and family-centered care. Therefore, future work should investigate the possibility that individual differences in other outcomes among caregivers who were exposed to SRT may have contributed to higher quality of life among ASD-C caregivers. This hypothesis is further explored as the results from other outcomes are discussed below.

Future work is also needed to determine whether specific SRT components (and the extent to which SRT components were adopted and used by providers) are associated with differences in quality of life (and specific dimensions of quality of life). The current study examined the effects of the unified SRT delivery model (i.e., PCP and Part C EI provider trainings). However, changes to specific provider practices following the SRT provider trainings could have affected specific dimensions of quality of life, which in turn could explain (at least in part) higher quality of life ratings among ASD-C caregivers following SRT implementation. For example, EI providers were trained to deliver RIT to children on their caseloads presenting with ASD concerns via direct administration of RIT to the child and teaching caregivers to implement RIT with their child as well. RIT is an evidence-based intervention that is efficacious for improving social communication among young children with ASD (Ingersoll, 2010). Results from the present study revealed that greater child social communication was associated with higher caregiver quality of life. Thus, the delivery of RIT may have increased child social communication (since it is efficacious for doing so), which in turn could have improved quality of life for ASD-C caregivers of children who received RIT. Future work should explore Part C EI provider use of RIT, and fidelity of RIT delivery, as possible mechanisms that contribute to higher caregiver quality of life, perhaps indirectly via increased child social communication. Moreover, this line of work would align with previous research stressing the importance of assessing the effects of ASD interventions on caregiver quality of life (Kuhlthau et al., 2014).

Additionally, it is possible that increased use of the M-CHAT-R/F in primary care and/or the STAT in EI settings (i.e., increased use of evidence-based, standard-of-care ASD screening practices) benefitted caregivers following SRT implementation. A robust literature on ASD-C caregiver experiences with providers highlights that caregivers are negatively impacted by a lack of appropriate ASD screening and referral practices used by providers (Crais et al., 2020; Locke et al., 2020; Stahmer et al., 2019), and that there is an association between ASD service needs of children and caregiver wellbeing (Bourke-Taylor, Pallant, Law, & Howie, 2012; Lopez, Reed, & Magaña, 2019; Vasilopoulou & Nisbet, 2016). For example, Bourke-Taylor et al. found that more unmet service needs among children with ASD predicted a decrease in maternal mental health (Bourke-Taylor et al., 2012). Moreover, caregivers commonly report that they received passive and/or dismissive provider responses when they first raised ASD concerns about their child (e.g., Zuckerman, Lindly, & Sinche, 2015), and they attribute these responses to a lack of provider knowledge about ASD (Crais et al., 2020; Ferguson & Vigil, 2019; Lappé et al., 2018; Locke et al., 2020; Pearson & Meadan, 2018; Sakai et al., 2019; Stahmer et al., 2019). In addition to being invalidating, these passive and/or dismissive provider responses directly contribute to diagnostic delays (Martinez et al., 2018; Zuckerman, Lindly, & Sinche, 2015) as well as frustration, anxiety, and stress for caregivers (Crais et al., 2020; Lappé et al., 2018; Locke et al., 2020; Stahmer et al., 2019). Consistent with these findings, both PCPs (Fenikilé et al., 2015; Morris, Greenblatt, & Saini, 2019) and EI providers (Stone et al., 2019) report that they do not feel equipped and/or comfortable talking about ASD with families. In addition to increasing the use of ASD screening tools and ASD-specific early intervention for children presenting with ASD concerns, the SRT provider trainings included didactics on ASD, how to recognized early signs of ASD, and ways to discuss ASD with families. Future work is needed to determine if implementation of specific screening tools and/or didactics aimed at increasing provider knowledge about ASD benefits ASD-C caregiver quality of life.

Parenting Stress

Caregivers of children with ASD concerns reported higher levels of parenting stress compared to DEV-C and NO-C caregivers. This replicates previous work by our research group that compared trajectories of parenting stress between ASD-C, DEV-C, and NO-C caregivers in the Pre-SRT cohort (DesChamps et al., 2020). Moreover, the current study used a larger sample and controlled for more covariates than our previous work, which provides further evidence that caring for a child with ASD concerns is accompanied by high levels of parenting stress. Although SRT was not designed to intervene on parenting stress, previous work suggests that negative experiences with service providers contribute to stress among ASD caregivers (Hodgetts et al., 2017; Parker & Killian, 2020) and it was reasonable to hypothesize that SRT implementation could have been associated with lower levels of parenting stress (e.g. via improved service delivery of specialized ASD services). However, changes in parenting stress were not observed.

From a *post hoc* perspective, it might seem curious that caregiver quality of life was higher for ASD-C caregivers in the Post-SRT group compared to ASD-C caregivers in the Pre-SRT cohort, but parenting stress did not differ between cohorts. Indeed, parenting stress is a well-known correlate of caregiver quality of life (Hayes & Watson, 2013) and exploratory analyses revealed that the two outcomes were strongly correlated within the sample of the present study. However, relative to the multidimensionality of quality of life (i.e., quality of life is assessed across psychological, social, physical, and environmental dimensions), the psychological construct of parenting stress is narrower in scope and this is reflected in what the PSI-SF measures. Specifically, the PSI-SF was developed based on Parent-Child Relationship Theory, which conceptualizes parenting stress as the combined stress associated with difficult child behavior, the caregiver's own level of distress, and conflict within the parent-child interaction (Abidin, 1995). Of note, this differs from broader conceptualizations of parenting stress that include daily hassles associated with being a parent (e.g., running extra errands to meet the child's needs; Crnic & Greenberg, 1990; Crnic & Low, 2002). Thus, it is possible that parenting stress was not lower among ASD-C caregivers in the Post-SRT group compared to ASD-C caregivers in the Pre-SRT cohort because implementation of SRT did not significantly affect parenting stress as operationally defined by the PSI-SF (i.e., stress that arises within the caregiver-child dyad).

However, the PSI (both long and short forms) is the most commonly used parenting stress measure in the context of ASD (Hayes & Watson, 2013) because it effectively captures stress associated with difficult child behaviors, such as many of the unique behaviors associated with ASD. Indeed, the present study found that lower child social communication, a hallmark behavioral symptom of ASD, predicted increased parenting stress. Although the unified SRT service delivery model was not associated with lower levels of parenting stress, the relationship between social communication and parenting stress raises the possibility that certain components of SRT that were designed to target child social communication directly (i.e., implementation of RIT in Part C EI) could have contributed to lower levels of parenting stress.

It was posited above that the delivery of RIT from an SRT-trained EI provider was one (of many) possible factors that could have contributed to higher quality of life for ASD-C caregivers in the Post-SRT cohort. This was based on evidence that RIT is effective for improving child social communication among young children with ASD (Ingersoll, 2010) and that child social communication was found to be associated with caregiver quality of life. Similar logic can be applied to parenting stress since results from this study (and others; e.g., DesChamps et al., 2020) found that child social communication is also associated with parenting stress. Moreover, the RIT trainings for SRT EI providers included a parent coaching component to teach caregivers to implement RIT with their child as a complement to provider-delivered intervention. In addition to evidence that parent-delivered RIT is effective for improving child social communication (Penney & Schwartz, 2019), parent coaching within the context of ASD EI is associated with reduced parenting stress (Dunn, Cox, Foster, Mische-Lawson, & Tanquary, 2012; Koegel, Bimbela, & Schreibman, 1996). Thus, individual SRT components such as RIT trainings for EI providers may have contributed to lower levels of parenting stress without producing an overall effect of the unified SRT model on parenting stress.

In the discussion on caregiver quality of life above, it was also proposed that individual differences in parenting stress could be a mediator of (at least in part) the observed difference between SRT cohorts for caregiver quality of life. This was based on robust evidence linking parenting stress to mental and physical health outcomes among caregivers of children with ASD (Hayes & Watson, 2013), and a strong correlation between parenting stress and quality of life in the current sample. Additionally, child social communication was associated with both parenting stress and caregiver quality of life. It is possible that RIT implementation could have contributed to higher levels of quality of life among ASD-C caregivers in the Post-SRT cohort through the sequential mediation of higher child social communication and lower parenting stress. Future work that utilizes an appropriate study design and analytic approach is needed to test this hypothesis.

Parenting Self-efficacy

Levels of parenting self-efficacy did not differ between the Pre- and Post-SRT cohorts or between groups. However, the relative difference in parenting self-efficacy between ASD-C caregivers and NO-C caregivers was on the verge of significance ($p = .054$) such that ASD-C caregivers reported lower parenting self-efficacy relative to NO-C caregivers. This reflects well-documented differences in parenting self-efficacy among caregivers of children with ASD (Karst & van Hecke, 2012; Smart, 2016) and is similar to a previous report of lower parenting self-efficacy among ASD-C caregivers compared to NO-C caregivers (DesChamps et al., 2020). Lower parenting self-efficacy among caregivers of children with ASD is often attributed to the challenging behaviors associated with the disorder (Karst & van Hecke, 2012; Schertz, Lester, Erden, Safran, & Githens, 2020; Smart, 2016), which is consistent with the finding from the present study that lower child social communication behavior was associated with lower parenting self-efficacy. Similar to the discussion of the parenting stress findings above, the link between child social communication and parenting self-efficacy suggests that the delivery of RIT may have had some impact on parenting self-efficacy even though the unified SRT service delivery model did not. Specifically, if child social communication improved as a result of RIT, this could have led to higher parenting self-efficacy. More work is needed to explore this hypothesis.

Additionally, caregivers of young children with ASD report greater parenting self-efficacy when they are more engaged in their child's intervention (Schertz et al., 2020). For example, parent coaching within specialized ASD EI specifically increases parenting self-efficacy (Minjarez, Karp, Stahmer, & Brookman-Frazee, 2020), and caregivers rate parent coaching within ASD-specific EI as very helpful (Ingersoll & Dvortcsak, 2006). As a clear example that is relevant to the present study, recent work by Russell and Ingersoll (2020) found that a parent-mediated version of RIT was associated with high therapeutic self-efficacy (i.e., the caregiver's self-perceived ability to deliver RIT), which was significantly related to higher levels of parenting self-efficacy (Russell & Ingersoll, 2020). Thus, in addition to potential improvements in child social communication, future work should explore the hypothesis that implementing RIT with parenting coaching into Part C EI is effective for increasing parenting-self efficacy. Moreover, parenting self-efficacy is a reported mediator of the relationship between challenging ASD-related behaviors and caregiver mental health (Smart, 2016), and exploratory analyses revealed a strong association between parenting self-efficacy and quality of life within the current sample. Thus, future work could investigate the possibility that differences in parenting self-efficacy following SRT (although not observed overall) contributed to higher caregiver quality of life among ASD-C caregivers following SRT.

Beyond the hypothesis that RIT implementation could have affected parenting self-efficacy, it was reasonable to think that other SRT components could have impacted parenting self-efficacy as well. For example, elements of SRT trainings aimed at implementing ASD screening tools, increasing provider knowledge about ASD, and giving providers recommendations for talking about ASD with families could result in caregiver's gaining more insight about their child's concerning behaviors. Caregivers report that a lack of knowledge about ASD is one reason they struggle to effectively advocate for their child's service needs (Lappé et al., 2018; Pearson & Meadan, 2018; Sansosti et al., 2012; Stahmer et al., 2019) .

However, some work suggests that knowledge about ASD does not necessarily translate to increased parenting self-efficacy *per se* (Kuhn & Carter, 2006). Thus, families may have received more specific and general information about their child's behaviors and service needs as a result of increased ASD screening and provider knowledge, which could have empowered caregivers to advocate for their child's service needs without increasing their self-efficacy for responding directly to their child's challenging behaviors.

Family-Centered Care

SRT was not associated with differences in caregiver ratings of family-centered care provided by PCPs or EI providers. However, ratings of family-centered care for both types of providers were generally high, and notably higher than ratings reported in previously studies of caregivers of older children with ASD (Carbone et al., 2013; Hodgetts, Nicholas, Zwaigenbaum, & McConnell, 2013; Mandak & Light, 2018). Thus, it is quite possible that a difference in family-centered care between SRT cohorts was not detected because of a ceiling effect. Although caregivers often report negative experiences with service delivery during the pre-diagnosis period, the higher ratings of family-centered care in the present study (relative to those found among caregivers of children with an ASD diagnosis) could reflect the fact that families in this study were at an earlier stage in their pursuit of ASD services compared to families of older children with an ASD diagnosis who have experienced a longer-term struggle accessing and managing ASD care.

Higher ratings of family-centered care may also reflect selection bias. For example, providers who chose to participate in SRT likely did so because they were motivated by the aim of SRT to improve service delivery for families of children with ASD concerns. Thus, SRT providers may have been more likely to provide high levels of family-centered care to families of children with ASD concerns even before they were trained on the SRT components. Additionally, since families were recruited through either their child's PCP or EI provider, the families who elected to participate in the study may have had a relationship with the recruiting provider that was more positive than families seen by the same providers who chose not to participate. These possibilities represent a limitation to the present study and future work assessing PCP and EI provider family-centered care for families of children with ASD concerns should seek to account for these types of potential biases to determine if the ratings of family-centered care observed here are representative of family-centered care provided to ASD-C families in the broader community.

Despite no difference in family-centered care ratings following SRT, certain SRT components may have affected individual domains of family-centered care despite no overall effect of SRT on family-centered care. The MPOC-20 is composed of five different domains of family-centered care: enabling and partnership, providing general information, providing specific information, coordinated and comprehensive care, and respectful and supportive care. As an example of how SRT could have affected a specific domain of family-centered care, the providing specific information subscale measures the degree to which the provider provides information about the child's health and progress, and the extent to which providers explain the results from a child's assessment. SRT trainings for PCPs could have affected this domain of family-centered care since PCPs were trained to use an ASD-specific screening assessment and were provide recommendations for talking to families about the results of the M-CHAT-R/F and ASD more broadly. Similarly, if SRT trainings led to an increase in PCPs providing families with general information about ASD and ASD-related resources in the community could have been captured by the providing general information domain of family-centered care.

SRT-implemented changes to EI provider practices could have contributed to increases within individual domains of family-centered care as well. For example, implementation of RIT with parent coaching into Part C EI could have improved the respectful and supportive care domain that assesses items such as the extent to which providers help caregivers feel competent in their parenting practices and treat caregivers as an equal rather than just the parent. Future work is needed to determine how different SRT-implemented practices impact provider family-centered care for families of children with ASD concerns.

Limitations

In addition to limitations already acknowledged above, the current study has multiple limiting factors that warrant further discussion. First, the SRT study was designed as a cross-sectional pragmatic trial, which limits the types of inferences that can be made based on the results of the present study. Although it was hypothesized that SRT would have a positive impact on caregiver wellbeing, and many possible mechanisms through which that could happen were discussed above, no causal inferences can be made due to the cross-sectional design of the study. Additionally, compared to the Pre-SRT cohort, the Post-SRT cohort was comprised of older children at the time of enrollment, a higher proportion of caregivers who identified as Latinx/Hispanic, and a higher proportion of families recruited from an EI provider. Although all models included these and many other covariates, it is possible that participant-level factors that contributed to higher quality of life in the Post-SRT cohort compared to the Pre-SRT cohort. Similarly, there could have been broader contextual factors such as social, political, and/or economic changes over the course of the study that differentially impacted caregiver quality of life within each cohort.

Second, the results of this study may not generalize to other ASD-C families and their providers. As mentioned above, families who elected to participate in the SRT trial may differ from those who declined participation or were never recruited to participate. Additionally, on the family level, the present results do not generalize to paternal caregivers since the vast majority of participants in the study identified as maternal caregivers. At the provider level, participating PCP and Part C EI providers may not be representative of the broader population of PCP and Part C EI providers who work with families of children with ASD concerns in the four counties studied here. Participation in the SRT pragmatic trial required providers to attend trainings in ASD screening and/or specialized ASD EI practices, which could reflect a higher level of motivation for providing evidence-based care to families of young children with ASD concerns relative to PCP and Part C EI providers in general. Finally, the specific process of implementing SRT, and the specific findings on caregiver outcomes reported here, may not generalize to other counties or states given many possible system-level differences in health care policies and practices.

Third, the present study examined the unified SRT service delivery model instead of examining PCP and EI provider components of SRT separately. Investigating the association between the unified SRT model and caregiver outcomes was intentional since SRT was designed as a holistic approach to building capacity for the provision of specialized ASD services within primary care and Part C EI service systems, and increasing care coordination between these two service systems. Moreover, the literature on quality of life, parenting stress, parenting self-efficacy, and family-centered care suggested that these outcomes could have been affected by both PCP and Part C EI components of SRT. However, as highlighted throughout the discussion, it is possible that certain components impacted caregiver outcomes while others did not.

Although hypotheses for future work investigating individual SRT components were discussed above, the results of the present study do not provide specific information about individual SRT components.

Finally, it is worth noting that the majority of ASD-C families who participated in the SRT pragmatic trial were recruited through the child's Part C EI provider, and only a minority of families were recruited through the child's PCP. As a result, more ASD-C families were exposed to SRT components implemented into Part C EI (e.g., RIT) than SRT components implemented into primary care (e.g., M-CHAT-R/F screening). Although this could be considered a limitation, this study sought to examine the effects of the unified SRT model and the unequal distribution of ASD-C families exposed to the EI versus PCP components of SRT reflects real-world factors inherent to the design of the SRT model. Specifically, more ASD-C families were recruited to the SRT pragmatic trial through Part C EI than primary care because the proportion of children presenting to Part C EI services with ASD concerns is higher than the proportion of children presenting to primary care services with identified ASD concerns. Moreover, statistically account for inherent differences between EI and primary care service systems, the different SRT components delivered through both systems, and differences in the ages of children recruited to the study from EI versus primary care, primary analyses in the present study included recruitment source (i.e., PCP or EI) as a covariate. Therefore, while not a limitation to the present study due to the aims, design, and statistical approach, future work investigating ASD-C family outcomes associated with individual components of SRT should consider that more families were exposed to EI components than PCP components of the SRT model and that inferences based on comparisons of individual components may be limited. Additionally, future work should consider limitations posed by the fundamental differences between the types of services provided (e.g., RIT versus ASD screening) and the frequency of service provision (e.g., EI providers interact with families more often than PCPs).

Conclusion

Despite limitations, this study has many strengths and provides critical information for ongoing efforts to improve ASD service delivery. Specifically, this is the first study to examine family outcomes following implementation of an innovative ASD service delivery model designed to increase ASD screening, improve ASD referral practices, and expedite the delivery of specialized ASD early intervention for young children with ASD concerns prior to a formal diagnostic evaluation. Additionally, this study provides preliminary evidence that implementation of the SRT service delivery model may have a positive impact on the wellbeing of caregivers of young children with ASD concerns. This is particularly exciting since SRT can be implemented through community partnerships and brief provider trainings. Indeed, the SRT pragmatic trial resulted in high ratings for SRT adoption, feasibility, and effectiveness among providers (Steinman, Stone, Ibañez, & Attar, 2021; Ibañez et al., *in press*), and demonstrated that SRT can be successfully implemented into both urban and rural communities characterized by diverse racial, ethnic, and socioeconomic demographics. As such, SRT shows promise as a scalable approach for implementing specialized ASD services in established health care systems that could contribute to more optimal outcomes for families of young children with ASD concerns.

Figure 1. Overview of the Screen-Refer-Treat Service Delivery Model

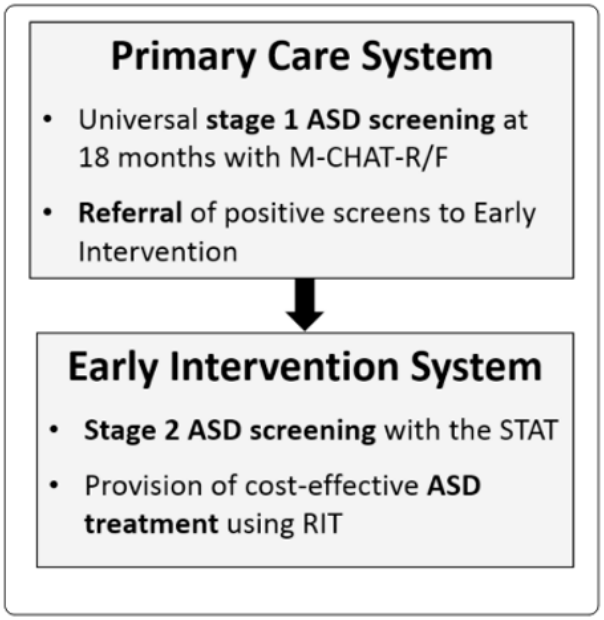


Figure 1. SRT model overview (Ibañez et al., 2019)

Figure 2. Stepped-wedge cluster design of the SRT pragmatic trial

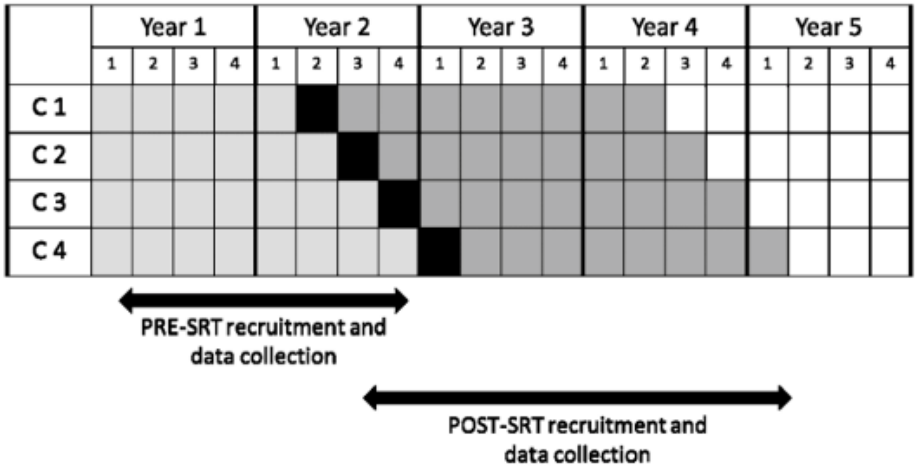
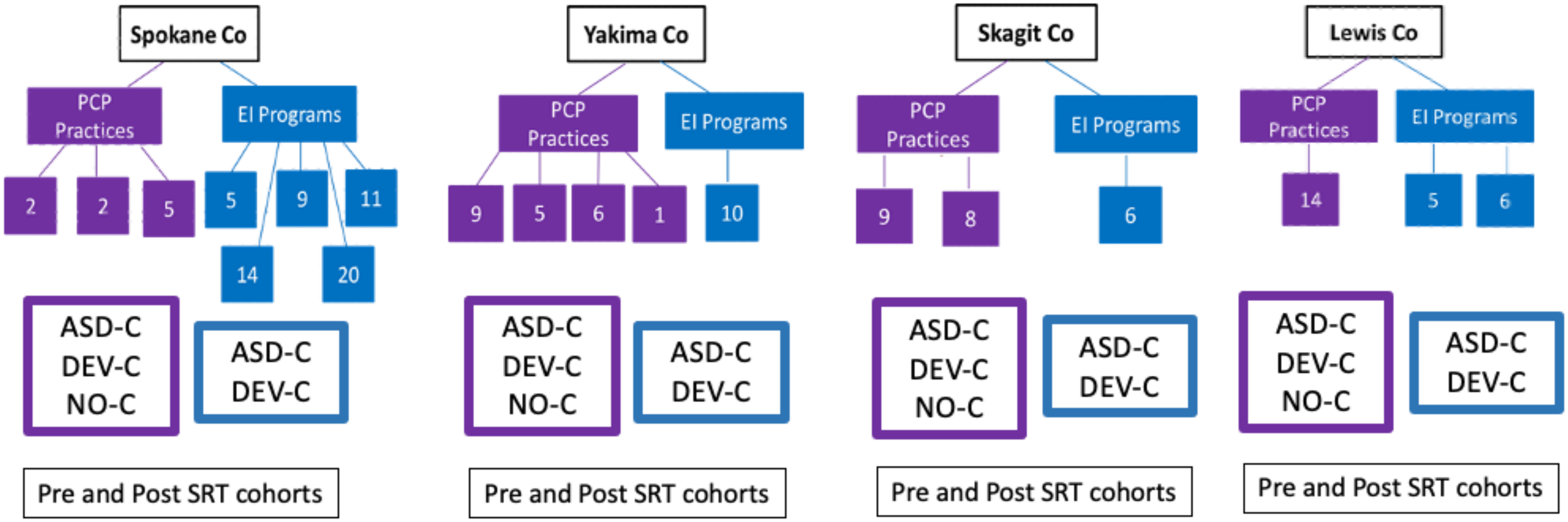


Fig. 2 Stepped-Wedge Cluster RCT Study Design. The four counties (C1-C4) are randomized to the timing of their SRT training workshops. Lighter shading indicates the period of Pre-SRT family recruitment and data collection, darker shading indicates the Post-SRT family recruitment and data collection window, and black shading indicates the 3-month training and technical assistance (TA) period for providers **(Ibañez et al., 2019)**

Figure 3. Nested structure of the SRT pragmatic trial



Note. Individual solid squares represent a provider practice/agency and numbers within solid squares indicate the number of providers from each practice/agency who participated in the SRT pragmatic trial.

Table 1: Sample demographics

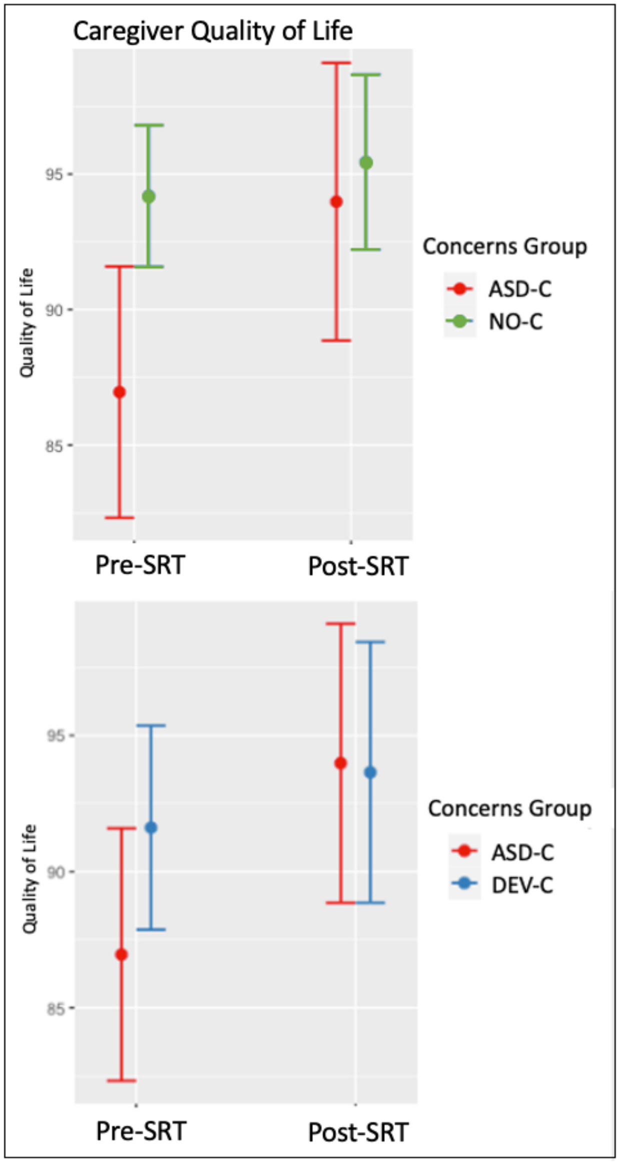
	Pre-SRT			Post-SRT		
	ASD-C	**DEV-C**	**NO-C**	**ASD-C**	**DEV-C**	**NO-C**
n	63	69	182	69	39	88
Caregiver Sex: *n* (% female)	62 (98.4)	67 (97.1)	171 (94.0)	62 (89.9)	37 (94.9)	82 (93.2)
Caregiver Age (months; *M*, *SD*)	403.9 (100.6)	408.2 (62.7)	386.8 (62.0)	374.4 (78.3)	380.2 (77.2)	395.8 (76.3)
Caregiver Race: *n* (%)						
non-White	7 (11.1)	7 (10.1)	13 (7.1)	15 (21.7)	3 (7.7)	4 (4.5)
White	54 (85.7)	58 (84.1)	166 (91.2)	44 (63.8)	32 (82.1)	83 (94.3)
Unknown	2 (3.2)	4 (5.8)	3 (1.6)	10 (14.5)	4 (10.3)	1 (1.1)
Caregiver Ethnicity: *n* (%)						
Hispanic/Latinx	13 (20.6)	11 (15.9)	20 (11.0)	29 (42.0)	9 (23.1)	7 (8.0)
Non-Hispanic/non-Latinx	49 (77.8)	55 (79.7)	160 (87.9)	38 (55.1)	30 (76.9)	77 (87.5)
Unknown	1 (1.6)	3 (4.3)	2 (1.1)	2 (2.9)	0 (0.0)	4 (4.5)
Household income: *n* (%)						
< $20,000 per year	17 (27.0)	12 (17.4)	19 (10.4)	17 (24.6)	8 (20.5)	7 (8.0)
>$20,000 per year	36 (57.1)	56 (81.2)	140 (76.9)	42 (60.9)	30 (76.9)	76 (86.4)
Unknown	10 (15.9)	1 (1.4)	23 (12.6)	10 (14.5)	1 (2.6)	5 (5.7)
Education: *n* (%)						
<4-year college degree	49 (77.8)	36 (52.2)	94 (51.6)	53 (76.8)	24 (61.5)	43 (48.9)
>4-year college degree	14 (22.2)	31 (44.9)	88 (48.4)	14 (20.3)	15 (38.5)	45 (51.1)
Unknown	0 (0.0)	2 (2.9)	0 (0.0)	2 (2.9)	0 (0.0)	0 (0.0)
Child Sex: *n* (% male)	40 (63.5)	42 (60.9)	87 (47.8)	44 (63.8)	27 (69.2)	40 (45.5)
Child Age (months; *M, SD*)	27.6 (5.8)	23.3 (4.9)	20.6 (1.4)	29.3 (4.7)	23.6 (4.8)	20.4 (1.7)
Child Social Communication (*M, SD*)	119.5 (18.7)	137.5 (15.4)	148.0 (12.4)	118.5 (17.3)	140.4 (15.3)	150.1 (11.8)
County: *n* (%)						
Spokane	26 (41.3)	32 (46.4)	56 (30.8)	16 (23.2)	19 (48.7)	20 (22.7)
Yakima	13 (20.6)	16 (23.2)	48 (26.4)	22 (31.9)	10 (25.6)	29 (33.0)
Skagit	12 (19.0)	12 (17.4)	51 (28.0)	16 (23.2)	3 (7.7)	29 (33.0)
Lewis	12 (19.0)	9 (13.0)	27 (14.8)	15 (21.7)	7 (17.9)	10 (11.4)
Recruitment Source: *n* (%)						
EI	46 (73.0)	26 (37.7)	0 (0.0)	62 (89.9)	21 (53.8)	0 (0.0)
PCP	17 (27.0)	43 (62.3)	182 (100.0)	7 (10.1)	18 (46.2)	88 (100.0)

Table 2. Full model results for caregiver outcomes

	Quality of Life	Parenting Stress	Parenting Self-Efficacy	PCP Family-centered Care	EI Family-centered Care
	B (SE)	*B* (SE)	*B* (SE)	*B* (SE)	*B* (SE)
(Intercept)	88.21 (3.50) ***	73.89 (5.54)***	33.22 (0.89)***	84.86 (13.13)***	101.45(11.42)***
Caregiver					
Sex (Female)	-1.65 (2.50)	5.09 (3.97)	-0.55 (0.64)	4.32 (8.06)	-1.47 (9.45)
Age (months)	-0.01 (0.01)	-0.01 (0.01)	-0.001 (0.002)	-0.04 (0.03)	-0.02 (0.02)
Race (BIPOC)	-2.84 (1.72)	0.18(2.85)	0.29 (0.46)	6.30 (7.61)	7.49(5.28)
Ethnicity (Latinx/Hispanic)	-3.33 (1.67)*	-0.21(2.62)	-0.38 (0.42)	3.89(6.01)	-6.04(4.92)
Education (<4yr college)	-0.75 (1.21)	-2.63 (1.90)	0.35 (0.31)	9.74 (3.85)*	6.10(4.05)
Income (<$20k)	-5.71 (1.39)***	5.09 (2.33)*	-0.59(0.38)	1.28 (5.62)	-4.71 (4.59)
Child					
Sex (Female)	-0.85(1.13)	0.97(1.78)	-0.03 (0.28)	-1.75 (3.59)	2.03 (3.91)
Age (months)	-0.18 (0.20)	0.25 (0.31)	-0.10 (0.05) *	1.10 (1.30)	0.28 (0.43)
High Risk Sibling	-6.10 (2.41)**	-0.62 (3.79)	-0.81 (0.62)	15.67 (12.62)	-6.95 (5.20)
Social Communication	0.15 (0.04) ***	-0.50 (0.06)***	0.12 (0.01)***	0.42 (0.14)**	-0.12 (0.11)
Referral Source (EI)	2.41 (2.40)	4.01 (3.79)	0.53 (0.60)	NA	4.44 (5.81)
SRT (Post-SRT)	**7.11 (2.26)****	-5.65 (3.60)	0.08 (0.58)	25.56 (16.33)	3.36 (4.75)
Group (ASD-C=0)					
DEV-C	**4.79 (2.39)***	**-12.83 (3.77)*****	0.34 (0.60)	-10.25 (10.15)	7.68 (5.52)
NO-C	**7.58 (2.50)****	**-13.06 (3.96)****	1.21 (0.63)	-13.76 (9.50)	-8.83 (13.22)
SRT*(ASD-C=0,DEV-C=1)	-4.92 (3.32)	2.70 (5.27)	0.46 (0.84)	-25.76 (18.78)	1.42 (7.59)
SRT*(ASD-C=0, NO-C=1)	**-5.75 (2.76)***	5.10 (4.38)	-0.14(0.70)	-19.27 (16.90)	26.79 (17.05)
N (Study ID)	503	505	506	352	189
N (County)	4	4	4	4	4
R^2 (Fixed)	0.16	0.26	0.34	0.05	0.06
R^2 (Total)	0.84	0.78	0.79	0.33	0.42

*** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$.

Figure 4. Estimated caregiver quality of life: SRT Cohort by Group



Note. Error bars represent 95% confidence intervals.

Table 3. Model results for caregiver quality of life within each group

	Quality of life: ASD-C	**Quality of life: DEV-C**	**Quality of life: NO-C**
(Intercept)	99.30 (4.95) ***	103.63 (7.31) ***	90.12 (3.01)***
Caregiver			
Sex (Female)	-7.81(4.50)	-7.11 (6.84)	0.14 (2.68)
Age (months)	-0.02 (0.01)	-0.02 (0.02)	0.02 (0.01)
Race (BIPOC)	-0.51 (2.24)	1.36 (3.20)	-3.58 (2.75)
Ethnicity (Latinx/Hispanic)	-7.11 (2.48) **	-9.08 (3.85) *	0.79 (2.17)
Education (<4yr college)	-0.88 (2.10)	-3.95 (2.57)	-0.96 (1.34)
Income (<$20k)	-7.85 (2.36) **	-7.28 (3.63) *	-5.24 (1.98) **
Child			
Sex (Female)	-2.44 (1.98)	-5.02 (2.58)	0.07 (1.25)
Age (months)	-0.10 (0.24)	0.06 (0.37)	-1.03 (0.44) *
HR Sibling	-3.95 (3.01)	-7.88 (4.52)	-16.71 (5.18) **
Social Communication	0.10 (0.05)	-0.02 (0.08)	0.26 (0.05) ***
Referral Source (EI)	-0.73 (2.88)	-2.96 (3.74)	
SRT (Post-SRT)	**4.69 (2.00) ***	2.80 (2.62)	0.61 (1.32)
N (Study ID)	234	106	269
N (County)	4	4	4
AIC	5369.26	2795.45	8569.19
BIC	5442.84	2859.11	8646.31

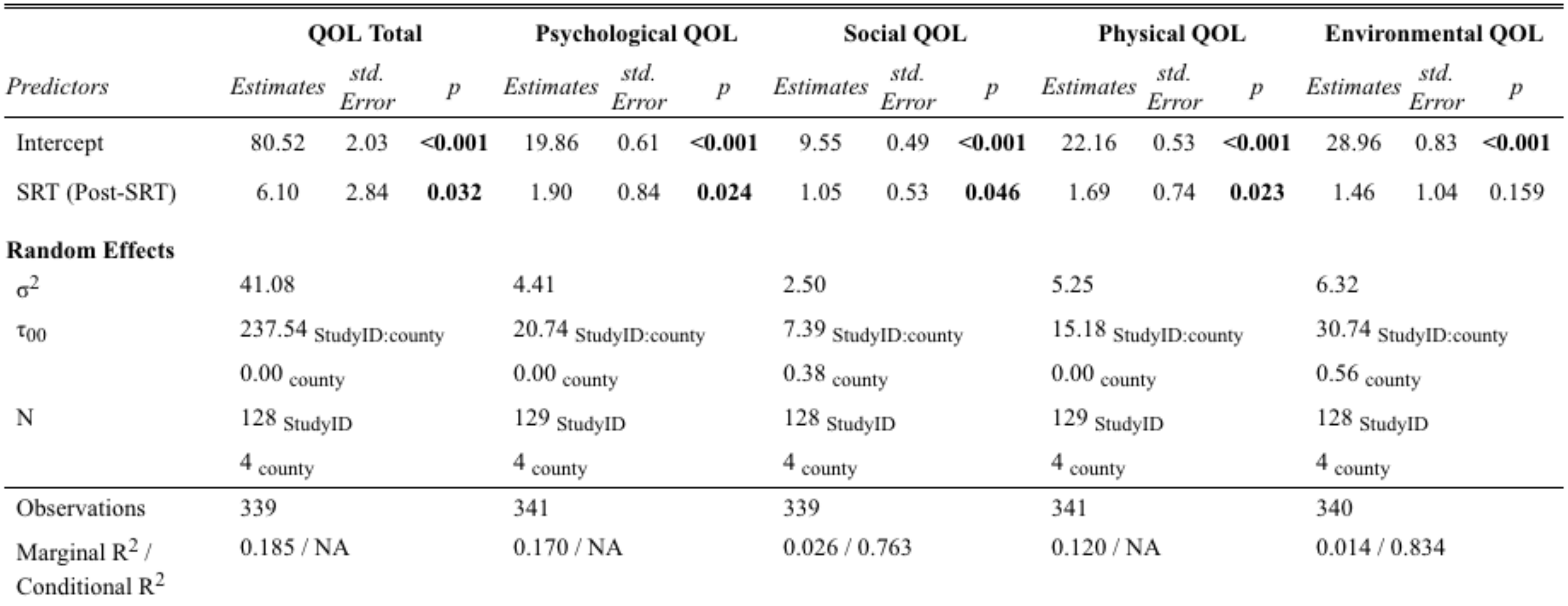
*** p < 0.001; ** p < 0.01; * p < 0.05

Table 4. Model results for caregiver quality of life within the Pre-SRT and Post-SRT cohorts

	Pre-SRT Quality of Life	**Post-SRT Quality of Life**
(Intercept)	90.89 (4.48) ***	93.50 (5.39) ***
Caregiver		
Sex (Female)	-2.82 (3.42)	-1.69 (3.81)
Age (months)	-0.12 (0.27)	-0.23 (0.29)
Race (BIPOC)	0.48 (2.61)	-4.99 (2.91)
Ethnicity (Latinx/Hispanic)	-4.26 (2.24)	-3.85 (2.61)
Education (<4yr college)	-2.43 (1.51)	-3.95 (2.57)
Income (<$20k)	-6.82 (2.02) **	1.70 (2.01)
Child		
Sex (Female)	-0.42 (1.43)	-1.43 (1.87)
Age (months)	-0.01 (0.01)	0.01 (0.01)
HR Sibling	-5.60 (3.08)	-7.25 (3.45)*
Social Communication	0.17 (0.05)	0.07 (0.06)
Referral Source (EI)	2.42 (3.23)	1.84 (3.78)
Group (ASD-C=0)		
NO-C	**6.52 (2.82)***	3.19 (4.19)
DEV-C	3.83 (2.52)	0.68 (3.18)
N (Study ID)	234	106
N (County)	4	4
AIC	5369.26	2795.45
BIC	5442.84	2859.11

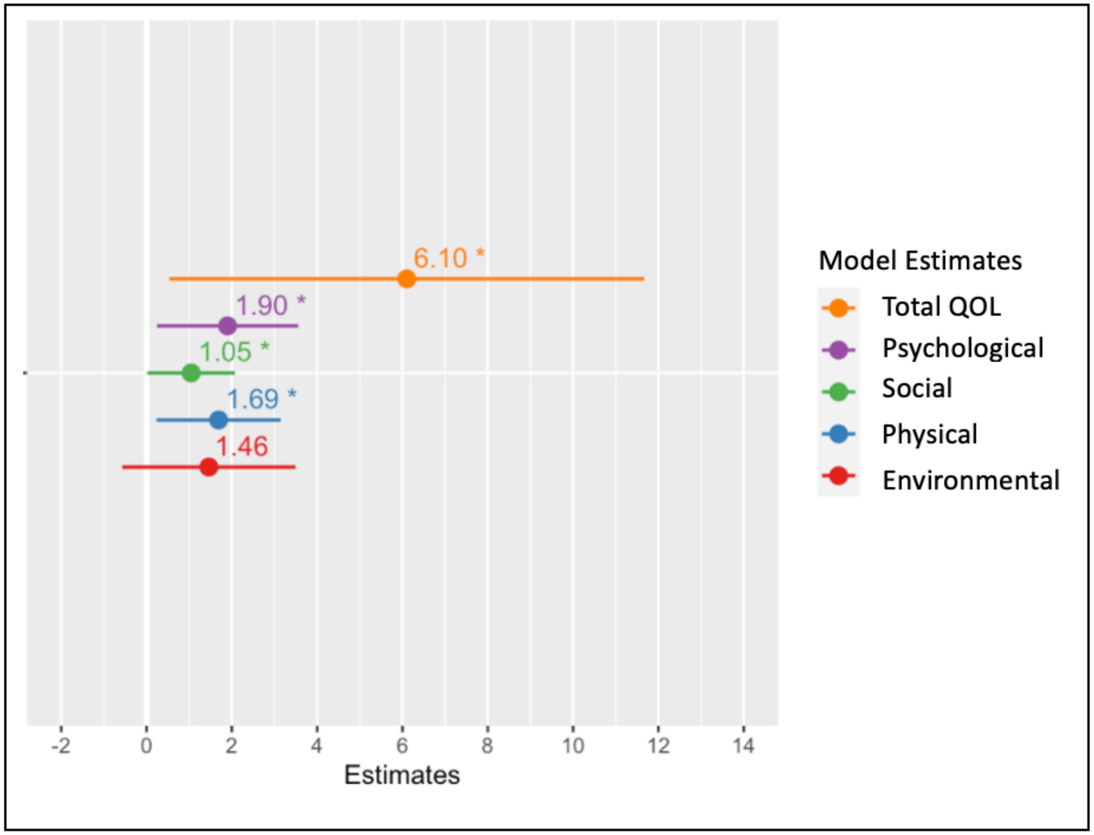
*** p < 0.001; ** p < 0.01; * p < 0.05

Table 5. Estimated effects of SRT on the total and individual dimensions of quality of life (QOL) among ASD-C caregivers



	QOL Total			**Psychological QOL**			**Social QOL**			**Physical QOL**			**Environmental QOL**		
Predictors	*Estimates*	*std. Error*	*p*	*Estimates*	*std. Error*	*p*	*Estimates*	*std. Error*	*p*	*Estimates*	*std. Error*	*p*	*Estimates*	*std. Error*	*p*
Intercept	80.52	2.03	**<0.001**	19.86	0.61	**<0.001**	9.55	0.49	**<0.001**	22.16	0.53	**<0.001**	28.96	0.83	**<0.001**
SRT (Post-SRT)	6.10	2.84	**0.032**	1.90	0.84	**0.024**	1.05	0.53	**0.046**	1.69	0.74	**0.023**	1.46	1.04	0.159
Random Effects															
σ^2	41.08			4.41			2.50			5.25			6.32		
τ_{00}	237.54 $_{\text{StudyID:county}}$			20.74 $_{\text{StudyID:county}}$			7.39 $_{\text{StudyID:county}}$			15.18 $_{\text{StudyID:county}}$			30.74 $_{\text{StudyID:county}}$		
	0.00 $_{\text{county}}$			0.00 $_{\text{county}}$			0.38 $_{\text{county}}$			0.00 $_{\text{county}}$			0.56 $_{\text{county}}$		
N	128 $_{\text{StudyID}}$			129 $_{\text{StudyID}}$			128 $_{\text{StudyID}}$			129 $_{\text{StudyID}}$			128 $_{\text{StudyID}}$		
	4 $_{\text{county}}$			4 $_{\text{county}}$			4 $_{\text{county}}$			4 $_{\text{county}}$			4 $_{\text{county}}$		
Observations	339			341			339			341			340		
Marginal R^2 / Conditional R^2	0.185 / NA			0.170 / NA			0.026 / 0.763			0.120 / NA			0.014 / 0.834		

Figure 6. Estimated effects (*b, CI*) of SRT on the total and individual dimensions of quality of life among ASD-C caregivers



*$p<.05$

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