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Predictive Analysis of Parent Activation and Autism

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Abstract

We examined parent activation in families with autistic children over time. Activation is one's belief, knowledge, and persistence in obtaining and managing one's care (e.g., patient activation) and others (e.g., parent activation) and is associated with better outcomes. Four aims were examined: the associations between baseline parent activation and follow up treatment/ outcome, between changes in activation and changes in treatment/outcome, differences in activation and treatment/outcome across demographic groups (e.g., gender, race, ethnicity, and income) and comparison of results using three different assessment approaches of parent activation, the Guttman scale (standard approach) and two factor subscales (Yu et al., in J Autism Dev Disord 53:110-120, 2023). The first factor tapped into behaviors aligned with highly active, assertive parental actions (Factor 1: Activated). The second tapped into behaviors representative of uncertainty, passivity, being overwhelmed, with growing awareness of the need for activation (Factor 2: Passive). Findings varied with assessment methods applied. The two subscales assessment approach produced the strongest effect sizes. Baseline activation was related to *improved* child outcomes at follow-up for Factor 1: Activated and to *poorer* child outcomes at follow-up for Factor 2: Passive. Changes in activation were unrelated to changes in treatment/outcomes. Outcomes differed based on the activation assessment approach used. Against expectations, activation remained the same over time. Further, no differences in outcomes were observed based on race, ethnicity, or family income. The results suggest that parent activation may behave differently than patient activation based on prior studies. More research is warranted on activation of parents of autistic children.

Keywords Autism · Parent activation · Predictive validity · Treatment outcomes · Longitudinal analysis

Introduction

Autistic children and youth use an array of services often provided from multiple medical, educational, and community-based agencies (Yu et al., 2023; Lavelle et al., 2014; Rogge & Janssen, 2019). Yet many parents describe problems obtaining services that are appropriate, timely, affordable, and accessible, resulting in high reports of unmet

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¹ Department of Psychology, Indiana University Purdue University Indianapolis, 402 N. Blackford St., LD124, Indianapolis, IN 46202, USA healthcare needs (Benevides et al., 2016; Carbone et al., 2010; Chiri & Warfield, 2012; Lindly et al., 2019; Mandell et al., 2009; Shattuck & Grosse, 2007). Examples of service problems include access to medical homes (Golnik et al., 2009; Harguanani et al., 2006) despite availability of best practice guidelines (Zwaigenbaum et al., 2015) and access to specific services, such as speech and language therapy, occupational therapy, and behavioral services (Chiri

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& Warfield, 2012; Dallman et al., 2021). Caregivers also report lower satisfaction with their child's services (Bitterman et al., 2008; Montes et al., 2009), compared to parents of children with other disabilities. The purpose of this study is to describe parent activation and its impact on services and outcomes.

For children with chronic, complex, and lifelong disorders such as autism, practitioners have models available that can serve as guides for addressing these service issues and providing evidence-based care (e.g., American Psychological Association Task Force on Evidence-Based Practice for Children & Adolescents, 2008; Committee on Hospital Care & Institute for Patient- & Family-Centered Care, 2012). One framework, the Chronic Care Model (CCM; Bodenheimer et al., 2002), results in improved outcomes for chronic conditions such as arthritis, asthma, depression, diabetes, and hypertension (Evidence for Better Care, "Condition-Specific Literature"). The CCM explicitly extends additional features related to outcomes-patient activation and selfmanagement. Activation is defined as being informed and having the skills, knowledge, and motivation to participate as an effective team member. That is, activation refers to one's belief, knowledge, ability, and persistence to manage one's own medical and behavioral health care (Greene et al., 2012; Greene & Hibbard, 2012; Hibbard et al., 2004) through enhanced self-management of health-related activities (Hibbard et al., 2004). Not surprising, activation is associated with better self-management of one's condition (Bodenheimer et al., 2002; Druss et al., 2010; Greene & Hibbard, 2012; Hibbard et al., 2004; Hibbard & Tusler, 2007; Mosen et al., 2007; Rask et al., 2009). Different from other measures designed to predict a single behavior, such as self-efficacy, self-management, or readiness to change (DiClemente et al., 1991; Prochaska & Velicer, 1997), activation represents a broad construct (Lorig et al., 2001). As predicted from the CCM, research on patient activation has been associated with better health outcomes across a variety of chronic health conditions such as diabetes, arthritis, hypertension, and heart disease (Hibbard et al., 2005; Mosen et al., 2007).

The most used measure of activation is the Patient Activation Measure (PAM; Hibbard et al., 2004). The PAM is comprised of four stages that are described as hierarchical. The first and lowest stage concerns (a) the individual's belief of the importance of one's role for taking care of one's own health. The second stage represents (b) the individual's confidence and knowledge to take action regarding one's health care; while the third stage is (c) taking action to maintain or improve one's condition. The last and most difficult stage to reach is (d) one's ability to persist in the face of obstacles related to one's care. The PAM assumes that the patient proceeds through these four developmental levels.

Activation is generally applied to the ability of the patient to manage their own care (i.e., patient activation), but recent research has suggested that activation may also be relevant with respect to the ability of parents of children with chronic conditions, such as autism, to help manage their child's care (i.e., parent activation). Autism impacts 1 in 44 children (Maenner et al., 2021), and is a lifelong, complex developmental disability that has no single etiology or treatment approach. Parents often must act as case managers because of the lack of unified systems of care (Corcoran et al., 2015; Marsack-Topolewski & Weisz, 2020; Smith et al., 2020; Snell-Rood et al., 2020). Further, autism is commonly associated with severe developmental delay and/or intellectual disability that interferes with the individual's ability to self-manage one's own care (Tonnsen et al., 2016).

Activation is particularly important for the study of autism services outcomes because research suggests that parents who report higher activation report less stress, better child outcomes, and better self-management of child-related issues (Crossman et al., 2020; Ruble et al., 2019, 2018). This is particularly salient because compared to parents of children with other disabilities, parents of autistic children report significantly higher stress and burden (Barroso et al., 2018; Craig et al., 2016; Gupta, 2007; Hayes & Watson, 2013; Watson et al., 2013). Further, activation may be particularly salient for addressing service disparities for racial and ethnic minority children (Magaña et al., 2013) and autistic children with different levels of support needs (Dallman et al., 2021; Zuckerman et al., 2017).

Assessment of activation has been limited almost exclusively to the Patient Activation Measure (PAM; Hibbard et al., 2004) and measures derived from it. The PAM and its derivative measures are Guttman scales, which are intended to be unidimensional in character, with higher scores indicating greater activation as the patient proceeds through the different levels. Individuals receive a total Guttman score (ranging from 0 to 100) and are classified into one of four increasing levels of activation. For example, at Level One, patients may not understand how or why they play an active role in their health; at Level Four, patients take action reflecting their knowledge, skills and confidence to effectively manage their health.

In a companion study to this paper, parent activation for children with developmental disabilities was evaluated cross sectionally using a nationwide sample of parents from the Autism Treatment Network (Yu et al., 2023). The measure of activation used was the PAM-DD (Developmental Disabilities; Ruble et al., 2018), and two factors were identified, one that correlated positively with parent and child variables (Factor 1: Activated) and a second scale (Factor 2: Passive) that correlated negatively with the same variables. These findings suggest that there were two non-unidimensional aspects of activation being measured by the PAM-DD not predicted by the Guttman approach. Also, differences in activation and outcomes differed depending on the measurement approach applied (Guttman; Factor 1/Factor 2).

Consistent with the foregoing conceptual concerns when applying activation to the measurement of parent activation for children with illnesses or disabilities, two studies (DeCamp et al., 2016; Liberman & Pham, 2018) using the parent version of the PAM (P-PAM; Pennarola et al., 2012) reported similar inconsistencies with the theory of activation when applied to parents and suggested future research is needed to understand their results. DeCamp et al. (2016) surveyed 316 caregivers of children who received publiclyfunded health insurance. Although, the psychometrics of the P-PAM were adequate for reliability ($\alpha = 0.90$), factor analysis of the raw item scores identified PAM factors inconsistent with previously conceptualized and reported factor structure of the original PAM (Hibbard et al., 2004), suggesting that the P-PAM may have different associations with health outcomes in pediatric populations compared to adults (e.g., Patient Activation). Similarly, Liberman and Pham (2018) surveyed 246 caregivers with the P-PAM. Once again, analysis of the four-factor model when applied to the P-PAM revealed that the model did not meet cutoff criteria for goodness of fit.

Given the potential significance of activation and variability in reported findings especially for parent versions of the scale, further research is clearly warranted. Moreover, we were specifically interested in the use of the PAM-DD with parents of autistic children. In addition to understanding the relative superiority of using the Guttman scaling suggested by and provided by Insignia, the copywrite holders of the PAM, vs. the two PAM-DD subscales identified in our prior study (Factor 1: Activated and Factor 2: Passive) based on raw item scores (Yu et al., 2023), we were interested in questions that could only be answered longitudinally such as the stability of activation over time and the impact of activation on treatment variables and child outcomes over time. To our awareness, there are no large scale studies on the changes in parent activation with PAM-DD. Moreover, answers to these questions may help identify active ingredients that could inform targets for an activation intervention (Mirza et al., 2018), and the results of intervention studies may reflect differences in measurement approaches, ingredients of interventions, and outcomes assessed (Crossman et al., 2020; Mirza et al., 2018).

The study had four research aims: (1) examine the association between parent activation collected at Time 1 and treatment and child outcome variables at Time 2; (2) examine the association between changes over time in (a) activation and (b) the same set of treatment and outcome variables; (3) examine potential disparities in activation across demographic groups (e.g., gender, race, ethnicity, and income) at Time 1; and (4) compare the consistency of results based on the different ways of measuring activation using Guttman vs. Factor 1 and Factor 2 when applied to research aims 1, 2 and 3 above. For our first and second research questions, our hypotheses were that activation would improve over time and be associated with treatment outcomes. Because patient activation literature suggests low activation in marginalized groups (Cunningham et al., 2011), we also predicted that disparities in activation would be observed based on race and ethnicity. For our last research question, we hypothesized that differences in activation would be observed based on the scale applied (Yu et al., 2023).

Methods

This was a secondary analysis of data from the Autism Speaks Autism Treatment Network (ATN) / Autism Intervention Research Network on Physical Health (AIR-P), which consists of 12 North American academic medical centers serving more than 35,000 children with ASD annually with a shared focus on research, best practice guidelines and toolkits for patients, families, and clinicians (Murray et al., 2016). To date, more than 7000 children and adolescents with ASD have been enrolled in the ATN Registry.

Study Design

Registry Call Back Assessment (RCBA) study data, a longitudinal substudy of the ATN registry study was obtained. Data were collected at two time points from 12 academic hospital affiliated clinics. A random eligible ATN registry participants were selected with a goal of enrolling 50 from each site (see Lindly et al., 2021 for further details concerning sampling). The inclusion criteria for RCBA Time 1 data collection were completed previous ATN assessment between the years 2011 through 2016 or present enrollment into the ATN Registry; non-missing domain scores for the Vineland Scale (Communication, Socialization, Daily Living Skills); meets DSM-IV criteria for any pervasive developmental disorder, or DSM-5 criteria for ASD; informed consent of parent/guardian; and assent/consent of child (minor) subjects, as required by the governing IRB/REB. For Time 2, RCBA participants were asked to return in one year. Standardized assessments (such as Child Behavior Checklist, Aberrant Behavior Checklist, etc.) collected by other agencies within 6 months of the first or second RCBA study visit, and IQ assessments completed within 12 months of a study visit were considered acceptable and used for study purposes. Further details about the design of the RCBA study and ATN registry studies are available in prior publications (Murray et al., 2016; Perrin et al., 2016). All work was carried out in accordance with the ethical standards

of the responsible committees on human experimentation and with the Declaration of Helsinki as revised in 2000. Informed consent was obtained from all participants for the use of their data.

Participants

Out of 1442 initially approached, a total of 658 families consented and completed the first annual visit for the ATN RCBA (Time 1), and 407 families completed the second RCBA annual visit (Time 2). Non-identifiable ATN registry study data was used to identify possible sampling biases at Time 1. Reason-for-refusal was tracked for individuals who refused consent or failed to respond to multiple contact attempts. Participants in the ATN RCBA did not differ substantially from families who declined enrollment (Fenning et al., 2020). Child participants' average age at enrollment was 72 months (SD = 39.40). Most were male (80%), White (77%), non-Hispanic (86%), and public insured (63%). For caregivers, about half had college or higher levels of education (49%), and 48% had annual incomes of \$50,000 or more. At enrollment, caregivers reported their children had about four comorbidities (SD = 3.62), seven parental concerns (M = 7.05, SD = 3.15), received about three therapies (M = 2.86, SD = 1.77), and received about 7 h of therapies (M = 6.80, SD = 13.32. See Table 1).

There were significant differences between the RCBA Time 1 and Time 2 samples. Non-completers (NC) were more likely to be non-White (25.2% _{NC} vs. 17.2%, X^2 [1, N=633)=5.88, p=0.015], to be Hispanic [16.6% _{NC} vs. 6.9%, X^2 (1, N=631)=14.69, p<0.001], have high school or lower education [21.5% _{NC} vs. 12.3%, X^2 (1, N=585)=8.51, p=0.004], and their children exhibited more externalizing behaviors (M=53.03, SD=10.78 vs. M=57.72, SD=11.28; t=-4.81, p<0.001). Except for the face-to-face Parent Visit assessment, participants could complete questionnaires online, in person, by phone or by mail.

Measures

Aberrant Behavior Checklist (ABC; Aman & Singh, 1986) is a 58-item parent-reported questionnaire that assesses problem and abnormal behavior among individuals with developmental disabilities, including autism spectrum disorders. There are five subscales: (1) Irritability, (2) Social Withdrawal/Lethargy, (3) Stereotypic Behavior, (4) Hyperactivity/ Noncompliance, and (5) Inappropriate Speech. The ABC subscales have high internal consistency, good test–retest reliability, and established validity (Aman & Singh, 1986). Higher scores indicate increased problem behavior. Total raw scores were used. Only subscale scores were available, so internal consistency was not calculated. Autism Impact Measure (AIM; Kanne et al., 2014) is a parent-reported measure of the frequency and effects of ASD symptoms. The AIM is designed to be sensitive to detecting the impact of treatment-dependent change on a child with ASD. Items are rated on two 5-point scales (frequency and impact). The total raw score was used. Higher scores indicate greater impact. Internal consistency reliability in the current sample was strong (Cronbach's alpha=0.95).

Caregiver Strain Questionnaire (CGSQ; Brannan et al., 1997) is a 21-item parent-reported measure of emotional, physical, and financial strain. Items are rated using 5-point Likert scale ($1 = not \ at \ all$ to $5 = very \ much$). The total raw score was used. Higher scores indicated greater caregiver strain. Total scale internal consistency was strong in the current study ($\alpha = 0.92$).

Child Behavior Checklist (CBCL; Achenbach, 1999) assesses childhood problem behaviors symptomatic of DSM-IV/DSM-5 diagnoses. The Preschool-age (1 ¹/₂–5) and School-age (6–18) versions were used. The CBCL and its respective subscales have good internal consistency and adequate validity (Ivanova et al., 2010; Pandolfi et al., 2012). Only the Internalizing Problems and Externalizing Problems scales were used. Higher T-scores indicate higher levels of internalizing and externalizing problems. Because only subscale scores were available, internal consistency was not calculated.

Children's Sleep Habits Questionnaire (CSHQ) assesses parent-reported occurrence, frequency, and impact of a child's sleep habits and sleep problems for children aged 4 to 12. Items are rated on a 3-point Likert scale (0=Usu-ally to 2=Rarely; or 0=Not sleepy to 2=Falls asleep for sleepiness items). The CSHQ demonstrated fair reliability and validity in both school and clinic-based samples (Owens et al., 2000). Higher scores indicate greater sleep problems. The total raw score was used. Internal consistency reliability was adequate in the current sample (Cronbach's alpha=0.62).

Parent Activation Measure for Developmental Disabilities (PAM-DD; Ruble et al. 2018) is a 13-item questionnaire adapted from the original Patient Activation Measure developed by Hibbard et al. (2004), measuring activation in parents and caregivers (Ruble et al., 2018) for their child with DD. Items are scored using a 4-point Likert scale (1 = Disagree Strongly to 4 = Agree Strongly). Originally scored using Guttman scaling (0 to 100), a prior paper determined that Guttman weighted scaling was not an ideal fit for the data (Yu et al., 2023). Specifically, a principal components analysis of the raw unweighted items revealed that the PAM-DD was not unidimensional and that the optimal fit for the data was a two-factor solution. Factor 1 scores seemed closely related to Level 3 and Level 4 descriptions of activation as proposed by Hibbard et al. (2004), i.e., parent behavior that was highly active and assertive on behalf

Table 1	Parent, Cl	nild, and Child C	linical Variat	oles for Time	1 sample,	Time 2 sample,	Non-complete	r sample	(present at	Time 1	and n	nissing at
Time 2)	and Time	1 statistical com	parisons for c	ompleters vs	. non-com	pleters						

Parent variables	Time 1 (<i>N</i> =658)	Time 2 (<i>N</i> =406)	Time 1 Nor completer (N=252)	n- Statistica pleters vs	l Comparisons: com- s. non-completers
Parent relationship to child (%)				$\chi^2 (1, N =$	=576) = .23, p = .631
Mother	81.9%	85.5%	71.8%		
Father	5.7%	5.9%	4.4%		
Others	1.7%	1.7%	2.0%		
Did not share	10.7%	6.9%	21.8%		
Primary Caregiver Education (%)				$\chi^{2}(1, N =$	=585)=8.51, p=.004*
High school or less	13.7%	11.3%	16.7%		, ,
Above High school	75.2%	80.3%	60.7%		
Missing	11.1%	8.4%	22.6%		
Income (%)				< 50,000 $\chi^2 (1, N=$	vs. ≥ 50,000: = 530) = .17, p = .682
\$0-\$24,999	14.4%	12.6%	17.5%		
\$25,000-\$49,999	18.1%	19.7%	15.5%		
\$50,000-\$74,999	14.3%	15.5%	12.3%		
\$75,000-\$99,999	11.5%	10.8%	12.7%		
\$100,000+	22.3%	22.7%	21.4%		
Did not report	19.4%	18.7%	20.6%		
Insurance (%)					
Public Insurance	62.9%	46.6%	43.7%	$\chi^2 (1, N =$	=655)=.55, p=.46
Private Insurance	45.4%	64.5%	60.3%	$\chi^2 (1, N =$	=655) = 1.23, p = .268
No Insurance	4.1%	3.4%	5.2%	$\chi^2 (1, N =$	=655)=1.15, p=.283
Child variables					
Child age at Registry, in months, Mean (SD)	72.02 (39.40), range 24—202	71.71 (38.89), range 24—202	72.58 (40.3 range 24–190	6), $t =27$,	<i>p</i> =.785
Child sex (%)			24-170	$\gamma^{2}(1 N =$	$(658) = 1.10 \ n = .294$
Male	80.3%	81.5%	78.2%	λ (1,1)-	-000)=1.10, p=.201
Female	19.7%	18.5%	21.8%		
Ethnicity (%)	131170	101070	211070	$\gamma^{2}(1, N =$	=631) = 14.69, n < .001*
Hispanic Origin	10.2%	6.7%	15.9%	λ (1,1)	001) 1100, p (1001
Non-Hispanic origin	85.7%	89.4%	79.8%		
Did not report	4.1%	3.9%	4.4%		
Race (%)				$\gamma^{2}(1, N =$	=633)=5.88, p=.015*
White	76.7%	80.5%	70.6%	<i>N</i> ()	, , , , , , , , , , , , , , , , , , ,
Non-White	19.5%	16.7%	23.8%		
Did not report	3.8%	2.7%	5.6%		
Child clinical variables	Mean (SD)	Mean (SD)) 1	Mean (SD)	
Child Health and Mental comorbidities (baseline)	4.94 (3.62)				
# of Therapies	2.86 (1.77)	3.04 (1.71)) 2	2.73 (1.70)	t = 1.24, p = .214
Therapy Intensity (hours/week)	6.80 (13.32)	6.13 (11.38	8) 5	5.86 (12.02)	t = 1.42, p = .158
Parental Concerns	7.05 (3.15)	6.70 (3.01)) 7	7.14 (3.23)	t =46, p = .649
Sleep problems	44.88 (9.00)	43.40 (7.90)) 4	45.50 (9.61)	t = -1.17, p = .242
Above Sleep problem cutoff (>=41), $\%$	58.7%	58%	e	67%	-
AIM	190.69 (45.74)	185.23 (43	.16) 1	96.41 (48.04)	t = -2.08, p = .038
Caregiver Strain	2.5 (0.77)	2.51 (.83)	2	2.50 (.76)	t = .01, p = .995
PedsQL	63.58 (16.09)	62.58 (16.1	18) 6	52.99 (15.73)	t = .64, p = .521

Table 1 (continued)

(containaed)				
Child clinical variables	Mean (SD)	Mean (SD)	Mean (SD)	
ABC				
Irritability	11.62 (9.41)	10.50 (8.90)	12.30 (9.46)	t = -1.26, p = .208
Lethargy	8.94 (7.43)	9.15 (7.29)	9.02 (7.08)	t =18, p = .86
Stereotypy	4.84 (4.63)	4.57 (4.19)	5.14 (4.78)	t = -1.15, p = .252
Hyperactivity	16.54 (10.96)	15.07 (10.34)	17.11 (10.77)	t =90, p = .369
Inappropriate Speech	3.54 (3.04)	3.39 (2.95)	3.62 (3.04)	t =46, p = .646
CBCL				
Internalizing Problems T Score	59.23 (10.27)	60.50(9.90)	59.88 (10.02)	t = -1.08, p = .283
Externalizing Problems T Score	54.64 (11.17)	56.84 (10.56)	57.72 (11.28)	t = -4.81, p < .001*
PAMDD				
Guttman scale	67.36 (10.87)	68.17 (11.60)	66.28 (10.99)	t = 1.75, p = .08
Raw total	42.15 (5.82)	42.37 (6.33)	41.68 (6.29)	t = 1.42, p = .155
Vineland				
Adaptive behavior	71.36 (14.69)	71.21 (15.36)	69.95 (17.40)	t = .21, p = .831

Non-completer: participants who only completed Time 1 measures

*Analyses that meet BH significance criteria

of the child (Example item "I am confident I can prevent or reduce problems associated with my child's behavior and development"). In contrast, Factor 2 scores appeared similar to Level 1 and Level 2 descriptions of activation (Hibbard et al., 2004), corresponding to being disengaged and overwhelmed, but becoming aware of the need for activation, and accepting of treatment recommendations (Example item "I know what each of my child's medications are for.").

Accordingly, three methods for calculating parent activation scores were used: two raw score factor subscales created from items identified in the principal components analysis (Yu et al., 2023), labeled (1) Factor 1 subscale or Activated and (2) Factor 2 subscale or Passive; and (3) the original Guttman item weighted score. Except for Factor 2, higher scores indicate higher activation. Internal consistencies in the current sample ranged from good to adequate: 0.83 for the Guttmann scale (Yu et al., 2023), 0.88 for Factor 1 and 0.66 for Factor 2.

Pediatric Quality of Life Inventory (PedsQL; Varni et al., 1999) is a 23-item parent-reported assessment of child health-related quality of life. Four age-based modules were used: ages 2–4, 5–7, 8–12, and 13–18. The total raw score was used. The scale has good internal consistency, construct and clinical validity (Varni et al., 1999). Because only subscale scores were available, internal consistency was not calculated.

Vineland Adaptive Behavior Scale II Edition (VABS: Sparrow et al., 2005) is a semi-structured caregiver-report of a child's adaptive functioning across four domains: (1) Communication, (2) Daily Living skills, (3) Socialization, and (4) Motor skills. Domain scores and an overall Adaptive Behavior Composite are provided. Items are rated 0, 1, or 2. Lower scores indicate poorer adaptive functioning. The Vineland-II has been shown to have good test–retest reliability and acceptable levels of internal consistency (Sparrow et al., 2005). Only the adaptive composite score was used. Higher scores indicate greater adaptive behavior. Because only subscale scores were available, internal consistency was not calculated.

The Parent Visit Assessment was developed for the study to collect demographic information (e.g., caregiver gender, parental education) and child treatment and symptom subscales (i.e., checklist of parent concerns, number of therapies received, list of comorbidities). See Appendix for copy. Parent concerns assessed a variety of areas, such as language use, sleep, aggression, hyperactivity, etc. Scores were based on the total number of parent concerns. Therapies received included behavioral and medical treatments, such as speech language therapy, occupational therapy, and academic tutor, social skills treatment. Two measures of treatment intensity were calculated: the total number of current therapies received and the total number of hours of current therapies received weekly were used. Comorbidities included both psychological and medical concerns (e.g., headaches, vision, ADHD, OCD). The total number was used. The internal consistencies for the Parent Visit subscales were acceptable in the current sample (Cronbach's alpha ranged from 0.72 to 0.78).

Statistical Analysis

For Aim 1 and 2, participants who completed both Time 1 and Time 2 surveys were included in the analyses. For Aim 1, Pearson correlations were calculated to identify significant bivariate associations between demographic, child, parent, and treatment variables at Time 2 (See Table 2 for variables included in the correlation analyses) and the activation measures collected at Time 1. For Aim 2, Pearson correlations were calculated to identify significant associations between change scores (Time 2-Time 1) for the activation measures and change scores for the demographic, child, parent, and treatment variables (Time 2-Time 1). Change scores were not calculated for variables which were not expected to change (e.g., race, ethnicity). To examine if there was significant change in parent activation, paired sample t-tests were conducted. Aim 3 was conducted cross-sectionally at baseline. For Aim 3, we used one-way MANOVA to examine differences in activation and in the demographic, child, parent, and treatment variables across gender, race, ethnicity and other demographic groups (e.g., income). Several variables were dichotomized in this analysis, including race (0 = White, 1 = Other), gender (0 = male, 1 = female), income

Table 2 Correlations between the three activation measures collectedat the first RCBA visit (Guttman scaled score, Factor 1 subscale andFactor 2 subscale) and caregiver and child predictors collected atTime 2

	T1 PAMDD Guttman	T1 PAMDD Factor1	T1 PAMDD Factor2
Caregiver education	-0.05	-0.07	0.03
Income	0.02	-0.05	0.02
Any Private Insurance	0.00	-0.04	.11
Any Public Insurance	0.07	0.08	-0.04
Total Comorbidities	0.04	0.08	.17*
Sleep Problems	14*	14*	.14*
Peds Quality of Life	0.10	.12	18*
ABC Irritability	15*	14*	0.10
ABC Lethargy	12	11	.13*
ABC Stereotypy	-0.05	-0.06	.10
ABC Hyperactivity	12	12	.11
ABC Inappropriate Speech	12	-0.03	.11
Internalizing Problems	14*	11	0.07
Externalizing Problems	16*	13*	0.09
Parental concerns	12	14*	.20*
Therapy Received	0.00	-0.01	0.08
Therapy Intensity (Hours/week)	01	08	.08
Adaptive Behavior	.12	.15*	16*
AIM	-0.05	-0.04	.13
Caregiver Strain	22*	29*	.11

*Analyses that meet BH significance criteria

(0 = < 50,000, 1 = > = 50,000), ethnicity (0 = Hispanic, 1 = non-Hispanic), having insurance (0 = having insurance, 1 = no insurance), and therapy (0 = no therapy, 1 = one or) more kind of therapy). All analyses were performed using SPSS 23 (IBM Corp, 2015). To control for the compounding Type I error due to the large number of analyses, the Benjamini-Hochberg (BH) procedure was conducted to control for the false discovery rate (Benjamini & Hochberg, 1995). We used a false discovery rate of 0.05. The procedure was applied separately within each aim. Only findings that were classified as statistically significant according to the Benjamini–Hochberg procedure are reported here.

Results

The Association Over Time Between Parent Activation and Treatment/Outcome Variables

Table 2 displays correlations between the activation measures collected at RCBA Time 1 (Guttman scale, Factor 1 subscale and Factor 2 subscale) and the caregiver and child variables collected at Time 2. Higher baseline activation scores were consistently related to improved levels of child or caregiver functioning at Time 2 for two of the activation measures (i.e., Guttman score and Factor 1-Activated). The pattern of significant correlations for the two scales was nearly identical for four of the Time 2 variables. Specifically, higher levels of Guttman or Factor 1 activation at Time 1 were significantly related to fewer sleep problems, r = -0.14, p = 0.01, r = -0.14, p = 0.006; decreased irritability, r = -0.15, p = 0.007, r = -0.14, p = 0.006; decreased externalizing problems, r = -0.16, p = 0.003, r = -0.13, p = 0.008; and lower levels of caregiver strain, r = -0.22, p = 0.000, r = -0.29, p = 0.000, at Time 2.

However, only higher levels of Guttman score activation at Time 1 were significantly related to fewer internalizing problems at Time 2, r = -0.14, p = 0.008, and only higher levels of Factor 1 activation at Time 1 were significantly related to decreased parental concerns, r = -0.14, p = 0.008, and greater adaptive behavior, r = 0.15, p = 0.005 at Time 2.

In contrast, Factor 2-Passive scores at Time 1, were significantly related to Time 2 variables in the reverse direction. Specifically, higher Factor 2-Passive scores at Time 1 were consistently significantly related to poorer Time 2 child and caregiver outcomes, i.e., more child comorbidities, r=0.17, p=0.001, increased child sleep problems, r=0.14, p=0.009, poorer pediatric quality of life, r=-0.18, p=0.001, increased child lethargy, r=0.13, p=0.010, increased number of parental concerns, r=0.20, p=0.000, and lower child adaptive behaviors, r=-0.16, p=0.004.

The Association Between Changes in Activation with Changes in Treatment/Outcome Variables

Paired sample t-tests indicated that there were no significant changes from Time 1 to Time 2 for any of the three activation measures (see Table 3). We next examined correlations between change scores in the three activation measures with change scores in the demographic, child, parent, and treatment variables (Time 2 - Time 1), excluding variables that were not expected to change (e.g., ethnicity; see Table 4). After applying the BH correction, there were no significant correlations between the change scores.

Disparities in Activation Across Different Demographic and Family Variables

Separate one-way MANOVAs were conducted with gender, race, ethnicity, income, having health insurance, and receiving therapy as the independent variables and the three measures of activation as the dependent variables. Significant predictors included receiving therapy, F(547) = 5.48, p = 0.001, Partial Eta Squared = 0.029; the remaining predictors were not statistically significant, race, F(529) = 1.17, p = 0.322, Partial Eta Squared = 0.007, ethnicity, F(526) = 1.76, p = 0.153, Partial Eta Squared = 0.010, parent gender, F(520) = 0.61, p = 0.611, Partial Eta Squared = 0.003, income, F(435) = 2.06, p = 0.105, Partial Eta Squared = 0.014, and having health insurance, F(544) = 0.91, p = 0.438, Partial Eta Squared = 0.005. That is, only the model for receiving therapy was significant. However, when the individual scales were examined, the between-subject effects were non-significant after applying the BH correction (Factor 1, p = 0.279; Factor 2, p = 0.016; Guttman total score, p = 0.067). Overall, there were no statistically associated differences found between the activation scales and race, ethnicity, gender, income, receiving therapy, and having health insurance, respectively, p > 0.05.

Table 3	Paired sample t-tests of
the three	e activation measures

	Time 1		Time 2		t	р	
	М	SD	М	SD			
Guttman PAM	67.48	10.59	67.88	11.61	-0.68	0.500	
Factor 1	28.55	4.48	28.67	5.04	-0.59	0.559	
Factor 2	13.70	2.24	13.67	2.28	0.30	0.765	

Table 4 Correlations between
change scores in the three
activation measures (Time
2 – Time 1)

	PAM Guttman change score	Factor 1 change score	Factor 2 change score
Caregiver Education	0.02	0.02	-0.01
income	-0.04	-0.03	0.00
Private Insurance	0.12	0.13	0.05
Public Insurance	-0.09	-0.08	0.01
Total Comorbidities	0.06	0.02	0.03
Change Sleep problems	0.02	0.03	-0.01
Change Peds Quality of Life	0.17	0.13	0.12
Change ABC Irritability	-0.06	-0.09	-0.01
Change ABC Lethargy	-0.10	-0.02	-0.08
Change ABC Stereotypy	-0.05	0.05	-0.08
Change ABC Hyperactivity	-0.01	0.01	-0.06
Change ABC Inappropriate Speech	0.08	0.10	-0.03
Change Internalizing Problems	0.04	0.04	0.09
Change Externalizing Problems	0.03	0.02	0.05
Change Parental Concern	-0.10	13	-0.02
Change Therapy Received	-0.05	-0.07	-0.01
Change Adaptive behaviors	0.05	0.12	-0.01
Change AIM	-0.04	-0.01	-0.03
Change CGSQ	-0.11	-0.10	-0.09

*Analyses that meet BH significance criteria

Discussion

Activation has caught the interest of researchers, health care and service organizations, and clinical providers as a means to reduce disparities in service outcomes and evaluate service quality for features of the Family-Centered Care or Chronic Care Model. Although activation was initially studied in adult populations with chronic health care problems, more recent research has focused on children and from the perspective of their caregivers. This is the second of two companion studies to characterize parent activation of autistic children in a large nationwide sample both cross sectionally (Yu et al., 2023) and over time using a predictive model. In this sample, we found that activation is consistent and stable over time. It appeared to act more like a trait or characteristic, with little evidence for potential change over time. However, research suggests that changes in activation can occur. In a randomized controlled intervention study, Thomas et al. (2017) examined the effectiveness of an activation intervention of 172 Latino parents of children with mental health needs. Called MePrEPA, their intervention resulted in higher activation scores using the parent PAM for mental health suggesting that changes in activation are sensitive to an intervention. In another study, Crossman et al. (2020) evaluated parent activation for parents before and after receiving family navigation and case management services. They observed that case management correlated with improvement in activation, but only for the group that received family navigation services prior to assessment of activation. Together these results suggest that on its own, activation may be largely resistant to change without targeted intervention.

Because of our prior study of evidence that the PAM-DD items were neither cumulative nor unidimensional (Yu et al., 2023), we analyzed results using the Guttman method and by the Factor 1-Activated and Factor-Passive method. Results replicate the prior study's two-factor interpretation of the PAM-DD, with each factor/subscale displaying dissimilar results. These differences in findings are consistent with DeCamp et al. (2016) who cautioned against use of the PAM with pediatric populations because of a different factor structure obtained in their sample of low-income English and Spanish speaking parents.

With respect to the association between parent activation and treatment and child outcomes at two time points, Time 1 activation, as assessed using either Factor 1 score or Guttman score, were nearly identically related to Time 2 demographic, child, parent, and treatment variables. Greater activation at Time 1, as assessed using either measure, related *improved* child and caregiver outcomes one year later (i.e., at Time 2). These results suggest that a more behaviorally active type of activation (such as feeling confident in "preventing or reducing problems associated with child's behavior and development," feeling confident in "helping child maintain changes, even during times of stress") may lead to improved child outcomes over time.

In contrast, Time 1 activation, when assessed using Factor 2–Passive, correlated with the demographic, child, parent, and treatment variables collected one year later in the opposite direction. Specifically, increased Time 1 Factor 2–Passive was consistently related to *poorer* child and caregiver outcomes at Time 2. Examples of Factor 2 items includes believe that "I am that person who is responsible for taking care of my child's behavior and development" and "I know what each of my child's medications are for." This suggests that there are two opposite constructs being measured (activated and passive) and that the more passive "activation" assessed by Factor 2, leads to poorer outcomes over time.

The stark differences between Factor 1 and Factor 2 subscales needs further investigation. Factor 1 defined activation seems most closely related to the original activation construct and to its predicted positive correlates. Specifically, activation should be a helpful characteristic, related to improved child (or patient) outcomes and thus should be encouraged, even developed. In contrast, Factor 2 activation defines a passive although supportive engagement with treatment, but, paradoxically, seems to be related, to poorer, more negative child outcomes. These results highlight the critical importance of understanding the differences between the two subscales and suggest, at a minimum, that treating PAM-DD scores as unidimensional risks missing important differences between factors within the scale, and argues for a more nuanced understanding of activation as represented by the PAM-DD measure.

Change in activation was not helpful in understanding changes in any of the other assessed variables. All the activation change scores were poor predictors of demographic, child, parent, and treatment change scores in general. In part this may be because activation scores tended to be quite stable over time, leading to small changes. These findings are in contrast with research from adult populations that show changes in patient activation are associated with health outcomes (Harvey et al., 2012; Hibbard et al., 2015).

Our final aim was to examine gender, racial, ethnic and other demographic group disparities in activation. Surprisingly, there were no significant differences in activation with respect to any of the demographic groups. That is, in our sample, activation, measured using any of the three methods, was quite stable both over time and across groups. These results were unexpected given prior research that Latinx populations experience lower levels of activation (Cunningham et al., 2011). Given the relatively smaller number in the minority groups, it is possible that this sample was not able to detect the disparities in parent activation. Racial differences in autism diagnosis and service access have been well documented in the literature (e.g., Maenner et al., 2021; Smith et al., 2020), which impact quality of life in marginalized groups (McManus et al., 2011). It is important to continue examining potential disparities in parent activation as it may be protective factors to caregiver outcomes.

Limitations and Recommendations

The study had several limitations. First, sample generalizability was limited. The sample was limited geographically to largely urban locations within the US. Further, the sample was limited to parents with reasonable transportation access to one of only 12 ATN sites. Another limitation is the higher attrition in parents from marginalized background at Time 2, which limited the representation of participants from diverse backgrounds in the sample. Also, it could be argued that the obtained sample was unintentionally limited to highly activated parents because the ATN represented services provided by tertiary care centers specializing in autism, possibly producing range restriction and ceiling effects in measured activation. However, a comparison of Guttman mean scores from our sample (range from 66.28 to 68.17) were lower than the mean scores reported by DeCamp et al. (2016). Their sample of 316 low-income parents reported Guttman mean scores for English speakers (79.1) and Spanish speakers (70.7). Further, Liberman and Pham (2018) sampled parent activation in a pediatric emergency department and observed an overall mean Guttman score of 73 for their Spanish speaking parents of children with chronic illness.

Implications

Our primary interest in activation is that it is one of several potential parent attributes believed to be positively associated with improving their child's socio-emotional/ behavioral outcomes. However, we know little about the relative strengths or relationships between these measures. The fact that the two subscales correlate in contradictory directions with treatment and outcome variables is of particular interest. There are now several parent activation measures—the Parent-PAM (PPAM, Pennarola et al., 2012; the parent PAM for Developmental Disabilities (PAM-DD; Ruble et al., 2018), and the parent PAM for mental health (P-PAM-MH; Green et al., 2019). Thus, we recommend further research to validate and understand activation as a helpful attribute when compared with alternate measures of parental adaptability (e.g., treatment acceptance, advocacy, resilience, self-efficacy, competency).

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Declarations

Conflict of interest The authors declare no conflict of interest.

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