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ORIGINAL PAPER

A Preliminary Study of Activation, Stress, and Self-Management of Parents of Children with Autism Spectrum Disorder

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Abstract Children with autism spectrum disorder (ASD) and developmental disabilities are high users of services, yet very little is known about how parents of these children interact with the health care system. Further, compared to parents of children with other developmental disabilities, parents of children with ASD experience more stress and dissatisfaction with services. Current efforts for improving services point to a need for understanding caregivers' perceptions of their own health-care related beliefs and actions. Activation is a construct that measures the belief, knowledge, action, and persistence of managing one's health care needs. The objective of this preliminary study was to evaluate the activation of parents of children with ASD using an adapted parent activation measure (PAM) for children with developmental disabilities called the PAM-DD. Data were collected from parents who received treatment as usual from a community-based outpatient treatment planning service for children with ASD. PAM-DD scores were compared with parent ratings of stress, self-management, and service satisfaction. Results indicated that increased activation correlated positively with parent report of satisfaction and ability to self-manage child issues such as eating, sleeping, and behavior and correlated negatively with parenting stress. The study of activation shows promise as a feature of quality of care for parents of children with developmental disabilities.

Key words Parent activation · Developmental disabilities · Autism spectrum disorder · Self-management · Parent stress

Introduction

Autism spectrum disorder (ASD) has a broad impact on the child and the family. For the young child, the diagnosis is based on significantly impaired development of social and communication skills as well as the presence of a restricted range of behaviors and interests. But developmental issues are often observed in other areas of basic self-help skills of daily living, such as eating (Schreck et al. 2004; Nadon et al. 2011) and toileting (Keen et al. 2007; Pituch et al. 2011), and problems with sleep (Andersen et al. 2008; Williams et al. 2004). Not surprising then, children with ASD are higher users of services and often require multiple types of services, including speech and language therapy, occupational therapy, and psychological services and may use between 3 and 7 different services simultaneously (Ruble and McGrew 2007; Thomas et al. 2007).

The impact of ASD also spills over to the family. Compared to parents of children with other types of disabilities, parents of children with ASD report higher stress (Hayes and Watson 2013), less satisfaction with their child's services (Bitterman et al. 2008; Montes and Halterman 2008b), and increased job loss and restriction with an accompanying loss of income (Buescher et al. 2014; Montes and Halterman 2008a)—issues that are exacerbated

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for racially and ethnically diverse families (Krakovich et al. 2016; Magaña et al. 2012).

Recognizing the need for better and more responsive services for those with chronic, lifelong conditions such as ASD (Carbone et al. 2013; Bitterman et al. 2008; Hodgetts et al. 2013), researchers have turned their attention to the study of two important constructs—self-management and activitation. Self-management is the ability to manage symptoms and consequences of a chronic condition (Barlow et al. 2002) that can include the medical aspects of the illlness, the changes in life roles as a result of the illness, and the psychological consequences of the illness (Lorig and Holman 2003). Activation is a closely aligned construct that includes aspects of self-management and refers to having the information, beliefs, skills, knowledge, and motivation to participate as an effective team member (Hibbard et al. 2004). Activation has been studied in a variety of contexts and is associated with improved outcomes across a range of health conditions, e.g., diabetes, arthritis, hypertension, and heart disease (Hibbard et al. 2007; Mosen et al. 2007). The most commonly used measure of activation is the Patient Activation Measure (PAM; Hibbard et al. 2004). The PAM assesses four stages of activation: (a) belief of the importance of the patient role for taking care of one's own health; (b) confidence and knowledge to take action regarding one's health care; (c) taking action to maintain or improve one's condition; and (d) persisting in the face of obstacles. The PAM assumes that activation proceeds through four developmental stages corresponding to the four levels. For example, the first level (belief) indicates the person may not yet believe or is just beginning to believe that the patient role is important. The second level (confidence) indicates that the person is developing confidence and knowledge to take action. The third level (action) means the person is beginning to take action. Finally, the last level (persistence) indicates that the person is developing skills to maintain behaviors over time. Persons with higher activation have better self-management skills (Druss et al. 2009; Greene and Hibbard 2012; Hibbard and Tusler 2007; Hibbard et al. 2004; Mosen et al. 2007; Rask et al. 2009).

For individuals with developmental disabilites such as ASD and their caregivers, research on activation is lacking. The lifelong impact, chronicity, and complexity of the disorder, which often mandates the need to coordinate care from multiple specialists (Beatson 2008) argues for the importance of understanding activation within this popoulation. The consumer-directed approach to health care rests on the assumption that involved, empowered, and activated consumers are critical for achieving an effective system of care. Accordingly, it is also essential to assess consumer activation and variables that facilitate or hinder one's belief, confidence, and ability to take action in one's own health care (Hibbard et al. 2004)—broad constructs that are different from other measures designed to predict a single behavior such as self-efficacy in self-management (Lorig et al. 2001; Lorig et al. 1996) and readiness to change (DiClemente et al. 1991; Prochaska et al. 1997). Studies of activation are needed to understand the levels and impact of activation across diverse populations to better inform services and as an important step in the development and implementation of clinical practices that are modeled from a family-centered or chronic care framework. For parents and caregivers of individuals with developmental disabilities, including ASD, activation may be particularly important as a number of studies describe the problems associated with obtaining care that is timely, of high quality, and is family-centered (Carbone et al. 2013; Bitterman et al. 2008; Hodgetts et al. 2013).

The original PAM only assessed activation of the individual adult with chronic health illnesses. Often for individuals with ASD, the critical actors involved in health care activation include the family, particularly the parents or caregivers. This is especially true for children and for many adults with intellectual disabilities whose parents and caregivers remain the primary support, legal guardian, and medical decision makers throughout adulthood (Arscott et al. 1999; Cantor 2005; Freedman 2001). For children with disabilities or adults with lifelong developmental/intellectual disabilities requiring caregiver support, activation of the proxy decision-maker can be just as important as patient activation in ensuring high quality care. One may argue, then, that the critical elements and "actors" that support and underlie activation will change based on aspects of the diagnosis (e.g., acute illness vs. chronic disability) and client characteristics (e.g., adults vs. children, independent vs. dependent on others). For young children and for families of those individuals with intellectual disabilities that may need support with decision-making, such as some individuals with ASD and/or intellectual disability, parental or caregiver activation is clearly paramount. Services researchers and providers, therefore, would benefit from studies of activation of the medical decision-makers. More specifically, the study of parent activation holds promise for the formal evaluation of practices designed to improve partnership with caregivers thereby improving the quality of life of children and adults with developmental disorders across the lifespan.

The goal of this preliminary study was to examine the relationships between parent activation and self-management, parent stress, and service satisfaction. To guide our research questions, we used a framework based on the Chronic Care Model that considers activation and self-management as critical for predicting healthcare outcomes (Bodenheimer et al. 2002). Our research questions were: (a) what stage of activation do parents of ASD report; (b) what is the concurrent and predictive relationship between parent activation and self-management, stress, and satisfaction at baseline and post-TPS (described in methods) and (c) what is the relationship between changes in parent activation from pre to post TPS with indicators of parent stress and satisfaction at post TPS?

Method

Participants

A total of 36 parents of children with ASD receiving TPS participated. Children of parents in the study all met the definition of Autistic Disorder according to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (American Psychiatric Association 2004) as confirmed by the Autism Diagnostic Observation Schedule (ADOS; Lord et al. 2000). The ADOS is a standard diagnostic instrument for identifying individuals with ASD and has good criterion validity and sensitivity. Children's ages ranged from 2.3 to 15 years, with a mean of 6.9 years (SD = 3.9). Eighty-nine percent of the children were male. Our study was approved by the human subjects committees at the Cincinnati Children's Hospital Medical Center and the University of Kentucky.

Procedure

Description of TPS

TPS is a model of outpatient multidisciplinary care based on collaborative parent–child service planning and decision-making developed at the Kelly O'Leary Center for Autism Spectrum Disorders (TKOC) at the Cincinnati Children's Hospital Medical Center (CCHMC). The aims of TPS are to identify parent concerns, assist parents in obtaining services based on parent priorities and concerns, and provide direction for navigating the complex service system. It was originally developed as a means to address the needs of parents and children who were on long waiting lists for direct services from the center by providing recommendations meant to help guide parents in the selection and receipt of community-based services and to have confidence in their decisions. Specifically, the TPS team gathers input from a multidisciplinary 2-hr assessment consisting of the caregiver, child, a psychologist, speech language pathologist, and occupational therapist. The session consists of direct interaction with the child as well as discussion with the caregivers. Recommendations are prioritized and developed based on caregiver top concerns and team observation. Specific next steps toward recommendations are reviewed with the family at the end of the session.

A consecutive recruitment approach was applied for parents referred to TPS. Parents provided informed consent prior to entry into the study. As part of the consent, parents agreed to allow researchers to access their child's electronic medical records for verification of ASD diagnosis and to complete questionnaires about the family and their child via an audiotaped phone interview. Families not comfortable speaking in English were ineligible for the study. If families had more than one child receiving TPS, one child was randomly selected for analysis. A total of 158 parents or caregivers who had scheduled a TPS were approached 1 month prior to date of services. Of these, 96 parents/caregivers were excluded for the following reasons: 11 failed inclusion criteria for not being comfortable speaking English ($n = 6$) or for cancelling or rescheduling the TPS ($n = 5$); 59 were nonresponsive to attempts to be reached by phone or mail for having a disconnected phone number ($n = 10$) or for not responding to at least three contact attempts of phone messages or mailings ($n = 49$); and 26 declined to participate because of a lack of interest ($n = 24$) or a family health issue ($n = 2$). Thus, a total of 36 parents/caregivers were enrolled in the study. Of these, 23 were able to be reached and completed time 2 of the study activities.

After the TPS was scheduled, a research assistant called the home and obtained oral consent from a parent. A written consent was then mailed and returned via US mail. Four measures were administered. With the exception of the TPS satisfaction measure that was administered only once following TPS, all other measures were administered twice, prior to and within approximately one to two weeks following the TPS.

Measures

Parent activation measure for developmental disabilities (PAM-DD)

Under license with Insignia Health and with permission, we adapted a parent version of the short form of the original PAM (Hibbard et al. 2004) for use with parents of children with developmental disabilities (PAM-DD). The original 13-item Parent PAM was tested with 198 parents of children with pediatric hematopoietic stem cell transplant and achieved good internal consistency (alpha = .85; Pennarola et al. 2011). For our measure, items from the parent version of the PAM were modified to better reflect the services used by children with ASD and other developmental disabilities in order to encompass behavioral health and developmental issues, as well as medical health issues (e.g., replaced the original item "When all is said and done, I am the person who is responsible for taking care of my child's health" with "When all is said and done, I am the person who is responsible for taking care of my child's development and

Table 1 Raw score mean and standard deviations for PAM-DD items and percentage of total scores by level

	Item	Raw mean[a] (SD)		Percent reporting at level[b]		Z[c]
		Pre	Post	Pre	Post	
Believes active role important	I believe that I am the person who is responsible for taking care of my child's behavioral and developmental needs	3.64 (.54)	3.81 (.40)	8	0	−1.0
	Taking an active role in my child's behavioral and developmental care is the most important thing that affects his/her developmental outcomes	3.75 (.44)	3.62 (.50)			
Confidence and knowledge	I am confident I can prevent or reduce problems associated with my child's behavior and development	3.17 (.65)	3.05 (.59)	19	19	−.45
	I know what each of my child's medications are for	3.70 (.47)	3.71 (.47)			
	I am confident that I can tell when I need to get services for my child and when I can handle my child's behavior and development concerns myself	3.31 (.75)	3.24 (.70)			
	I am confident I can tell my service provider concerns I have about my child, even when he or she does not ask	3.50 (.70)	3.62 (.59)			
	I am confident that I can follow through on behavioral and developmental treatments I need to do for my child at home	3.28 (.66)	3.29 (.72)			
	I understand the nature and possible causes of my child's behavior or developmental concerns	2.97 (.70)	3.14 (.57)			
Taking action	I know what treatments are available for my child's behavior and development	2.83 (.65)	3.14 (.73)	33	43	−1.4
	I have been able to implement recommendations to help my child maintain behavioral and developmental skills	3.17 (.56)	3.33 (.48)			
	I know how to prevent problems with my child's behavior	2.81 (.67)	3.10 (.70)			
Staying the course under stress	I am confident I can figure out solutions when new situations arise with my child's behavior and development	2.81 (.67)	3.00 (.71)	39	38	−1.0
	I am confident I can help my child maintain changes (progress), even during times of stress	3.00 (.68)	2.91 (.70)			

Based on Likert Scale 1 "disagree strongly" to 4 "agree strongly"

[a] Based on item raw score

[b] Percentage of responses based on total PAM-DD score that fell within each level

[c] Based on Wilcoxin Signed Ranks Test

behavior"). Table 1 provides a description of the PAM-DD. This preliminary version of the PAM-DD was reviewed by a group of parents and providers at TKOC, whose feedback was incorporated into the final version. Items are scored using a 4-point a Likert-type scale (1 = disagree strongly to 4 = agree strongly). Raw scores are summed and scaled from 0 to 100 using weighted scores based on Guttman scaling. The weighted scores were used for data analysis. Higher scores correspond to higher activation. PAM-DD internal consistency was .83. Stability over time was good (r = .76, p = .00) based on correlations between PAM-DD given prior to and following receipt of TPS.

Self -management assessment (SMA)

The SMA is a site specific measure that was adapted from a tool created as part of a CCHMC quality improvement (QI) initiative on self-management and reviewed and adapted based on feedback from parents of children with ASD who are members of the Kelly O'Leary Quality Assurance team. The SMA asks parents to rate how well they can manage their child's behavior across five areas (a) sleep, (b) behavior, (c) eating, (d) toileting, and (e) school issues. Each area was rated using an 11-point scale (0 = cannot manage; 10 = can fully manage). The mean score for each of the five areas was used in the analysis as well as the overall mean score for all areas combined. The internal consistency (alpha) was .57.

Parenting stress index (PSI)

The PSI-Short Form (PSI-SF; Abidin 1995) is a 36-item instrument derived from the original 101-item PSI questionnaire to assess parenting stress. The PSI-SF yields a Total Stress score and three subscale scores: Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCDI), and Difficult Child (DC). The PD subscale assesses the distress a parent experiences as a result of the parenting role and personal factors associated with parenting, such as a lack of social support or parental depression. The PCDI subscale assesses parent perceptions of his or her interactions with the child as positive (rewarding) or negative (not satisfying). The DC subscale measures behavioral characteristics of the child that makes it easy or difficult to manage the child due to temperament, noncompliance, or demandingness. Items are rated using a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree). The PSI-SF has been shown to be a valid and reliable measure for parents of typically developing children, with internal consistency coefficients (Cronbach's alpha) of .80 to .87 for the three subscales. Research (c.f. Zaidman-Zait et al. 2010) indicates that Parent–Child Dysfunctional Interaction and Difficult Child subscales should be used with caution with parents of young children with ASD due to difficulty in discriminating parents across a range of total stress severity. Thus, only the Total Stress score was used.

Parent satisfaction with TPS

A satisfaction measure was adapted for use in the current study from a satisfaction survey developed by the investigators for randomized controlled trials (RCT) of a consultation intervention for children with ASD. Items were rewritten to replace "consultation" with "TPS." The satisfaction survey tapped into two different domains. The first area assessed satisfaction with TPS and the second area assessed satisfaction with the TPS clinician. The TPS related items were comprised of 11 questions such as "I gained a better understanding of my child across settings." The clinician items were comprised of six questions such as "I felt involved during the TPS and able to express my views." Respondents rated items using a 4-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). The internal consistency (alpha) was .94 for the TPS satisfaction items and .81 for the clinician satisfaction items.

Data Analyses

Our data analytic plan was designed to answer our three primary research questions. For the first question, to describe the stage of activation prior to and following TPS, descriptive statistics were applied based on raw scores. Raw scores were used instead of weighted scores because the weighted scores are based on the overall PAM-DD score, not allowing for comparison at the item level. For the second question, to assess cross-sectional associations, Pearson correlations were calculated between the PAM-DD weighted scores and stress, and the mean and individual level scores of the five domains of self-management, i.e., sleeping, behavior, eating, toileting, and school issues, measured concurrently. For the third question, to assess the potential impact of change in activation, PAM-DD change scores (post-scores minus baseline scores) were calculated and then correlated with post measures of mean and individual level scores of stress, and satisfaction with clinician and satisfaction with TPS. Because prior studies of patient activation indicate that activation is related to increased self-management and well-being, including reduced stress, and increased satisfaction (Hibbard et al. 2007; King et al. 1999; Mosen et al. 2007), tests for these correlations were interpreted as one-tailed, with significance set at $p < .05$.

Results

Analysis of the overall weighted mean score prior to TPS revealed a score of 62.9 (Mdn = 63.1; SD = 11.1).

According to Insignia, this score falls within Level 3 of the PAM—beginning to take action. Analysis of the percent of parents who fell within each stage of the PAM revealed that 8.3% fell within Stage 1; 19.4% fell within Stage 2; 33.3% fell within Stage 3; and 38.9% fell within Stage 4 (see Table 1).

Following TPS, the overall weighted mean score slightly increased from 62.9 to 66.4 ($\text{Mdn} = 60.6$; $\text{SD} = 15.1$), which reflects the same stage of activation assessed prior to TPS; although the post TPS score just missed level 4 by 0.6 points. Analysis of PAM-DD items by raw score means and standard deviations are reported in Table 1. When examining the percent of parents whose total weighted score fell within each stage of the PAM following TPS, no parents fell within Stage 1; 19% fell within Stage 2; 43% fell within Stage 3; and 38% fell within Stage 4 (see Tables 1 and 2). Compared to pre scores, the largest percent change was Stage 3, from 33.3 to 43%. Although the percent of parents who fell within the ranks changed over time, statistical analysis of change based on Wilcoxin Signed Ranks Test was not significant overall, $z = -.33$, $p = .74$.

With respect to activation, raw scores for each domain of activation obtained pre and post TPS showed patterns consistent with the developmental approach aligned with activation (see Table 2). That is, at baseline, scores were highest for the lowest numbered items and lowest for the highest numbered items. Specifically, raw scores at baseline were highest for areas of belief of the importance for taking responsibility (3.63) and an active role (3.75) for child's behavioral and developmental care as well as knowledge of medications (3.70). These items fall within the first four items in the scale and as mentioned are thought to emerge first and to be the easiest to achieve (Hibbard et al. 2004). At baseline, the lowest mean raw scores were reported for knowing how to prevent problems with child behavior (2.81), confidence for figuring out solutions when situations arise with child behavior and development (2.81), and knowing what treatments are available for child behavior and development (2.83). Although these items represented belief and skills thought to be more difficult to achieve compared to the earlier items, unlike the overall mean scores by area, at the item level, parent mean scores did not rank from least to most difficult as predicted by the developers (Table 1).

Table 2 T-test comparison of mean score by level pre and post TPS ($n = 21$)

Area	Raw mean (SD) Pre	Raw mean (SD) Post	T-test	Sig	Effect size[a]
Believes active role important	3.71 .37	3.71 .37	.0	1.0	0
Confidence and knowledge	3.27 .40	3.35 .38	−.83	.42	.21
Taking action	2.98 .57	3.19 .52	−1.7	.10	.38
Staying the course under stress	3.00 .67	2.95 .65	.37	.72	.08

[a] Effect size Cohen's *d*

Assessment of PAM-DD scores following TPS did not result in many changes in relative ranking of scores. For the highest scored items, the same top three reported at baseline were also reported following TPS. Analyses of lowest item scores showed a generally similar pattern pre and post TPS. However, whereas before TPS, four items exhibited mean scores of less than three (3 = agree), indicating not quite full agreement with those concepts, only one item after TPS had a mean score below three. The lowest scored (most difficult) item was the last question—I am confident I can help my child maintain changes (progress), even during times of stress.

Analysis of the concurrent relationships between parent activation assessed prior to TPS with key variables of stress and self-management is shown in Table 3. Results indicated a significant negative correlation between activation and parent stress ($r = -.53$, $p = .001$) and a positive correlation with overall mean self-management scores ($r = .54$, $p = .001$). Significant correlations were observed between activation and mean self-management skills for two of the five child issues assessed: child problem behavior ($r = .71$, $p = .000$) and eating issues ($r = .37$, $p = .014$). Analysis of the relationships between post measures of TPS activation and key outcomes is shown in Table 4. Results revealed similar significant concurrent correlations with parent stress ($r = -.57$, $p = .004$). Surprisingly, however, post parent activation assessed at the same time-point as satisfaction with TPS and satisfaction with the clinician were not correlated ($r = .23$, n.s.; $r = .22$, n.s., respectively). Also, it should be noted that parents reported high satisfaction with TPS. The mean score for satisfaction with TPS was 3.1 ($\text{SD} = .60$) out of a possible 4.0 and for satisfaction with clinician was 3.7 ($\text{SD} = .43$).

Longitudinally, evaluation of the amount of pre-post change in activation told a similar story overall (see Table 4). Change in activation correlated negatively with post parent stress scores ($r = -.41$, $p = .034$). That is, parents with higher pre-post change in TPS activation (i.e., improved activation) reported lower stress. When change in activation was examined with change in parent stress, a trend was found in the expected direction ($r = -.33$, $p = .075$, one-tailed). There also was a significant correlation between pre-post change in activation and clinician satisfaction ($r = .41$, $p = .032$) only.

Table 3 Intercorrelation matrix of time 1 PAM-DD, self-management, and stress

	1	2	3	4	5	6	7
1.T1 PAM-DD	–						
2.T1 Sleep	.19	–					
3.T1 Behavior	.71**	.25	–				
4.T1 Eating	.37*	.12	.15	–			
5.T1 Toileting	.15	.33*	.28*	.12	–		
6.T1 School^{a}	.27	.37*	.20	−.00	.19	–	
7.T1 Overall self-management	.54**	.74**	.59**	.41**	.74**	.55**	–
8.T1 Stress	−.53**	−.32*	−.39**	−.46**	.00	−.23	−.36*

Note: Based on 1-tailed test; Because prior studies of patient activation indicate that patient activation is related to increased self-management and well-being, including reduced stress (Golnik et al. 2012), tests for these correlations were interpreted as one-tailed, with significance set at $p < .05$.

T1 baseline weighted scores prior to TPS ($n = 36$), *T2* post scores following TPS ($n = 21$)

[a] 4 children not in school

$^{*}p < .05$; $^{**}p < .01$; $^{***}p < .001$

Table 4 Intercorrelation matrix of PAM change and time 2 stress and satisfaction

	1	2	3	4
1.T2 PAM-DD	–			
2.PAM Change (T2-T1)	.60**	–		
3.T2 Stress	−.57**	−.41*	–	
4.T2 Satisfaction with TPS	.23	.33	−.24	–
5.T2 Satisfaction with clinician	.22	.41*	−.54**	.66**

Note: Based on 1-tailed test

T2 post weighted scores following TPS ($n = 21$)

$^{*}p < .05$; $^{**}p < .01$; $^{***}p < .001$

Discussion

In the current study, we examined the relationships between activation of parents of children with ASD who received a community-based outpatient service designed to provide guidance and support addressing primary concerns for their child. We also examined how activation impacted parent stress, self-management, and satisfaction with services.

The PAM was created to reflect a developmental model that assumes that beliefs about one's role as a patient and basic knowledge about one's condition are critical early steps and require less activation compared to skills and confidence for identifying when care is needed, follow up with treatment recommendations, maintain changes, and persist when facing challenges related to care. Our data supported these underlying theoretical assumptions concerning a developmental process in activation. Analysis of item mean raw scores indicated highest scores for belief of the importance of their role in their child's developmental and behavioral care and lowest scores for maintaining a course of action in the face of challenges.

Analysis of overall change in activation weight scores revealed no change following a single TPS visit, however we observed a general pattern reflecting an increase in the percentage of parents moving to a higher level. For example, prior to TPS, PAM scores for three parents fell within Level 1 of the PAM, but following TPS, no scores fell within the first stage. Overall, analysis of the distribution of parents within each activation level was consistent with activation from other populations. For comparison, Insignia (2013) reports that less than 12% of patients are categorized as Level 1 and about 29% are categorized at Level 2. The largest majority score at Level 3, 36.5% and about 22% score in Level 4. Similarly, our parents showed the highest number in Level 3 prior to and following TPS.

Further, analysis of change in activation revealed significant correlations in change in important outcomes, such as stress—findings that are consistent with other research (Harvey et al. 2012). Importantly, not only did activated parents rate themselves as more able to manage their children's issues, they also reported less stress. This finding may seem counterintuitive because activation seems to imply activity, and activity can be stressful. Perhaps activation represents a problem focused or other active coping style, as suggested by Hibbard et al. (2004) an approach often associated with less stress. Moreover, the preliminary evidence is that the PAM-DD is sensitive to measuring the kinds of issues that are relevant to parents of those with ASDs and that are extremely challenging and stressful for parents. Taken together these findings provide initial support for the significance of studying parent activation.

Because stress is frequently elevated in parents with ASD (Hayes and Watson 2013; Krakovich et al. 2016), these results potentially have implications for clinical intervention. Specifically, interventions that target activation with the intention of improving services for children with ASD may potentially reduce parent stress at the same time.

Preliminary results also indicated as expected that activated parents, i.e., those with higher PAM-DD scores, were more likely to rate themselves as able to self-manage their children's needs across a variety of domains that are often extremely difficult for parents and occur with high frequency (sleep, eating, toileting, behavior). These significant associations between activation and self-management are consistent with prior work (Hibbard et al. 2007), while also extending this work to the parent domain of children with ASD.

One key question is how activation might work to generate better self-management. Self-management encompasses a variety of potential behaviors and has a much longer history compared to activation. First coined in the 1960s (Lorig and Holman 2003) by Creer who worked with children with pediatric asthma (Creer et al. 1976), self-management was viewed as active participation in treatment. Activation expands on self-management by considering one's belief of the importance of care, in addition to management of care. Our assessment of self-management was based on a simple clinical parent rating that is administered as part of routine care—parent report of ability to manage issues common to children with autism. The measure was sensitive to changes in activation and also parent stress assessed at the same time point.

In the current study, compared to our assessment of self-management, activation is considered a more complex set of behaviors that range from being involved and active in treatment to having the knowledge, skills, beliefs, and behaviors that a patient needs to manage a chronic condition. In developing their conceptualization of activation, Hibbard et al. (2004) reviewed the literature on skills and knowledge needed to manage a chronic illness. Their summary pointed to the importance of self-management for symptoms, engagement in activities to maintain function, involvement in treatment and choices, collaboration with providers, selection of providers based on quality, and navigation of the health care system—factors that lead to better health outcomes, including better preventive health behaviors, better clinical outcomes, lower rates of hospitalization and costs, and more positive experiences of care (Hibbard and Gilburt 2014).

A major question is whether intervention can impact activation. Activation interventions for ASD are warranted given the chronicity of concerns, high use of services across the lifespan of individuals, and the stress associated with obtaining services. Insignia (2013) provides guidelines for using the PAM to adapt care. They describe strategies for moving the interaction style between provider and patient from provider-centered to a patient-centered approach using motivational interviewing strategies and action planning. Further, they provide a breakdown of patient characteristics for each level of the PAM, strategic goals, and specific action plans. A study designed to reduce the attrition of minority clients in mental health care services showed that participants receiving an activation and empowerment intervention were more than twice as likely to be retained in treatment and more than three times as likely to have scheduled at least one visit during the 6-month follow-up period than comparison participants (Alegría et al. 2008). Thus, activating the parent seems like an important potential goal for treatment. Our own data, while not targeting activation specifically showed an increase in raw activation scores. Also the fact that activation increased most for those satisfied with the clinician implies the importance of the clinician in motivating this change. Moreover, activation, in this study, lead to desirable outcomes for both the child potentially (i.e., better self-management) and the parent, (i.e., less stress).

Limitations

This study was based on a small and limited sample that represented services as usual. While this is strength, there are several variables that would be important for a future study such as the impact of income, education, race, and ethnicity on activation. Moreover, most users of TPS did not choose to participate in the study, implying that our sample was different in some ways and that the results may not generalize. Further, data were not gathered on clinician adherence to the TPS intervention. This information would provide data on the consistency in delivery of the intervention across therapists.

Future research should include the study of activation within a larger sample of parents from a diverse population and also include children across a broader age range or with other disabilities. Another focus of future research should include activation as an outcome measure within a chronic illness framework. For example, future work is needed evaluating whether standard clinical practices are leading to improved parent activation and in evaluating the impact of parent activation on overall patient outcomes. Another possible area is to study activation associated with underserved and minority families given the documented disparities in medical and educational services. Thus, future studies on parent activation have promise as an area of intervention, but also as a variable of service effectiveness. In particular, intervention studies of models such as TPS that emphasize care coordination might examine longitudinal impacts of activation on parent and child outcomes.

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Compliance with Ethical Standards

Conflicts of interest The authors declare they have no competing interests.

Ethical Approval The study was approved by the human subjects committees of the University of Kentucky, Cincinnati Children's Hospital, and the University of Cincinnati.

Informed Consent All participants provided informed consent prior to participation in the study.

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