Psychological Inflexibility and Adherence to the Therapy among Parents of Autistic Children

Inflexibilidad psicológica y adherencia a la terapia entre padres de niños autistas

Abstract
The parenting strategies applied to address the developmental demands of children with autism generate emotional difficulties, affect the emission of behaviors related to their children’s psychological processes, and consequently influence therapeutic adherence. This study aimed to determine the relationships among the different processes of psychological inflexibility (experiential avoidance, obstruction, cognitive fusion) and therapeutic adherence (communication and actions) among parents of children diagnosed with autism spectrum disorder (ASD). The data were collected through a sociodemographic data survey, the Therapeutic Adherence Scale, the Cognitive Fusion Questionnaire (CFQ), the Valuing Questionnaire (VQ), and the Experiential Avoidance Scale (AAQ-II). The analysis was done using a retrospective simple ex post facto group design. The structural equation analyses revealed that parents show patterns of psychological inflexibility, which affect the behaviors related to treatment adherence.

Keywords: Autism; psychological inflexibility; adherence; parents.
acciones) entre los padres de niños diagnosticados con trastorno del espectro autista (TEA). La muestra consistió en 25 padres de entre 30 y 62 años ($M = 40; \text{DE} = 1.45$) de niños diagnosticados con TEA, quienes se sometieron a una terapia de modificación de la conducta. Se administraron una encuesta de datos sociodemográficos, la Escala de Adherencia Terapéutica, el Cuestionario de Fusión Cognitiva (CFQ), el Cuestionario de Valoración (VQ) y la Escala de Evitación Experiencial (AAQ-II). Para el análisis, se utilizó un diseño retrospectivo de grupo simple ex post facto. Los análisis de ecuaciones estructurales revelaron que los padres muestran patrones de inflexibilidad psicológica que afectan los comportamientos relacionados con la adherencia al tratamiento.

**Palabras clave:** autismo; inflexibilidad psicológica; adherencia; padres.

**Resumen**
As las estrategias de crianza aplicadas para abordar las demandas de desarrollo de las niñas con autismo geran dificultades emocionales, afectan la emisión de conductas relacionadas con los procesos psicológicos de sus hijos, y por lo tanto, influyen en la adherencia terapéutica. Este estudio tuvo como objetivo determinar las relaciones entre los diferentes procesos de inflexibilidad psicológica (evitación experiencial, obstrucción, fusión cognitiva) y adherencia terapéutica (comunicación e acciones) entre los padres de niños diagnosticados con trastorno del espectro autista (TEA). La muestra consistió en 25 padres de entre 30 y 62 años ($M = 40; \text{DE} = 1.45$) de niños diagnosticados con TEA que se sometieron a una terapia de modificación de la conducta. Se administraron una encuesta de datos sociodemográficos, la Escala de Adherencia Terapéutica, el Cuestionario de Fusión Cognitiva (CFQ), el Cuestionario de Valoración (VQ) y la Escala de Evitación Experiencial (AAQ-II). Para el análisis, se utilizó un diseño retrospectivo de grupo simple ex post facto. Los análisis de ecuaciones estructurales revelaron que los padres muestran patrones de inflexibilidad psicológica que afectan los comportamientos relacionados con la adherencia al tratamiento.

**Palavras-chave:** autismo; inflexibilidade psicológica; adherência; pais.
An aspect to be considered regarding the parents’ role in the treatment of children with ASD is caregiver wear and tear, which is the result of the children’s low social functioning, their marked difficulties in expressing affection and reciprocity toward their parents, communication problems, and the manifestation of stereotyped behaviors. In addition, knowledge regarding the etiology and prognosis of the disorder are lacking (Jennings-Dunlap, 2019). Additionally, previous studies have reported emotional difficulties in parents associated with the situation of having a child with ASD. Parents of children with autism experience chronic stress characterized by guilty feelings toward themselves or emotions of anger toward their partner associated with their child’s condition, as well as depression, denial, and confusion after the autism diagnosis (Blackledge & Drake, 2013; Crowell, Keluskar, & Gorecki, 2019; Eikeseth, Klintwall, Hayward, & Gale, 2015).

Thus, autism has been identified as one of the most complex childhood disorders; it has also been determined that intervention models that apply a behavioral approach have shown higher levels of effectiveness (Szabo, 2019; Virués et al., 2010). In these interventions, parents are crucial for achieving important, lasting changes. Therefore, treatment adherence should be considered a fundamental factor with regard to the success of interventions established by professionals addressing this issue (Burnham Riosa, Khan, & Weiss, 2019; Fteiha & Al Bustami, 2018). Adherence is understood as the ability of parents to comprehend and perform behavioral modification procedures in a conscious and consistent manner (Allen & Warzak, 2013).

Bagner and Eyberg (2003) studied the effects of parental adherence on their children’s treatment. They concluded that when parents are involved in the intervention process, the skills learned by the children in a formal training context achieve generalization, and children acquire higher levels of independence and self-care in daily life. Additionally, it has been emphasized that adherence is promoted when linked to personal goals (Levin, Potts, Haeger, & Lillis, 2018).

Few studies have focused on parental adherence to ASD treatment. Moore and Symons (2011) found that adherence to behavioral treatment recommendations was significantly lower than adherence to drug-based treatments among parents of children with ASD. The low adherence to behavioral recommendations is likely to have important consequences for children with ASD because their treatments often involve generalized changes in parental behavior (Hock, Kinsman, & Ortaglia, 2015).

This study aims to be a reference in the major needs of parents of children with ASD, given the effects that exposure to situations of high demand and little control have on mental health. In addition, it seeks to clarify the strategies used to address child interventions and investigate how these strategies affect adherence to the programs offered to treat children with ASD.

Therefore, we evaluated the processes of psychological inflexibility based on contextual therapy, specifically, and the Acceptance and Commitment Therapy (ACT). Psychological inflexibility occurs when the person is unable to get out of the verbal rule that governs their behavior in a given situation and creates difficulty in making their behavioral repertoire more flexible (Spiedel, Lecomte, Kealy, & Daigneault, 2018).

According to ACT, the primary source of psychopathology and human unhappiness is associated with the way language and cognition interact with the circumstances of each individual’s life, producing an inability to persist or make changes focused on achieving valuable long-term goals (Hayes & Walsh, 2007; Ribero-Marulanda & Agudelo-Colorado, 2018). As such, ACT is organized into six components or processes: acceptance, cognitive diffusion, being present, self as a context, values, and committed action toward these values (Hayes, Wilson, Robinson, & Strohsal, 2014). These processes interrelate, overlap, and complement each other to achieve psychological flexibility (Hayes et al., 2006).
Each ACT process determines a particular feature that explains psychological inflexibility: a) a lack of self-knowledge related to a lack of self-contact in the present moment; b) a lack of clarity when people engage in actions that are inconsistent with their values; c) attachment to the conceptualized self as the way in which people define themselves with qualifying language; d) cognitive fusion, where the contents of thoughts, emotions, bodily sensations, and memories are taken as the true interpretations of experience, and e) experiential avoidance expressed as the unwillingness to contact unpleasant psychological events or as attempts to change the content or reduce the frequency of these undesirable experiences (Ciarrochi, Bilich, & Godsel, 2010).

Thus, the relevance of thorough studies (such as the current research) that account for issues of clinical significance includes three fundamental aspects: the increased prevalence of children with autism, the development of emotional and affective alterations among the parents of children with this diagnosis, and the clinical need for effective processes with positive effects on the development and quality of life of caregivers and children with autism. Therefore, the following research question was posed: What is the relationship between the psychological inflexibility of parents with children with ASD and their children’s treatment adherence? This study hypothesizes that the psychological inflexibility of parents to address the developmental demands of their children with ASD, characterized by cognitive fusion, experimental avoidance, obstruction, lack of clarity in values, difficulty in being in the present moment, inactivity, or impulsivity generate greater emotional disturbances that affect the emission of ineffective behaviors related to the psychological processes of their children and, consequently, interfere with therapeutic adherence. For that reason, we seek to determine the role that psychological inflexibility plays in parents of children with ASD on their children’s treatment adherence.

Method

Participants

The participants were selected via convenience. The sample was composed of 25 parents between the ages of 30 and 62 years old ($M = 40; DS = 1.45$) whose children were diagnosed with ASD and who were attending to behavioral modification therapy at an institution specialized in the treatment of ASD. A total of 28% were teachers, 36% had professional training, and 72% were married (table 1).

Table 1. Sociodemographic characteristics of the participants

| Variable    | Category | $F$ | %  |
|-------------|----------|-----|----|
| Age         | 30-40 years | 13  | 52 |
|             | 40-50 years | 6   | 24 |
|             | 50-60 years | 5   | 20 |
|             | Older than 60 years | 1   | 4  |
| Occupation  | Technical  | 4   | 16 |
|             | Engineer   | 5   | 20 |
|             | Independent | 3   | 12 |
|             | Homemaker  | 6   | 24 |
|             | Teacher    | 7   | 28 |
|             | High school | 4   | 16 |
|             | Technical  | 2   | 8  |
|             | Technologist | 5   | 20 |
|             | Professional | 9   | 36 |
|             | Postgraduate | 4   | 16 |
|             | Doctorate  | 1   | 4  |
| Civil status| Free union | 6   | 24 |
|             | Married    | 18  | 72 |
|             | Separated  | 1   | 4  |
| Total       |           | 25  | 100|

Instruments

Acceptance and Action Questionnaire-II — AAQ-II— (Ruiz, Langer, Luciano, Cangas, & Beltrán, 2013). This questionnaire, initially designed by Hayes et al. (2004) for the North American population, was subsequently adapted and validated for...
Spain by Ruiz et al. (2013) to assess psychological inflexibility and experiential avoidance. The items reflect the unwillingness to experience unwanted emotions and thoughts, and the inability to be in the present moment and behave in accordance with value-driven actions while experiencing undesired psychological events. It uses a seven-point Likert-type scale (7 = always true, 1 = never true). The instrument has been validated in Colombia and shows excellent psychometric properties (mean alpha between 0.88 and 0.91). The mean of the clinical sample was significantly higher than the scores of the nonclinical samples.

**Cognitive Fusion Questionnaire — cfq —** (Ruiz, Suárez-Falcón, Ríaño-Hernández, & Gil-Ilanders, 2017). This questionnaire was adapted for Spain to measure cognitive fusion as a fundamental construct of the psychopathology model according to act. It applies a seven-point Likert scale (7 = always true, 1 = never true). The original cfq was adapted into Spanish, and the psychometric properties were determined using a sample of 1763 participants. The internal consistency was high (Cronbach’s alpha between 0.89 and 0.93). The mean of the clinical sample was significantly higher than that of the nonclinical one.

**Valuing Questionnaire — vq —** (Smout, Davies, Burns, & Christie, 2014). This questionnaire evaluates the aspects of life established as valuable, and the committed actions performed, oriented toward those aspects. It uses a six-point Likert scale (6 = always true, 1 = never true). The vq has shown strong internal consistency, as well as convergent and incremental validity. It had high internal consistency across the different samples (Cronbach’s global alphas of 0.83 for progress and 0.82 for obstruction). The bifactorial model showed a strong fit to the data, and measurement invariance was found throughout the sample and with regard to gender. The means of the clinical sample for progress and obstruction were lower and higher, respectively, than those of the nonclinical samples. The correlations with other constructs were in the expected direction.

**Therapeutic Adherence Scale.** It consists of two subscales: communication (e.g., when you have a concern, you communicate with the therapist) and actions (e.g., implements the procedures that have been trained at home). The final scale comprised 18 items. It qualifies on the Likert scale of three response options (never, sometimes, always). It was elaborated and validated by five expert judges (three in the treatment of parents with children with ASD and two methodologists). This instrument was completed by the therapists who performed act. Subsequently, a concordance analysis was performed through Kendall’s W, which obtained acceptable consistency, with a score of 0.77 (which exceeds the value of 0.05).

**Sociodemographic Data Questionnaire.** This questionnaire was developed to collect information for the study, including personal data such as age, marital status, social stratum, educational level, occupation, health status of the mother during pregnancy, number of children, and period of diagnosis.

**Procedure**

This study was conducted across three phases.

First phase: The Likert scale was constructed to identify the adherence level of the parents, and a content validation was performed through the establishment of inter-rater reliability.

Second phase: The institution provided acceptance for the study and participant recruitment. The participants were presented with the objective of the research project, and informed consent was explained for subsequent agreement. The researchers applied the psychological inflexibility and sociodemographic data instruments to each parent. Then, the adherence scale was administered to the therapists in charge of the intervention of each child with autism.

Third phase: The data were processed using the Rasch and Winsteps model. Once the data were obtained, a structural equation analysis was used to establish the predictive model.
**Ethical Considerations**

According to the Declaration of Helsinki (World Medical Association, 1964) and Ley 1090 of 2006 (Congreso de Colombia, 2006), the objectives were explained to the participants and their informed consent was requested to participate in the study, emphasizing the willingness of participation and the confidentiality of the information provided. This study is classified as a minimum risk according to the guidelines of Resolution 8430 (Ministerio de Salud, 1993) since no manipulation of the variables was made, and only the scales were applied to the participants.

**Data Analysis Plan**

Initially, the content validation of the adherence scale was performed, seeking inter-rater reliability. As such, the instrument was evaluated by five expert judges, three of whom had knowledge of and experience with ASD cases; two were experts in methodology. The evaluation was performed using a Likert scale and three evaluation criteria: pertinence, writing, and language clarity. Once the results were obtained, the data and the respective analyses were performed in SPSS version 22.

The technique of structural equations was used in order to establish the relationship between the variables: psychological flexibility and adherence to treatment, and analyze the best fit model between these variables.

A model fitted to the sample was obtained and subjected to exploratory factor analysis (EFA) using the software AMOS version 22. To determine the fit of the data to the model, the CMIN/df (X² ratio, over the degrees of freedom) requires less than 3.0. When the sample is small, the non-centrality parameter (NCP) is used, which is an alternative measure of Chi-square; values less than 2 are acceptable (Escobedo, Hernández, Estebané, & Martínez, 2016). The GFI (Goodness of Global Adjustment Index), IFI (Incremental Fit Index), TLI (Non-Standardized Adjustment Index or Tucker Lewis) and CFI (Comparative Fit Index) vary between 0 and 1, where 0 means no adjustment and one means optimal fit; values higher than .90 represent an acceptable fit, while values of .95 or higher are considered excellent. The RMSEA (square error approach to medium roots) needs to be less than .08, and preferably less than .06 because if the model is greater than .10, it must be rejected (Pilatti, Godoy, & Brussino, 2012).

**Results**

The results are presented in three sections. First, the results of the content validity of the adherence scale are shown; then, the descriptive and correlational analyzes of the variables are presented. Finally, the adjustment model between the study variables is analyzed.

Relevance was evaluated using Kendall’s W coefficient of concordance, a nonparametric statistic for ordinal scale data, which allows researchers to establish the degree of agreement between ranks of n individuals. This analysis produced a score of .77, which exceeds the value .05; thus, the null hypothesis was rejected.

The extension and use of technical language were adjusted to facilitate understanding among non-expert therapists. In addition, items with an agreement greater than .05 were selected, whereas items with lower scores were eliminated. The final scale comprised 18 items that evaluated the two concepts addressed by the definition of adherence used for this study (communication and action).

Statistical analyses were performed depending on the normality of the sample, which was verified using the Kolmogorov-Smirnov statistic. All of the variables of psychological inflexibility (obstruction, experiential avoidance, and cognitive fusion) but actions variable was not normal, considering the level of measurement of each variable for the use of different statistics.
The three variables that compose the psychological inflexibility construct have a significant and inverse correlation with the actions of adherence to treatment. The correlations between experiential avoidance and cognitive fusion with the actions were significant at the .05 level. The correlation between the obstruction and the actions was significant at the .01 level (table 2).

The analysis of the structural equations shows that psychological inflexibility (experimental avoidance, obstruction, and cognitive fusion) and adherence to the therapy (actions) are significantly related. A negative effect of the first variable on the second was found since the relationship between these two variables has an estimated value load of -.51. In addition, it was found that the three variables (experimental avoidance, obstruction, and cognitive fusion), that make up the construct of psychological inflexibility, have loads of significant factors, which explain this variable from .78 to .98 (figure 1).

Table 2. Correlation analysis of the psychological inflexibility and adherence scales

|                | (n=24) | Obstruction | Experiential avoidance | Cognitive fusion |
|----------------|--------|-------------|------------------------|------------------|
| Communication  | Rho    | -           | -                      | -                |
|                | Sig.   | -           | -                      | -                |
| Actions        | Rho    | -.575**     | -.413*                 | -.419*           |
|                | Sig.   | .003        | .045                   | .041             |

Note: ** The correlation is significant at the level .01
* The correlation is significant at the level .05

Figure 1. Structural model of psychological inflexibility and its correlation with adherence. Adapted from Statistical Package for the Social Sciences (SPSS) version 22 (IBM, 2013)
As the actions’ variable was not distributed in a normal way, the procedure used to analyze the fit of the model was asymptotically distribution-free. Using a structural model, the implications of a theory are integrated into a model that reflects its conceptualization and relationships. Latent variables are included, their relationships and effects are evaluated, and the complete structure of these relationships is subjected to simultaneous verification (table 3).

According to the above results, significant relationships were found among obstruction, experiential avoidance, cognitive fusion, and the category of actions regarding the assessment of the adherence scale. The degrees of freedom are less than 3 (with a value of 2), showing fit to the data; the goodness-of-fit index was .99, and the $\chi^2$ was 1.00, which are within the expected range of 0-1 for an optimal fit; and the RMSEA was .00, the non-normed fit index was 1.00, and the IFI was 1.00. These data support the unidirectional relationship that was established between psychological inflexibility and adherence.

**Discussion**

Based on the objectives proposed by this research, this section has the following structure: First, the contributions of the adherence scale are indicated; then, the levels of psychological inflexibility and treatment adherence of the parents of children with ASD are analyzed; finally, the findings of two aspects are considered the most conclusive of this study. Specifically, we analyze parental psychological inflexibility and the variables used to approximate a predictive model in relation to the processes that constitute treatment adherence.

The design and validation of the adherence scale led to the creation of a valuable tool to objectively quantify the communication and actions evidenced by parents, regarding the behavioral treatment their children with ASD receive (Allen & Warzak, 2013; Buela-Casal, 2008), given that the ranges assigned by the experts coincided significantly (Escobar-Pérez & Cuervo-Martínez, 2008). As such, it was possible to establish a measurement of the level of communication that parents maintain with the work team, as well as implement the recommendations and procedures delivered by the professional in charge of the intervention. Thus, this study provides an approach to obtain relevant and useful psychological instruments. These tests become a necessary tool and must be subjected to a rigorous process of permanent construction and evaluation so that they have high levels of validity and reliability (Hernández, Tomás, Ferreres, & Lloret, 2015).

The levels of adherence shown by the parents evaluated from the observer’s perspective can be effective in identifying the parents’ committed actions on the therapy of their children (Suppo & Floyd, 2017). In addition, with ACT, parents increase their competencies to participate in treatment, probably because greater psychological flexibility is achieved and, therefore, more resistance to distress and greater acceptance of the emotional experience of having a child with a disability (Spiedel et al., 2018).

| Table 3. Analysis of the structural model of psychological inflexibility and adherence |
|---|---|---|---|---|---|---|---|---|
| $N$ | DF | $\chi^2$/DF | NCP | GFI | IFI | TLI | CFI | RMSEA |
| 25 | 2 | .79 | .000 | .99 | 1.00 | 1.00 | 1.00 | .00 |

Note: $\chi^2$/DF (Chi square on degrees of freedom); NCP (Non Centrality Parameter) GFI (goodness of fit index); IFI (Incremental Fit Index), TLI (non-standardized adjustment index or Tucker Lewis); CFI (Comparative Adjustment Index); RMSEA (Root of the Average Squared Error of Approximation).
This research revealed that parents generate communication strategies with professionals who care for their children regarding treatment in order to reinforce at home the same guidelines established in therapy. However, important work must be done regarding the committed actions that must be taken to successfully treat children to improve the quality of parent-child interaction. This is consistent with studies that have indicated that behavioral training for parents is a critical component of the treatment of children with autism (Caron, Bérubé, & Paquet, 2017; Edwards et al., 2019; Gould, Tarbox, & Coyne, 2018; Robertson, Sobek, Wynkoop, & Schwartz, 2017). Nevertheless, involving parents effectively can be a challenge. Despite the evidence that shows that private events can strongly influence the behavior of parents and the therapy of their children, this issue has not yet received more than minimal attention in behavior literature.

From a perspective of functional contextualism, the results obtained revealed that participants featured high and medium levels of psychological inflexibility according to the classification of the clinical scores established by Hayes et al. (2004). Thus, parents exhibited behaviors characterized within a behavioral spectrum of high demand with regard to their children’s upbringing (Smith & Anderson, 2014).

On the other hand, parents frequently exhibit behaviors related to focusing their attention on particular situations such as planning the next day’s activities and concerns regarding issues that might arise with their children (anticipation). These behaviors fit with the explanation of Bond and Flaxman (2006), who stated that in the process of cognitive diffusion, people are not generally aware of the processes of thinking, feeling, remembering, or living the experience of the present moment, and their actions are determined by fused psychological content. Additionally, experiential avoidance occurs when people are unwilling to experience unpleasant psychological events and instead attempt to change the content or reduce the frequency of these undesirable experiences, which is counterproductive and harmful and restricts living.

As such, the results showed that these behaviors consist of control strategies whose function is related to the avoidance of sensations, emotions, or aversive thoughts that are usually related to value interactions within the family or the couple and vary for each participant according to their learning history (Neff & Faso, 2015). In this sense, the inverse relationship between high scores in cognitive fusion and adherence to treatment could indicate that when mothers have difficulties in differentiating thoughts from their reality, they may have difficulties in evidencing committed actions to follow the indications of therapies on the treatment of their children with ASD. They could also avoid actions related to taking care of household demands and stop exercising their other roles—for example, those related to their work and social environment—(Virués et al., 2010).

According to the model tested, it was discovered that the psychological inflexibility of the parents has an inverse relationship with the actions of adherence to the treatment, which means that such inflexibility could interfere in parents applying the suggestions given in the therapy for the behavior management of their children with ASD (Edwards et al., 2019; Kirkpatrick et al., 2019; Li & Lo, 2016).

In addition, because the structural equations model showed an inverse correlation between the variables that explain psychological inflexibility (cognitive fusion, experiential avoidance, and obstruction) and greater adherence with the actions committed in therapy, we conclude that working with parents is crucial for progress within the intervention process (Allen & Warzak, 2013). In this sense, another starting point can be emphasized based on behavioral modification programs, where the initial axis that might show greater effectiveness is the approach of the needs of parents as fundamental agents regarding interventions with their children.

The study might serve as a tool for the comprehensive contextualization of the needs of parents...
who face the challenges of teaching their children at different learning paces. It is essential to continue with this work by designing and validating intervention protocols focused on the therapeutic needs of parents that favor the developmental processes of children with ASD and improve parental quality of life.

**Limitations and Future Directions**

The current sample was not representative with regard to variables such as gender because only three fathers were included in it. In addition, given the size of the sample, the data should not be generalized. However, we must highlight the motivational nature of this study regarding clinical practice and caregivers, so that adherence and goal achievement are favored. An important clinical implication is to provide psychological support to parents for the modification of cognitive fusion, experiential avoidance, and obstruction in such a way that they develop actions in congruence with their values on the needs of themselves and those of their children, which have a predictive role in adherence to treatment in their children with ASD.

It is suggested for future studies to expand the sample with more fathers and mothers in order to have a better understanding of the processes of psychological inflexibility present in parents of children with ASD. The effect of a program for modifying psychological inflexibility on participation and adherence to treatment in the parents of these children could also be evaluated.

**Conflict of Interests**

The authors have no conflicts of interests to declare in relation to the research, authorship, or publication of this article.

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