

Satisfaction With Treatment for Attention-Deficit/Hyperactivity Disorder

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Abstract

Patient satisfaction with treatment services is an important variable in ascertaining overall outcome; however, it is not a substitute for improving target symptoms and function. This article reviews the general determinants of satisfaction, including the effectiveness of the treatment, patient expectations, acceptability of the specific treatment, and provider factors as they apply to the treatment of attention-deficit/hyperactivity disorder (ADHD). Generally, parents and teachers are more receptive to or prefer nonmedication or behavioral therapies to medication, despite the established effectiveness of medication. Children are similarly ambivalent about medication. These preferences probably result from the lower acceptability of medication treatment for ADHD. Data does not establish greater patient satisfaction with a particular medication class or formulation. However, parents and children/adolescents may prefer the newer longer-acting medications.

Measuring satisfaction with ADHD treatment serves several purposes, such as identifying acceptable treatment modalities, defining patient expectations for treatment, and determining those providers that may be deficient in communicating with their clients.

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Attention-deficit/hyperactivity disorder (ADHD) is the most common mental health problem affecting children and adolescents. Epidemiological studies have reported from 3% to 8% of children and adolescents meet diagnostic criteria for ADHD.¹ In recent years, there has been an increase in both office visits and stimulant prescriptions for ADHD.¹⁻³ In part, this increase in patients seeking treatment reflects the fact that ADHD can be successfully treated.⁴ More than 200 controlled studies have established the efficacy of stimulant medications and specific behavioral interventions for children and adolescents

with ADHD.^{5,6} In the past several years, several new medications have been marketed. While most of these are new versions or formulations of stimulant medications (ie, methylphenidate [MPH] or amphetamine), others such as atomoxetine are new, non-stimulant drugs approved for the treatment of ADHD by the US Food and Drug Administration (FDA).

With all of these medication options, as well as numerous nonmedication psychosocial therapies to choose from, clinicians, particularly primary healthcare physicians, seek guidance and advice about which specific medications, formulations, modalities, or combinations of modalities to prescribe. Studies such as the National Institute of Mental Health Multimodal Treatment Study of ADHD (MTA)⁷ and guidelines from the American Academy of Pediatrics⁴ and American Academy of Child and Adolescent Psychiatry^{5,6} may assist clinicians in their clinical decision-making process. Although the efficacy and safety of these modalities may primarily determine the intervention selected, patient or parent satisfaction may also be a primary consideration for the clinician.

The literature examining satisfaction for ADHD treatments is limited; therefore, this article will examine parent and patient satisfaction with treatments for ADHD and similar behavioral disorders in children and adolescents, using the literature for satisfaction of medical treatment and mental health treatments. The general determinants of satisfaction with medical care and behavioral healthcare of children and adolescents, satisfaction with medication and specific medications for ADHD, and finally differential satisfaction with various treatment modalities for ADHD will be examined.

Why Is Satisfaction With Medical Care Important?

Satisfaction with a particular treatment is one element of the perception of medical care that is often related to outcomes and quality.⁸ With the recent increase in emphasis for providers of services to be more accountable and to provide both quality and effective treatments, satisfaction with services is often the only variable measured, as it is believed to be an indicator of the quality or effectiveness of services. More than 90% of behavioral health organization representatives view consumer satisfaction as an important outcome and perhaps the most helpful for their purposes.⁹ Many providers now mandate the inclusion of consumer satisfaction measures as a way of assessing the quality and perceived benefits of a service.^{10,11}

One of the primary reasons for considering consumer satisfaction is the large number of people with diagnosable mental disorders who do not seek treatment or discontinue treatment. Approximately 40% to 60% of children and their families discontinue treatment prematurely.¹² Treatment retention is a significant predictor of mental health treatment outcomes in youth with disruptive behavior disorders.¹³ Satisfaction is presumed to predict adherence or compliance to treatment.^{14,15} For example, studies examining compliance with ADHD medication show short-term compliance with medication between 67% and 80%, although longer-term compliance is lower with rates of 56% to 60%.¹⁶ Because of increased emphasis on consumer control and perception of their healthcare, satisfaction and patient preference are increasingly important determinants of care.

General Determinants of Satisfaction

Satisfaction does not correspond to a specific variable such as outcome. Rather, satisfaction is composed of several primary variables or determinants. Satisfaction may be influenced by culture, which affects one's beliefs, perceptions, and reactions to symptoms. Other determinants of satisfaction include demographic characteristics and the effectiveness, social validity, or acceptability of the treatment, the expectations of the

consumer(s), and provider factors. The importance of each of these specific determinants in contributing to treatment satisfaction likely varies for the disorder being treated, the treatment modalities being used, and the characteristics of the provider and client. Different factors predicting satisfaction may be more important at different times in the treatment process. For example, early treatment factors of satisfaction may include aspects of the patient-clinician relationship (including expectations), while symptom resolution and functional status may be more important later on in the course of treatment.¹⁷

Demographic Characteristics. Older patients are generally more satisfied with their healthcare than younger patients. Similarly, parents show higher rates of satisfaction than their children, particularly in the treatment of ADHD.¹⁸ Other demographic characteristics such as sex seem to be less important or unimportant.^{19,20}

Several recent studies have reported lower ADHD medication use among ethnic minorities.²¹⁻²³ While these results may be an indication of reduced access or provider bias, minority attitudes about the use of medication may also have a role. Cultural factors may affect the acceptance of and adherence to specific interventions.²⁴ Compared with Caucasian parents, non-Caucasian parents appear less likely to recommend medication, less likely to prefer medication over counseling, and tend to be less satisfied with medication.²⁵ Results from the MTA study show no difference between ethnic/racial groups in initial satisfaction with modality assignment or adherence as measured by attendance at parent management training sessions.²⁶

Effectiveness. Consumers should be more satisfied with treatments that actually work (ie, produce change in the target symptoms or behaviors). Research on the relationship between satisfaction and changes in other outcome domains in children's mental health treatment studies is mixed.^{27,28} Unfortunately, there are few studies examining the relationship between satisfaction and patient/parent satisfaction. Several studies

of mental health treatment have found no correlation between satisfaction and pathology change.^{29,30} Parents may be satisfied with and report more improvement with traditional child mental health treatment than with control treatment, despite there being no significant differences in child functioning between the compared treatments.³¹ When considering therapist-rated outcomes, the literature offers contradictory results, with some studies showing a correlation between outcomes and satisfaction,¹⁷ while other studies show stronger relationships between satisfaction and patient ratings of effectiveness or outcome.³² Interestingly, parents and adolescents differed in their ratings of satisfaction with treatments as symptoms changed. In one study of satisfaction with mental health treatment, ratings of satisfaction from adolescents were correlated with symptom change, while parent satisfaction was not correlated with symptom change.²⁹ Differences between the satisfaction and outcome relationship may be present in different types of health problems, with a greater relationship between satisfaction and outcome or functional improvement in medical than with mental disorders.³³ Some investigators have noted a distinction between perception of benefit and satisfaction,²⁰ and insist that satisfaction should not presume a specific treatment outcome. Unfortunately, some may be satisfied with ineffective and possibly dangerous interventions.³⁴

In the case of ADHD, disproved treatments such as diet changes and unproved treatments such as attention-training or herbal remedies may produce considerable parental satisfaction despite the fact that they may not be effective. As seen in the MTA study, satisfaction is greater for specific treatments that are less effective than for treatments (ie, medication) that are less favored. Many of the professional guidelines of the American Academy of Pediatrics or the American Academy of Child and Adolescent Psychiatry are only partially congruent with parent ADHD treatment preferences.³⁵

Findings that suggest satisfaction is not always related to outcomes or functional improvement may be related to patient or parent perception of improvement rather

than more objective measures of improvement in symptoms or functioning. Several factors are likely to influence the perception of improvement. These include the patient or parent's acceptability of the specific treatment modality, as well as the general and specific expectations for treatment.

Many of the same factors that apply to adult satisfaction apply to younger patients. For adolescents some of the strongest correlates of satisfaction are attitudinal variables such as expectations for treatment and perceived motivation or choice for continuing treatment.^{36,37}

Social Validity and Acceptability. In response to concerns about the difficulty of implementing experimental treatments, Wolf³⁸ and Kazdin³⁹ defined several concepts under the rubric of social validity.⁴⁰ The 3 components of social validity include treatment goals, procedures, and outcomes. In treatment outcome studies, social validity of an intervention must be established by demonstrating that the outcomes or goals are meaningful in the family's life and that the goals and procedures are acceptable or perceived relevant by families or "consumers." The social validity of goals often relates to matching consumer expectations. The "acceptability" of a treatment procedure refers to the willingness and ability of consumers to use or participate in the intervention. Despite any intrinsic effectiveness of a treatment, if consumers are unwilling or unable to use it, the treatment does not have social validity, cannot be considered effective in the real world, and is unlikely to produce satisfaction by its consumers. Such factors as perceived stigma of the disorder and treatment, as well as misconceptions about the etiology or nature of the disorder, could affect acceptability.

Acceptability may affect satisfaction with a particular treatment despite the efficacy of the treatment. A few studies of treatment acceptability have indicated that parents are more likely to enroll in a treatment regimen if they have a higher opinion of it.⁴¹ Acceptability of a given treatment has not been shown to affect short-term compliance with the treatment.^{41,42} However, there

appears to be a relationship between perceived barriers to treatment, including items tapping treatment satisfaction, and treatment dropout/noncompliance.^{12,43}

Parents usually consider stimulant therapy, the cornerstone of ADHD treatment in the United States, as a difficult modality to consider and accept for their children.³⁵ In general, when treating ADHD, parents rate behavioral treatment as more acceptable than medication.⁴⁴ In the MTA study, 9% of families whose children were assigned to the medication-management-only group refused assignment while only 3.4% assigned to the combination medication and behavioral management group refused assignment.⁷ Parents rate behavioral treatments, in particular positive behavioral techniques and daily report cards, as much more acceptable than medication treatment.^{41,42,45-48} Teachers have similar attitudes about the acceptability of behavioral treatment over medication.^{49,50} Some studies^{45,48,50} have also shown that ratings of combined treatments are superior to those of medication alone.

Why is this discrepancy present? While the primary analyses of dimensional symptoms related to ADHD showed no significant difference between the combined and medication (only) groups, a number of secondary analyses have suggested that combined treatment was superior to medication alone for the following outcomes: a composite measure of symptomatic and impairment-related functioning, normalization of symptoms, parent-child relationships, and for multiply-comorbid children.⁵¹⁻⁵⁵ The behavioral components of the MTA study were largely designed to increase the positive skills of ADHD children while medications reduce the negative or core ADHD symptoms. Studies of parents with children who have disruptive behavior disorders suggest that these parents evaluate modalities that focus on increasing acceptable behaviors more highly than modalities that reduce negative behavior.⁵⁶

Acceptability can change over the course of treatment. For example, patient or parent knowledge base about a disorder may affect acceptability. Some researchers have shown that providing parents with more information regarding ADHD and its treatment

increases their acceptability ratings for medication.^{42,45} Acceptability may also be improved by receiving the treatment.^{45,47} In the MTA study,⁷ most of the parents who were initially disappointed at being assigned to the medication-management-only group and not the combined behavioral or behavioral treatment-only groups reported general satisfaction at the end of treatment.¹⁹ Other studies have shown that acceptability ratings increase when behavioral treatments are added to the medication.^{48,50,57} Similarly, providing a rationale for ADHD treatment by presenting additional information about treatment modality options increases parents' acceptability for treatments involving medications but not for behavioral treatments.⁵⁸ In the same study, this effect was not observed for teachers. A parent's experience with treatment may influence acceptability. A history of ADHD medication use predicted an increased willingness to use medication, while a history of counseling predicted an increased willingness to use both medication and counseling.⁵⁹ A positive experience with medication or treatment may be a critical determinant of acceptability. Comparing the acceptability of behavioral, medication, and combination treatment, parents of children with ADHD rate the acceptability of the medication treatments higher than parents of children without ADHD.⁵⁸

Expectations. Expectations of a medical encounter may also influence satisfaction. Of course, unfulfilled expectations can lead to lower compliance, which can lead to lower symptom relief. Several studies indicate that attitudes and expectations about mental health services are related to satisfaction with service. Satisfaction is higher when expectations are met^{18,60-63} and lower when expectations are not met.⁶⁴ When expectations are positive, satisfaction is higher.^{36,37}

Expectations may affect satisfaction through the acceptability of a treatment modality. Parental ambivalence about medication treatment may be driven by the sources of information about ADHD and its treatment. Prior to treatment, psychoeducation, and informed consent, a parent's infor-

mation and knowledge of ADHD are primarily gleaned from the popular media in which ADHD medications have been the source of much controversy.³⁵ Despite knowing that their children need treatment, parents may be wary about some ADHD modalities, especially medication. They may expect unacceptable adverse effects or fear social stigma that they expect would be related to medication use.

Provider Factors. Mental healthcare consumers identified bonding with the provider along with the provider's knowledge and competence as the most important factors that contribute to consumer satisfaction.⁶⁵ Such factors are known to be part of clinicians' "bedside manner." Patient satisfaction is strongly influenced by patient-provider communication variables, such as receiving an explanation of symptom cause and likely duration of treatment.⁶² Studies, such as by Gage and Wilson,⁵⁷ demonstrate the importance of provider psychoeducation in changing parental attitudes about treatment. Satisfaction related to provider factors may be largely fulfilled through meeting the patient's expectations or modifying those expectations through psychoeducation.

Provider or physician knowledge and competence are also critical. In the MTA study, the medication management condition did much better than those assigned to the community condition, despite the fact that most of the community assigned to controls received medication.⁷

This difference was attributed to the likely higher quality of care delivered by the MTA pharmacotherapies that used the most current procedures and knowledge base. As much of ADHD management concerns medication management, future research should study determinants of satisfaction with this practice.

Satisfaction With Specific ADHD Medications

Clinical trials of medications for ADHD, including both phase 3 and postmarketing of specific medications, often include parent satisfaction as a variable. Parents are asked how satisfied they are with the specific medication treatment and, if previously treated,

how satisfied they were with the medication treatment compared with the previous treatment? Satisfaction ratings by parents who were very or moderately satisfied in recent trials range from 87%⁶⁶ to 62%.⁶⁷ Recent studies of stimulant medication have reported rates of satisfaction with medication treatment,⁶⁷⁻⁶⁹ with 50% to 74% of parents and teachers making positive endorsements of satisfaction for treatment that involves medication alone.

Unfortunately, little may be gained from these satisfaction ratings of medications within the context of clinical trials for several reasons. First, children and their parents participating in a medication trial likely represent a biased sample. Few would agree to participate in a study if they were satisfied with their previous medication or treatment, which may be the control or comparison treatment. Many families are happy to receive treatment or at least an evaluation by "experts."⁷⁰ Johnston and Fine⁷¹ reported higher satisfaction with a double-blind, placebo-controlled medication trial than with typical clinical procedures. Second, there are few well-controlled, blinded, head-to-head comparisons between rigorously determined equivalent doses of the comparative medications (ie, MPH vs amphetamine or between different formulations of MPH), particularly those that compare relative satisfaction. One prominent exception is a double-blind, double-dummy comparison between once-daily osmotic release oral system (OROS) MPH (Concerta) and 3-times-daily MPH immediate release (IR), in which 47% of parents preferred OROS MPH, 31% chose the MPH IR 3 times daily, and 15% chose their previous MPH regimen.⁷² In 2 open-label studies of OROS MPH, about 85% of parents were satisfied, very satisfied, or extremely satisfied with once-daily OROS MPH in the first months of therapy. In the second year of the study, 97% to 99% of parents were satisfied with once-daily OROS MPH. This suggests that long-term parent satisfaction can be maintained with once-daily OROS MPH therapy.⁷³

However, these results involve a forced preference rather than satisfaction with a particular medication or treatment. Third,

medication trials may produce high levels of satisfaction for no pharmacological reasons (ie, provider factors, etc). Finally, consumers typically report high levels of satisfaction in such trials and there is often little variation.¹⁰

To make more salient conclusions from clinical trials regarding the level of satisfaction across treatments, investigators must incorporate better designs relating to satisfaction measurement. The new long-acting medications for ADHD do improve compliance by eliminating the disadvantages of multiple-day dosing.^{72,73} Evidence from other pediatric therapeutic areas supports the value of daily dosing in improving compliance.¹⁶ Clinical experience suggests that most parents prefer the once-daily preparations, primarily for convenience reasons.¹⁶

The introduction of nonstimulant medications, such as the recently FDA-approved atomoxetine, as well as other nonstimulants may provide an alternative for those patients who experience stimulant-induced insomnia or tics. In addition, nonstimulants may be appropriate for individuals at risk of stimulant abuse.⁷⁴ However, more research is needed to fully understand the implications of nonstimulants and their role in affecting patient and parent satisfaction.

Satisfaction With ADHD Medication versus Nonmedication Treatments

Pelham and colleagues²⁰ examined treatment satisfaction and global improvement after 14 months of treatment as part of the MTA study.⁷ Parents of children randomly assigned to the behavioral or combined (behavioral plus medication) treatment conditions reported more satisfaction and were less likely to decline or to drop out of treatment than parents of children assigned to medication only. Teachers were also more satisfied with treatments that included a behavioral component than with medication alone, and they indicated that the behavioral treatments made them better able to deal with ADHD in the classroom than did medication alone. These results are consistent with parent perception that children in the combined group were more improved than those in the medication-only or other comparison groups. Prior to the onset of treat-

ment, more parents of children assigned to the combined group were generally or very positive about their assignments and fewer were disappointed when compared to those assigned to the medication-only group. However, outcomes were best for the medication-only group.

Positive attitudes about medications are associated with greater satisfaction.²⁵ A study by Sleator and associates⁷⁵ found that a majority of children taking stimulant medication disliked taking medication, although this may reflect a general dislike of medicine. However, another study reported that most children treated for ADHD with medication view medication favorably, but a larger percentage of children versus parents viewed medication in a negative light.¹⁸ However, this was not once-daily medication and could have affected the results. Provision of education and information about ADHD and medication is often seen as an important aspect of the treatment process. However, a higher level of knowledge of ADHD may not affect parents' opinion of medication or predict treatment compliance, despite predicting an increased willingness to accept both medication and nonmedication treatments.^{36,37} These studies suggest that knowledge alone may not improve acceptability. It is possible that the stigma or philosophic aversion against medication for behavior problems in most societies is sufficient to create ambivalence about medication or, at least, medication treatment without any medication modalities. Once-daily treatments have demonstrated better compliance rates and greater satisfaction and increased preference. In 2 laboratory school studies with double-blind, double-dummy tablets for MPH IR 3 times daily and OROS MPH, parents showed a strong preference for OROS MPH. Because overencapsulated tablets were taken for both drugs throughout the study, the preference did not reflect the convenience of once-daily dosing.^{72,76}

What Should Be Done About Satisfaction for ADHD Treatments

As with treatment for other mental health problems, satisfaction should not serve as a proxy for treatment outcome in ADHD. Ex-

pensive, unsupported, or disproved therapies for ADHD, such as diet, attention training, electroencephalogram, and/or biofeedback, may produce significant levels of satisfaction, yet little in the way of objective improvement. Outcomes should be based on improvements in target symptoms and/or functioning. However, treatments offered must not only be effective, but should have social validity and acceptability as well.

Measuring satisfaction in the case of ADHD treatment serves several purposes. First, parent, child/adolescent, or teacher satisfaction may identify modalities that are more acceptable, and hence, may predict better compliance or adherence. Once-daily medication has demonstrated this as well.^{72,73} These preferences may be particularly important when there are several effective modality options. In treating ADHD, despite the seeming superiority of medication as a single modality, the literature suggests that multimodal treatment, which combines the preferred treatment, behavioral therapy, with medication treatment that produces more parental, patient, and societal ambivalence may be optimal for both outcome and satisfaction. Second, satisfaction may relate to physicians, some with poor knowledge and skills and others with poor "bedside manner" who, while knowledgeable and competent, nevertheless fail to inspire a family's confidence. Despite improvements in symptoms and functioning, families may prematurely end treatment with such providers or even disenroll in health insurance plans. Finally, satisfaction measures may allow both provider and plan to identify expectations of their patients. Providers can then address these expectations through the treatment plan and selection of acceptable modalities or through psychoeducation. Most patients will appreciate when providers are listening to them and their concerns.

Providers must ask about specific expectations when starting assessment and treatment and prompt families to reply whether these expectations are being met or not on an ongoing basis during treatment. Anticipating what effective modalities may be preferred, the provider should facilitate the provision of these modalities or the referral

to qualified providers of these modalities. Managed care organizations (MCOs) can also anticipate and identify preferred modalities and facilitate their access and use. In addition to examining clinical outcomes, MCOs should also survey their enrollees regarding satisfaction in an objective manner.

Clinically, for ADHD, the existing literature points to several more specific recommendations. First, as noted above, providers need to be aware of consumer preferences and expectations. Second, providers may be able to change such preferences through careful, sensitive psychoeducation procedures and informed consent. Third, providers with the skills and knowledge of best practices in ADHD treatment will likely deliver better care than those who do not have these skills. Improving the quality of ADHD-related practice involves following best-evidence practice through clinical guidelines for the evaluation and management of ADHD as provided by the American Academy of Pediatrics and the American Academy of Child and Adolescent Psychiatry.^{4,6} Finally, providers should respect the fact that consumers have specific preferences. Even if medication or combined medication and behavioral treatment are superior to behavioral treatment alone, behavioral treatment alone can be effective.

Future Research

Although the existing literature on satisfaction with ADHD treatment and with treatment of mental health problems can provide valuable lessons for today's providers, future research will have to anticipate the importance of satisfaction research and the need for establishing the social validity of a treatment modality. Although several satisfaction measures exist, the development of consistent, uniform variables to compare across studies would be useful. All clinical trials should build in satisfaction measures with the same methodological rigor as primary outcome variables. Studies should consider and study whether participants assigned to their a priori preference do better than those who are not assigned to their preferred treatment. Finally, treatment researchers should consider alternatives to random assignment,

such as experimental models where participants are assigned to specific treatment conditions or modalities according to their preferences.

Conclusion

ADHD is a common disorder of children, adolescents, and even adults. With the many types of modalities, medication and non-medication, as well many types of medications to choose from, consumer satisfaction is an important consideration for consumers, providers, and MCOs. Consumer satisfaction should take its place beside best practices for measuring optimal outcomes in guiding treatment selection and procedures.

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