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Discovering the complexities of adolescent compliance to treatment

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Abstract: To explore the challenges faced in enhancing adolescent treatment compliance and to understand the roles of key players in this endeavor: the adolescent, parent and healthcare provider. Obtaining compliance from adolescents requires collaboration from the adolescent, caregiver and provider and depends on well-established relationships between each person in the triad: adolescent-provider, adolescent-caregiver, and caregiver-provider. Ensuring and improving adherence to treatment by adolescents is a challenging task but crucial to overall health outcomes. It requires the collaboration of the adolescent, parent and physician to create the optimal treatment plan, specifically tailored to the adolescent. For the clinician, maintaining good communication and relationships, active listening, as well as partnering with the adolescent and parent are keys to positive outcomes.

Keywords: Adolescent compliance, parents, parental education

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INTRODUCTION

The concept of compliance to treatment, synonymous with treatment adherence, is a topic that has challenged clinicians for ages and around the world. This concept refers to the act or behavior of a patient coinciding with treatment plans negotiated between the provider and patient (1). Compliance is the fundamental act necessary for effectiveness of treatment delivery (2). Despite its importance, noncompliance is often the culprit for lengthened illnesses, elongated treatments, repeat visits to health care centers, increase in medication dosage, unnecessary healthcare expenses, and treatment failure (3). Non-adherence rates spanning from 15% up to 93% dictate the 1.8 billion prescriptions written each year and exceed $100 billion in monetary costs (1). Although it can be a health hazard and an economic drain, non-compliance luckily can be minimized. This literature review will explore the challenges of treatment compliance specifically faced by adolescents, define parental roles in adolescent compliance, and evaluate physician guidance for parents regarding their adolescent’s treatment adherence.

Understanding patient compliance is not a new research topic, but the most studies have been conducted on adults or children in general (1). Specific studies and clinical trials regarding adolescent compliance are much less abundant (4). Some studies have illustrated that an important moderator of adherence is age; therefore an understanding
of adolescent compliance is tremendously needed (1,5). In addition, developing compliant behavior during the adolescent years may establish adherence patterns in adulthood and therefore should be given great attention (4).

The challenges of adolescent compliance are actually multifaceted. Winnick et al (3) pinpoints the collaboration needed for effective compliance by adolescents and describes it as the provider-caregiver-patient triad. Each part affects the other and the whole. Direct compliance is based on the choices and actions of the adolescent; nevertheless, clinicians can educate, motivate, and influence adolescent compliance through good communication and partnership. Parents also contribute a crucial aspect to compliance that will be discussed in more detail later.

Challenges for adolescent in adhering to prescribed treatment
Mental, emotional, physical, and social factors were often reported by adolescents in regards to their noncompliance. Lack of a belief system, knowledge, or motivation to adhere to treatment plans due to absent symptoms, desire to defy parental requests, or culture were often mentioned in articles. These were reported in addition to the emotional factors of feeling sad, stressed, bored, anxious, lonely, depressed, fearful of societal perceptions, and dealing with dysfunctional families or lack of support (1,3,5,6). Physical barriers to treatment centers or clinic visits, i.e. no transportation means, also hindered compliance (3).

Distractions from dynamic lifestyles and environments—from school, friends, eating outside of the home—presented limitations to adherence and seemed to be the justification for forgetfulness. Furthermore, the challenges of managing busy schedules along with incorporating a treatment plan also contributed to adolescent perceptions of their noncompliance (1,6). An article on anti-retroviral therapy adherence concluded that adults and adolescents often face similar difficulties in complying with complex regimens; adolescents, however, must deal with additional stresses of having less privacy, less mobility, less autonomy, possible over-involvement of the family, and struggles with balancing how to live in the present versus living for the future (1).

Unique from challenges in adult and young children compliance, adolescents also must face a transition period into adulthood. According to McLaughlin et al (7) each year in the United States, more than 500,000 adolescents with special health care needs reach the adulthood age and face additional obstacles in maintaining compliance (7). This transitioning process has been described as two tiered: shifting the responsibilities of decision-making and healthcare coordination from parent to adolescent and transferring from pediatric to adult facilities (8). That adolescent adherence is already a challenge in the first step of the transition—where adolescents are given more independence and responsibility for their health—predicts more noncompliance in the second step; therefore great effort to build compliant behaviors and self-management skills in the first step is critical for the next (7,8). Unfortunately, little attention has been given to the healthcare transition of adolescents in the past, and only recently has it become more emphasized. A recent article mentioned that only one out of six adolescents with special healthcare needs reported discussing and making plans for their healthcare change. Furthermore, transitioning issues were more likely to be addressed with adolescents having more complex health needs (9).

In addition to the personal preparation
needed during healthcare changes from adolescent care to adult care, decreasing medical care funding is another large obstacle that adolescents face, having an impact on not only their compliance but also their overall health outcomes. According to Wolraich (5), young adults between the ages of 18 to 24 are more likely to be uninsured than any other age groups. Older adolescents often lose their insurance coverage, especially if they are not enrolled in an academic institution full-time; government special needs health care programs significantly decrease once an adolescent (who is single and has no children) passes age 18. Furthermore, although medical care costs increase for these adolescents, the majority do not have substantial jobs to pay for their medications and continuing medical care.

Impact of clinician on adolescent compliance
From a clinician’s perspective, maintaining good communication and partnering with the adolescent can help minimize the difficulties in treatment compliance. Multiple articles have emphasized the importance of listening to and understanding the adolescent’s perception of treatment plans, past difficulties with adherence, beliefs and fears about his or her illness, familial involvement, and cultural perspectives (3,10-12). From gathering this information, the clinician can respectfully and more accurately collaborate with the adolescent to identify and keep account of treatment outcomes and goals (11).

Furthermore, having a basis of the adolescent’s perception can assist in focusing the education as needed. Leaving space for the autonomy of the adolescent while encouraging and convincing the adolescent of the need for compliance can also help increase motivation to adhere and reduce resistance (5). Moreover, providing accessibility, availability, and continuous care for the adolescent can help compliance as well (3).

“Anticipatory guidance” from physicians is needed to address issues concerning healthcare transitioning for adolescents to adult-oriented care, (5). A study on improving the transition from pediatric to adult cystic fibrosis (CF) care concluded that the time allotted for discussing and planning the transition was often inadequate, occurring at a median age of 17 years. The study suggested for CF programs and clinicians to introduce self-care skills and transition ideas earlier for better success (7).

Parental impact on adolescent compliance
The role of parental involvement in achieving adolescent compliance is significant and should not be overlooked, despite a possible relationship-distancing between parent and child during adolescent years (5). Through their ability to monitor and encourage adherence as well as to apply consequences for non-adherence, both between and during clinic visits, parents have the unique position of managing their children’s adherence (2). A recent cross-sectional study on diabetes care demonstrated that parental monitoring had a direct impact on enhancing adolescent compliance, which subsequently helped to improve metabolic control (13). Other studies focused on reducing risky behaviors among adolescents also emphasized that ‘parental oversight’ ensures better health outcomes (13). Furthermore, with monitoring and maintaining good parent-child relationships, parents can get a better sense of the challenges that their adolescents face and help them to express what is needed for improvement (13).

In addition to monitoring, parents are often the ones taking care of the logistics
surrounding the actual treatment that are vital for carrying out compliance—providing transportation, covering monetary costs, and scheduling referrals or clinic visits (14). A small school-based health center study performed to assess medication adherence among adolescents (between the ages of 10 to 15 years) without parental involvement further illustrates the need of parents to assist their children, even in initial acts of filling their prescriptions. Of the medications prescribed, approximately half the students in this study never had their prescription filled (4). With regard to parental involvement, other studies discussed the relation of treatment non-adherence to caregivers with higher stress, worse communication with child, lower quality of life, lower cognitive functioning, and psychopathology (1,2).

Influence of clinician-parent relationship on adolescent compliance
With the awareness that parents can greatly influence adolescent compliance, parental adherence to treatment is equally as significant as adolescent compliance. Hence, it is important for clinicians to build ‘high-quality relationships’ with parents: to address and understand the parents’ knowledge, concerns, and beliefs about the treatment; their motivation; and their relationship with the adolescent (9). An article discussing communication between clinicians and families stated that the most frequent criticism by parents regarding healthcare practice involves relationships with clinicians. Not only does this clinician-parent relationship have an impact on parental satisfaction and recall of instructions it also affects treatment adherence (12).

Clinicians can use these relationships for motivating parents to become more involved in their child’s health and educating parents on how to coach their adolescent to be more compliant (12). A study showed that increasing parent adherence to assist treatment plans helped improve parental discipline practices (with ~40% change), subsequently improving their adolescent’s behavior. Additionally but not surprisingly, when compared with adherent parents, non-adherent parents were found more likely to terminate their adolescent’s treatment prematurely (2). Furthermore, a cross-sectional survey given to parents of asthmatic children concluded that the better a clinician understands the medication beliefs of parents and their impact on adherence, the better he/she can counsel more effectively to promote compliance (15).

Further explorations to be made
In general, it would be worthwhile to research more about adherence assessment methods used for various treatments. Some of the methods used in the studies that were read for this review include measuring clinical variables, surveys, self-reports, electronic drug monitoring, pharmacy refill data, and records from programs logs. The review written by Simoni et al (1) on assessing compliance in highly active antiretroviral therapy (HAART) suggests that there is no perfect method of measuring compliance; the explanations for the inadequacy of methods used in the studies from this review seem translatable to treatment adherence assessments overall. (For example, the inadequacy of using parent and adolescent reports to assess HAART adherence due to a high probability of recall bias due to high probability of recall bias is a reasonable conclusion to make for other treatment reports.) Each test has its advantages and disadvantages (or limitations), whether it is epidemiologically accurate, cost efficient, or subject to bias. This review suggested the use of multiple assessment methods to obtain more-accurate
data (1). Furthermore, many generalizations in articles seem to come from small-population sized studies. It is important to be aware of these factors when evaluating rates of adherence.

With regard to the healthcare transition from pediatric to adult care, it is wonderful that clinical assistance has increased. While improvements can always be made to further aid the transition process particularly for adolescents with chronic illnesses or special healthcare needs at the present time of transitioning, retrospective (follow-up) studies every several years would be beneficial to see the effects and progress of the transition. In addition, it would be great to incorporate these transition assistance methods into adolescent care in general.

Although studies have been conducted on the ways that clinicians can more effectively communicate to and build rapport with parents (2,3,16), how to guide parents in treating certain diseases (17), as well as in monitoring adolescent behavior (13), quantitative research assessing the number of healthcare providers who have implemented such methods into their practice was not found in the articles read for this review. Here are some other questions to consider—what are the percentages of providers who take the time to educate parents and adolescents about compliance or refer families to educational facilities? What percentages of those parents who are educated by providers actually implement what they learn?

CONCLUSIONS

Compliance with treatment plan depends on multiple factors and is more difficult in adolescents than in adults by virtue of the developmental stage of adolescents, in addition to economic factors, logistic support, and emotional issues. Ensuring and improving adherence to treatment by adolescents is a challenging task but crucial to overall health outcomes. Based on published studies and on our own observations in our clinics, improving adolescent compliance requires the collaboration of the adolescent, the parent, and the physician to create an optimal treatment plan that is specifically tailored to the adolescent. For the clinician, maintaining good communication and relationships, active listening, as well as partnering with the adolescent and parent, are keys to positive outcomes.

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