



Mini-symposium: Ethics in the workplace

## Ethical considerations in pediatric chronic illness: The relationship between psychological factors, treatment adherence, and health outcomes

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### Educational aims

The reader will be able to

- Describe common challenges experienced by pediatric, adolescent, and young adult patients with chronic illness.
- Describe psychological interventions that can be used by psychologists and other healthcare professionals to promote healthy behaviors in managing chronic illness.
- Illustrate the use of evidence-based psychological interventions with adolescent and young adults with chronic illness.
- Provide recommendations for working with challenging yet rewarding pediatric, adolescent, and young adult patients and their families.

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### ABSTRACT

Children, adolescents, and young adults with chronic illnesses are often faced with complicated and burdensome treatments that not only require a great deal of time and energy to manage, but will also likely impact relationships with parents, siblings, and peers. Adolescents and young adults with chronic illness are often impacted by several unique and challenging factors that can ultimately impact health behaviors and treatment outcomes. Working with a psychologist can help to ameliorate these unique challenges, which will positively impact health behaviors and health outcomes. The present paper provides an overview of psychological interventions that were designed to target the unique challenges that are often associated with maladaptive health behaviors and ultimately poor health outcomes. As demonstrated in this commentary, when working with adolescents and young adults who have unique developmental challenges, it is important to deliver multi-faceted intervention approaches that utilize a number of different strategies and frameworks. These eclectic intervention approaches provide a unique opportunity to improve health behaviors during critical developmental periods, including the transition from childhood to adolescence to young adulthood.

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### COMMON CHALLENGES FOR PEDIATRIC AND YOUNG ADULT PATIENTS WITH CHRONIC ILLNESS

In the context of pediatric chronic illness management, children, adolescents, and young adults are often faced with complicated and burdensome treatments that not only require a great deal of time and energy to manage, but will also likely impact relationships with parents, siblings, and peers. For example, pediatric

type 1 diabetes requires children and adolescents to maintain a healthy diet, check blood glucose frequently, manage hypoglycemia and hyperglycemia episodes, and give insulin injections or use a subcutaneous insulin infusion pump. These activities must be performed at certain times of day and/or during certain activities (e.g., exercise, sports, school, and during peer activities). In addition to the effort required to complete these complex and time consuming tasks, it is also not possible to always conceal them from peers or other individuals unless the individual leaves the group for an extended period of time or chooses to omit various aspects of their treatment regimen.

Affiliation, which is the act of associating or interacting with one or more individuals [1] potentially has an impact on health behaviors like treatment adherence and self-management in pediatric chronic illness. For example, children's hospitals often promote affiliation between children with chronic illness by offering summer camps so that younger and older children can interact and learn positive coping skills. This promotes acceptance and belonging and decreases the potential for rejection by peer groups because of deviations in normality (i.e., being different because of a chronic illness diagnosis). However, most children and adolescents with chronic illness regularly interact with healthy peers. Adolescents, in particular, seek acceptance by peers, in part by ensuring they are similar to their peers. Thus, adolescents may make adjustments to their health behaviors and illness management to ensure that they can maintain similarity to, and social contact with, their peers. These behavioral adjustments can mean avoiding actions that contribute to positive health outcomes, such as adherence to treatment regimens. This is especially troublesome during a developmental period in which the child is responsible for more of their own adherence [2]. In fact, peer relationships and deviations from normality are known barriers to treatment adherence in a number of chronic conditions, including asthma [3] and renal transplant [4], which will be illustrated below in the two case examples.

It has been proposed that engaging in self-disclosure is a positive characteristic when developing relationships [1]. This suggests that it would be beneficial for individuals with a chronic illness to disclose their conditions to their significant others and peers. However, it has also been noted that helplessness can be viewed as a negative characteristic that contributes to rejection by peer groups and significant others [1]. Disclosing that one has a chronic illness, which is viewed as positive, also carries the risk of being deemed helpless, which is viewed as negative and could lead to rejection by peer groups. Thus, it may be less threatening to “hide your illness” by non-adhering to a treatment regimen or failing to inform others you have a chronic illness.

It is also possible that adolescents and young adults engage in risky behaviors like nonadherence because of normative brain development; they have heightened emotionality and susceptibility to reward (e.g., from peers) coupled with low impulse control [5]. They may feel invincible (e.g., “*I’ll be fine!*”) or utilize nonadherence as a maladaptive coping strategy (e.g., “*If I do not take medications then I am not sick*”). Additionally, internal conflicts include how adolescents perceive how the treatment affects other aspects of their life (e.g., 6 hour dialysis versus movie with a friend) and how the chronic illness causes a deviation from normality. Furthermore, the perception that one is devalued or rejected because of their illness can contribute to changes in self-esteem, loss of perceived control, and a belief that one's life does not have meaning [1]. The effects of rejection may ultimately contribute to treatment nonadherence and poor self-management, which will in turn impact health outcomes.

From a clinical perspective, it is important for medical professionals to assess youths' illness acceptance and their social support from both family and friends when working with children, adolescents, and young adults with chronic illness. This can be done in

the context of routine medical visits. Additionally, it may be crucial to offer peer group opportunities for children and adolescents with a chronic illness so that they could be affiliated with other children and adolescents like them, which would ultimately decrease the probability of rejection from healthy peers who are not able to handle the complex treatment regimen. Finally, managing a chronic illness during adolescence and young adulthood is not an easy feat. Adolescents and young adults have unique challenges which are likely to impact illness management. As described below, adolescents with chronic illness are often impacted by a number of challenging factors that can ultimately impact health behaviors and treatment outcomes, including: academics, sports, work, peers, family, executive functioning, maladaptive coping mechanisms, poor knowledge of medical condition or associated treatments, and increased parent–child conflict. Working with a psychologist can help to ameliorate these unique challenges, which will positively impact health behaviors and outcomes.

## CASE EXAMPLES

The cases described here were exempt from Institutional Review Board (IRB) approval. All patients and families consented to psychological treatment and provided verbal assent (<18-years-old) or consent (>18-years-old) for use of de-identified information.

### *Common challenges with managing asthma: the complex role of adolescent-family dynamics, self-management, and health outcomes during a critical developmental period*

Pediatric asthma is the most common chronic illness in childhood and results in increased hospitalizations, emergency room visits, and other functional limitations, such as missed school and decreased quality of life [6–8]. Previous research has found that using a daily inhaled corticosteroid for managing moderate to severe persistent asthma can prevent airway inflammation [9]. Although adherence to daily prescribed treatment regimens for asthma is a primary factor for successful health outcomes; nonadherence to treatment has been directly related to increased rates of asthma-related morbidity and mortality, including increased healthcare utilization and impact on daily functioning [6,10–15]. In fact, nonadherence to inhaled steroids and other medications commonly prescribed for asthma is often estimated to be 50% and higher with adolescents reportedly having worst adherence than younger peers [6,7,10–15].

For many adolescents, asthma management can be very difficult. For patients who have severe, persistent asthma, taking a daily inhaled corticosteroid coupled with an oral medication can be challenging in the context of other daily responsibilities, sports, peers, and academics. The first patient we will discuss is a 14-year-old African American male who was diagnosed with severe, persistent asthma and followed by a pulmonary clinic for monthly follow-ups. He was prescribed a daily inhaled corticosteroid, rescue medication as needed, and daily montelukast [Singular™] for his asthma management. He was referred to a pediatric psychologist for a history of chronic nonadherence to oral medications and inhaled corticosteroids, high levels of parent–child conflict which exacerbated difficulties with adherence and self-management patterns, and chronic maladaptive health behaviors that were ultimately impacting his health outcomes [16]. The referral to psychology was initiated by an emergency room visit for asthma exacerbation immediately after discharge from a prolonged hospitalization; the hospitalization was the result of severe asthma exacerbation that required intubation and admission to the intensive care unit. His primary pulmonary team suspected that his

recent presentations and increased morbidity were directly related to chronic medication nonadherence coupled with poor education about proper disease management (i.e., the rationale for why preventative medications like his daily inhaled and oral medications were important). This patient was seen for a total of 29 psychology sessions where he met with a psychologist at weekly or monthly intervals.

The patient lived with his primary caregiver (biological maternal grandmother) and four younger siblings. The family had several ongoing psychosocial stressors: multiple family members with chronic illnesses, significant financial difficulties, low socioeconomic status, single-parent household, minimal social supports, and ongoing environmental and housing issues that were not being resolved by the local housing authority (e.g., presence of mold and roaches). Protective factors included his supportive caregiver, motivation to play sports, drive to attend college, and his desire to reduce medical and psychology visits.

**Interventions and Treatment Outcomes.** As shown in Table 1, psychological treatment included a multi-faceted approach that included adherence and health promotion interventions, problem-solving techniques, motivational interviewing, and family-focused interventions. This patient also received an electronic monitor for his oral medications (Medication Event Monitoring System™) and an electronic monitor to assess his adherence to inhaled corticosteroids (SmartInhaler™). The primary focus of psychological treatment was improving his medication adherence by identifying facilitators and barriers to treatment success. This patient and his grandmother also received consistent feedback regarding his medication adherence. During each session, the electronic monitoring devices were downloaded and medication adherence results were reviewed to identify barriers to success [16].

As shown in Fig. 1, this patient's medication adherence varied significantly over time for both inhaled corticosteroid (ICS: Advair™; red line) and oral medication (Singular™; blue line). There were notable improvements in adherence following psychology sessions (as indicated by green triangles). One factor that contributed to poor medication adherence was forgetting, thus multiple strategies were used to identify which set of strategies improved medication adherence for a prolonged period of time (e.g., use of a visual self-monitoring calendar, alarm clock, increased parental monitoring, and implicit reminders like pairing medication with established routines and using post-it notes as reminders to take medication).

This patient also reported that he was not aware of the rationale for taking preventative daily oral medications for asthma. Thus, part of his sessions was focused on education about asthma and medication regimens, including their relationship to health outcomes like pulmonary functioning (see Fig. 2). This patient

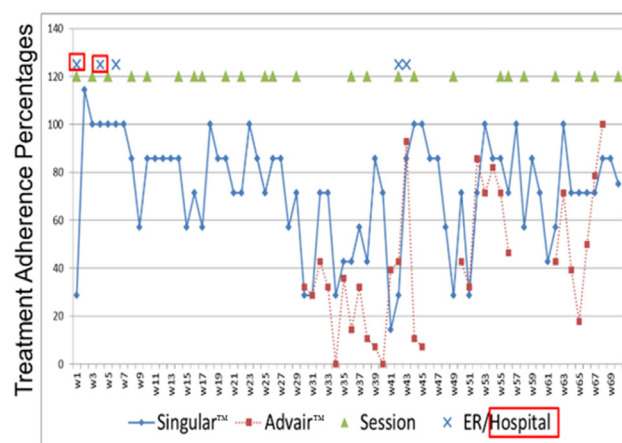


Fig. 1. Medication Adherence Patterns for a Patient with Severe Persistent Asthma.

received education about the relationship between airway functioning (forced vital capacity; FVC) and lung volume and ventilation (forced expiratory volume in 1-second; FEV-1). Motivational interviewing was used to identify patient-centered factors motivating health behavior change. The clinician would often review how poor adherence was associated with declines in health status as indicated by pulmonary functioning, use of rescue medications, and increased healthcare utilization; and, how this could impact his future goals like being recruited for varsity basketball and attending college. Finally, the patient and grandmother engaged in family-centered interventions to decrease parent-child conflict and promote developmentally-informed parent support for adolescent autonomy.

*Common challenges with managing solid organ transplant: the complex role of executive functioning, self-management, and ethical considerations for patients and donors*

It is well documented that adherence to an immunosuppressant (e.g., tacrolimus) is imperative for long-term treatment success in patients who receive a solid organ transplant [17–21]. Despite the significant risk for negative health consequences (e.g., graft loss, higher rates of morbidity and mortality), rates of nonadherence remain significantly high in this population with estimates of nonadherence ranging between 0–70% [18,20,22]. In fact, non-adherence to treatment regimens following kidney transplantation accounted for ~20% of late acute rejections and ~36% of graft losses [20,22]. It is well known that systematic and reliable measurement of treatment adherence in solid organ transplant recipi-

Table 1  
Intervention Strategies to Promote Health Behavior Change (Asthma).

Adherence and Health Promotion	Problem-Solving Interventions	Motivational Interviewing	Family-Centered Interventions
Self-monitoring calendar for visual cues of how often medication was taken	Reviewing barriers to medication adherence and strategies to remove barriers	Providing education about asthma and importance of medication	Decreasing family conflict
Implicit reminders (post-it notes, medication in a location that he looks every day)	Identifying facilitators to medication adherence and strategies to promote successful adherence	Providing education about medication, including difference between preventative vs. rescue medications	Promoting parent-adolescent support for adolescent autonomy
Medication taking with established routines	Developing a list of pros and cons to various strategies	Utilizing empathy, patient-/family-centered interventions	Reinforcing positive behaviors
Parental/career monitoring		Eliciting change talk and supporting motivation for change	
Alarm clock (phone)		Assessing confidence for health behavior change	

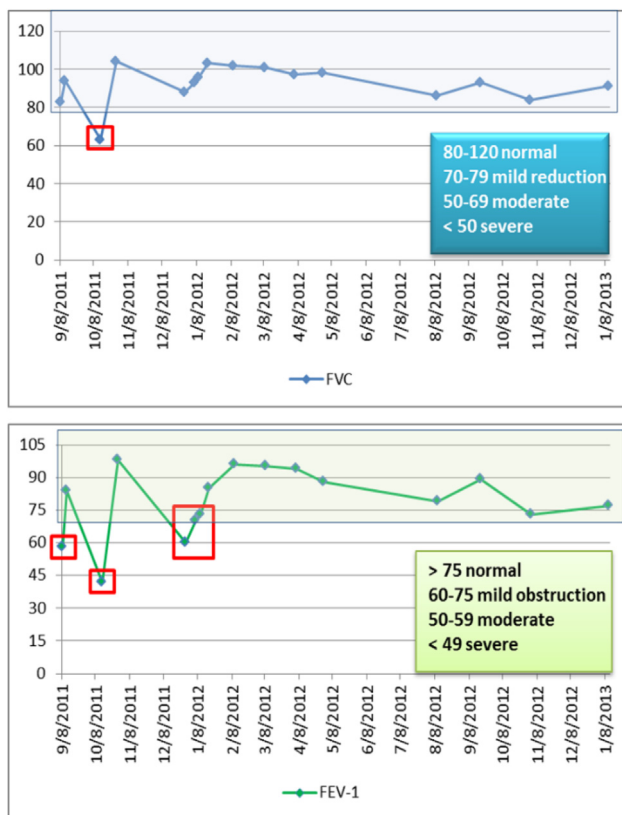


Fig. 2. Pulmonary Functioning During Psychological Treatment.

ents is necessary for determining the precise relationship between medication adherence and its relationship to health outcomes [17,18,22].

A number of challenges and ethical concerns need to be considered when patients with chronic kidney disease present with organ rejection related to their enduring nonadherence and need to have a second transplant. The second patient we will discuss is a 20-year-old Caucasian male diagnosed with chronic kidney disease, stage IV. He had a living-related donor renal transplant three years ago. He was prescribed multiple oral medications, including an immunosuppressant. In the three years following transplant, he had a history of recurrent acute cellular rejection episodes and antibody mediated rejection of kidney transplant (i.e., four rejection episodes in one-year). Following his most recent rejection episode, he was referred to a pediatric psychologist for a history of chronic nonadherence to oral medications, executive functioning concerns, and maladaptive self-management behaviors. The primary goal was to improve adherence in order for him to receive his second renal transplant, which was also from a living-related donor. This patient met with a psychologist at weekly to biweekly intervals with several extended “breaks” in between treatment sessions, ultimately comprising a total of 12 sessions over the course of 1.5 years.

The patient lived with his biological parents and two siblings. There were a number of challenges identified at the intake session, which included: poor insight regarding adherence difficulties (e.g., reporting that although he had a history of chronic nonadherence, things were “better” now attributing his low tacrolimus levels to “unknown” factors); significant distrust of “authority;” and an avoidant coping style (i.e., “I don’t have a problem;” “Why is adherence important, I have two living-related donors, which means if this transplant does not work then I have another option after this second transplant.”). He attended the intake and a follow-up session and then

did not return to treatment for five months. He returned to treatment following results of neuropsychological testing and recommendations from medical team that his second transplant was contingent on seeing a psychologist to improve medication adherence. At that time, he was issued an electronic monitor to measure daily adherence to immunosuppressants. Adherence monitors have been effectively used in prior psychological interventions targeted at improving medication adherence by identifying adherence patterns, including barriers and facilitators to illness management and treatment success [16,23–26].

**Interventions and Treatment Outcomes.** As shown in Table 2, psychological treatment included a multi-faceted approach: adherence and health promotion interventions, problem-solving techniques, and anticipatory guidance. This patient received consistent feedback regarding his medication adherence during each treatment session to identify barriers and facilitators to success. As shown in Fig. 3, this patient’s medication adherence was significantly variable over time as demonstrated by both lab values and electronic monitoring results that monitored the same medication. Factors that contributed to poor medication adherence were forgetting and daily schedule changes; thus, multiple strategies were used to improve adherence (see Table 2).

Another challenge when working with this patient was his insight into consequences of nonadherence (“I will lose another kidney”) while also recognizing there are options if this happens (“I have a third related donor”). Thus, all psychology sessions were focused on providing objective results of medication adherence to identify effective strategies to improve adherence while also helping him understand that his primary strategy for adherence issues cannot be to rely on a third donor, especially since many things can impact this option, including the ethical obligations for assessing candidacy for transplant and assessing donor-specific knowledge and risks associated with transplant. Although motivational interviewing was not routinely used with this patient given deficits in executive functioning, the clinician often reviewed how poor adherence was associated with declines in health status and how this could impact the patient’s future goals (e.g., starting a family; working full time). We also routinely reviewed how rejection related to nonadherence could impact his family relationships.

Given that objective measures of medication adherence were not a standard of care to determine transplant readiness and candidacy for transplant, daily adherence results could not be used to inform decisions regarding transplant readiness or candidacy. However, clinicians could provide weekly to bi-weekly averages of medication adherence to the medical team, which was a standard of clinical practice for our psychology service. With the primary transplant team, we frequently discussed his progress in psychological treatment and his readiness for transplant, including reviewing summary results of medication adherence assessments.

## PSYCHOLOGICAL INTERVENTIONS TO IMPROVE ILLNESS MANAGEMENT: TAILORING THE INTERVENTION TO A DIGITALLY-MINDED AND TECHNOLOGICALLY-SAVVY COHORT

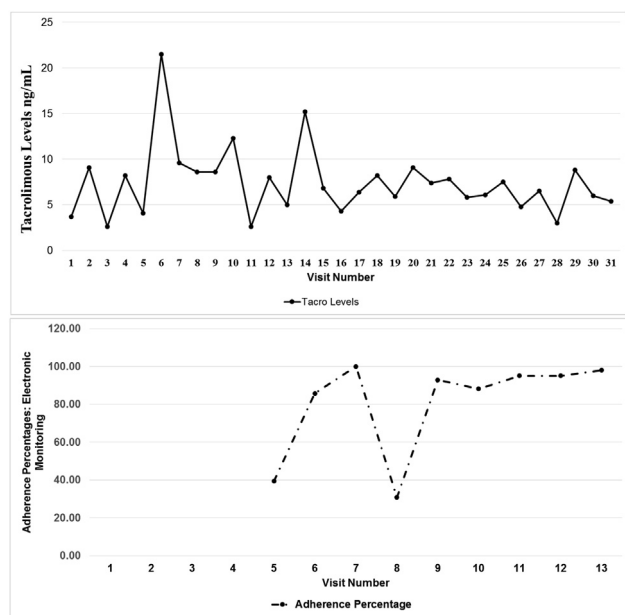
As illustrated in these two clinical cases, managing a chronic illness poses a number of unique challenges for patients and their families. Not only is managing a chronic illness difficult, but managing it during a critical and vulnerable developmental period creates another set of challenges and barriers that could impact health outcomes. When working with adolescents and young adults who have unique developmental challenges, it is important to deliver multi-faceted intervention approaches that utilize a number of different strategies and frameworks [16].

Although not utilized with the two patients presented here, previous research has examined the use of technology (e.g., computer-



**Table 2**  
Intervention Strategies to Promote Health Behavior Change (Transplant).

Adherence and Health Promotion	Problem-Solving Interventions	Anticipatory Guidance
Electronic monitoring feedback	Reviewing barriers to medication adherence and strategies to remove barriers	Ways of managing changes in routine
Medication taking with established routines	Identifying facilitators to medication adherence and strategies to promote successful adherence	Increased awareness that if miss timed dose by a short period of time (e.g., 2–3 hours), they can still take the dose as expected
Parental/career monitoring and reminders	Developing a list of pros and cons to various strategies	Changing alarm time based on changes in schedule due to work
Alarm clock (phone)	Developing strategies to improve executive functioning (e.g., multiple reminders in multiple formats)	Changing time of dose based on schedule changes
		Planning medication doses based on daily schedule, which may change during the week and weekend



**Fig. 3.** Tacrolimus Values and Medication Adherence Rates to Tacrolimus.

assisted interventions, text messaging) in adherence promotion research for various chronic conditions. For example, text messaging has been found to be an acceptable format for adherence promotion because adolescents are likely to receive and send daily text messages. Additionally, the intervention is cost-effective and does not require clinic time and travel to the hospital or other community locations; it can also be administered to individuals in rural areas [27,28]. For instance, an adherence promotion intervention with pediatric liver transplant patients improved adherence over time [29]. Researchers provided patients with daily text message reminders to take medication and patients were given one hour to respond to verify the medication was taken. If the patient did not respond within the hour, a text message was sent to the parent. These researchers found that patients had less variability over time in the amount of medication present in blood. Additionally, the researchers found that there was a significant reduction in risk levels for organ rejection compared to pre-intervention numbers. It was concluded that improved medication adherence was a result of text messaging reminders and that reminders improved health outcomes for liver transplant patients [29].

In summary, brief problem-focused interventions that utilize several components of evidence-based intervention strategies (e.g., cognitive behavioral therapy, adherence-health promotion,

problem-solving, motivational interviewing, anticipatory guidance, etc.) are effective in improving and maintaining optimal levels of medication adherence over time. Interventions also provide a unique opportunity to improve health behaviors during critical developmental periods, including during the transition from childhood to adolescence and adolescence to young adulthood.

## DIRECTIONS FOR FUTURE RESEARCH

Future research should investigate the clinical efficacy and effectiveness of multi-factored health promotion interventions targeting pediatric, adolescent, and young adults with chronic illness. Tailoring interventions to patient and family needs is of upmost importance, thus using multi-factored preventative and therapeutic interventions individualized for each patient and family will be important for maximizing the clinical effectiveness of such interventions. Furthermore, determining what specific tenets of each intervention component results in the most impactful outcomes is important to determine in future research initiatives.

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## CONFLICT OF INTEREST STATEMENT

There are no conflicts of interest to disclose.

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