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Overview

Advances in medical care have led to an increasing number of adolescents and young adults (AYA) surviving into adulthood with childhood onset chronic health conditions. Examples of such conditions include asthma, cystic fibrosis, diabetes, human immunodeficiency virus (HIV), inflammatory bowel disease, sickle cell disease, chronic renal disease, and cerebral palsy. As AYA with a range of diagnoses transition from pediatric to adult-focused healthcare systems, developing strategies to maintain health outcomes during this period is critical [1]. A key driver for maintaining optimal outcomes is adherence to recommended care therapies and condition-specific management plans. However, for AYA, particularly those with complex chronic health conditions, adherence to a daily regimen is a challenge. Therapeutic regimens are often complex, multifaceted, and time consuming to administer. Chronic health conditions often progress during adolescence and early adulthood, so the need to maintain prescribed regimens increases at a very time of life when youth are vulnerable from a physiologic perspective. Additionally, normal adolescent devel-

opment, including a desire for independence from caregivers, can hinder appropriate adherence behaviors and disease self-management. Illness perceptions and beliefs are being established during this period, and struggles with parents and caregivers over roles and responsibilities can negatively influence adherence behaviors. Therefore, improving adherence is a key part of transitional care. This chapter reviews the clinical approach to adherence for AYA with chronic health conditions, including the recognition of distinct patterns of adherence behaviors, outlines barriers to optimal adherence, and suggests strategies to improve adherence in this high-risk population.

Defining Adherence Behaviors

Broadly defined, adherence to medical therapies is the extent to which an individual completes a mutually agreed upon treatment plan. “Adherence” and “disease self-management” are sometimes used as interchangeable terms to describe an individual patient’s behavior related to maintaining a chronic therapeutic regimen [2]. Unlike the term “compliance,” which indicates a unidirectional directive in which an individual receives a treatment plan or prescription from a healthcare provider, the term “adherence” encompasses a shared decision-making approach to therapies in which both the individual and their healthcare provider have provided input

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into the therapeutic regimen. Therefore, labeling health behavior as “non-compliance” suggests that the individual is solely responsible for the failure to complete a therapeutic plan, whereas “non-adherence” implicates challenges for an individual, their support network, and their healthcare providers and system.

Although non-adherence is a common occurrence among AYA with chronic health conditions, an understanding of the type of non-adherence behaviors is important to develop appropriate individualized interventions. An individual may exhibit *unwitting* non-adherence in which they do not realize that they are failing at maintaining a prescribed treatment plan. An example of unwitting non-adherence is an adolescent with asthma who uses their controller medication once daily instead of twice daily as prescribed. They may not understand the prescription directions, or may have been misinformed, but they do not realize that they are not following a prescribed plan. A second type of non-adherence behavior is *erratic*, in which an individual has periods of good adherence interspersed with periods of non-adherence. Such an individual likely understands and agrees with therapy but has difficulty consistently maintaining their regimen. An example of erratic non-adherence is a young adult with cystic fibrosis who is able to complete all recommended therapies during the week, but on weekends often neglects his therapies as his schedule differs during those days. Similarly, a transplant patient may not consistently take oral anti-rejection medication on a daily schedule. Erratic non-adherence generally results from lack of structure, forgetfulness, or competing priorities, which may be variable. A third type of non-adherence is *intentional*, in which an individual understands their treatment plan but chooses not to follow it. For instance, an adolescent with diabetes may not use insulin during every meal or snack or a young adult with inflammatory bowel disease may avoid her anti-inflammatories on a regular basis. Such intentional non-adherence often results from anger at a health condition, health system, or caregivers, or may be due to underlying

depression or other mental health comorbidities common with chronic illness. Similarly, such behaviors may be due to the avoidance of side effects or a desire to remain “normal” in the eyes of peers by not disclosing an illness. Finally, *rationalized* non-adherence, occurs when an individual deliberately alters or discontinues therapy, often without consulting with their healthcare team. This type of behavior may result if an individual does not believe that they need a particular therapy or they feel no immediate benefit from a therapy. For instance, an individual with epilepsy may perceive no immediate benefit symptomatically from a daily medication, or a person with asthma may not notice any difference after several weeks of not taking a daily inhaler. For AYA, such rationalized behavior is quite common, and may indicate a desire for risk taking, or, similar to intentional non-adherence, be a manifestation of anger, depression, or misinformation.

When approaching non-adherence, therefore, a clinician needs to evaluate the type of behavior that each individual is exhibiting and use that information and assessment to guide intervention plans.

Assessing Adherence: Measurement Tools

It is important for clinicians to obtain measurement data to help assess adherence among their patients. Biomarkers, such as serum drug levels, would appear to be the best measure of adherence, but are only routinely available for certain classes of medications. For most therapies, there is no “gold standard” for adherence measurement, and types of measures vary depending on therapies prescribed. It is clear, however, that self-report and caregiver report of adherence is inadequate. Multiple studies have shown that self-report is subjective and overestimates true adherence behaviors when compared to direct observation, monitoring, or other measurement methods [3]. This does not mean that clinicians should not ask subjectively about non-adherence during routine clinical care; rather, they should

carefully phrase questions about adherence to allow an individual to report their challenges. Asking “do you take medication X?” sets up a response that will lead to overreporting, whereas framing a question “over the past week, how often did you miss taking medication X?” may elicit more accurate self-report.

Ideally, a clinician has access to additional objective measures of adherence. Various measurement tools exist, including data from prescription refills and electronic monitors [4]. Each of these tools has advantages and disadvantages as outlined in Table 26.1. Access to such measurements may be limited to research studies, but increasingly, electronic medical records have improved capabilities for such data to be captured in the context of routine chronic disease case management. With such data becoming more available, clinician training on how to communicate adherence data to individuals is also critical. Accurate, yet practical measures of adherence that provide real-time data are essential to provide patients, families, and their care team useful information to guide interventions if needed, and these measures need to be aligned with efficacious adherence interventions. Several monitoring devices are on the market or in

development and are increasingly acceptable in our society as we become more “quantified,” yet there is little evidence that this big data approach has improved health [5]. Online data platforms in which individuals with a chronic illness interact with the healthcare system present a viable opportunity for both adherence measurement and intervention designs. There is also an increasing desire for cell phone applications to be tailored to the chronic illness experience, include multiple functions, and facilitate coordination and communication, yet be low burden and customizable [6]. Currently, there is still a need for technology-based systems that integrate adherence and clinical data with decision support and also provide a platform for coordinating and executing effective adherence promotion interventions. Such technology also needs to be created in a practical and feasible manner to enable wider spread dissemination.

Barriers and Facilitators of Adherence

Adherence behaviors are affected by multiple factors stemming from (1) individuals, (2) fami-

Table 26.1 Measuring adherence

Measurement tool	Example	Advantages	Disadvantages
Prescription refill history	Medication possession ratio (MPR) Number of refills Proportion of days covered (PDC)	Identify what medications an individual has obtained as opposed to what is prescribed Allows for evaluation of adherence over a longer time period without need for individual input/recall	Only measures dispensing of medication Not always clear exactly what has been prescribed Does not account for “overfilling” of a prescription May not correlate with written treatment plans May not account for changing treatments over time
Electronic monitors	Metered-dose inhaler counters Continuous glucose monitors CPAP monitors	Continuous, long-term, real-time measures More objective than diaries or self-report Can identify a spectrum of issues Underdosing Delayed dosing Drug “holidays” “White-coat” adherence	Device malfunction/Technology failure Recording events that did not occur or failure to record events that did occur Cost Privacy concerns

CPAP continuous positive airway pressure

lies, (3) health systems, and (4) communities [2]. For many chronic health conditions, treatment complexity is an important barrier to adherence, and the degree of complexity may be associated with differing rates of adherence. In cystic fibrosis, for example, adherence rates vary between types of treatments, with higher rates of adherence with oral medications, lower rates with nebulized therapy, exercise and physiotherapy, and nutritional care [7]. Broadly, treatment complexity can lead to time tradeoffs based on other competing priorities, particularly those that allow a youth to engage in “normal” developmentally appropriate activities with their peers. Other key barriers include immediate time pressures, lack of time to complete therapies, uncertain schedules, and forgetfulness, either accidental or purposeful. Many youth may avoid therapies in favor of other activities and may skip therapies in order to be “normal.” Finally, for many youth a barrier to adherence is a lack of perceived consequences, specifically not seeing an impact on one’s health right away after skipping treatments or medications.

Conversely, key motivators for adherence behaviors for AYA include developing trusting relationships with clinicians, being treated as an adult, and early and repeated practice and skill building. Therefore, effective health care for AYA needs to address the developmental progression from adolescence to young adulthood. While in childhood, self-management of a chronic disease generally rests in the hands of the parents. At school age, optimally there should be an initiation of the transition to a shared model based on partial self-management, and in adolescence, there should be an increasing assertion of independence on the part of the teenager. The gradual immersion into independent self-management needs to be tracked by clinicians throughout adolescence, and parental support needs to be augmented. Encouragement of this progression into adulthood should be the cornerstone for programs to enhance adolescent disease knowledge, skills, and self-management. Additional facilitators such as improved communication and engagement of social support

have been identified in multiple studies of adherence interventions [8].

Strategies to Improve Adherence

Interventions to improve adherence often are multicomponent, and may be costly, labor-intensive, and complex [9, 10]. However, there are relatively straightforward interventions that clinicians in practice can use to address non-adherence among individuals. One mnemonic that has been developed is “SIMPLE”: Simplifying regimen characteristics; Imparting knowledge; Modifying patient beliefs; Patient communication; Leaving the bias; and Evaluating adherence [11]. Examples of behavioral intervention strategies aligned with these strategies are shown in Table 26.2 [11].

Adherence interventions can also be embedded into the Chronic Care Model (CCM), a framework with documented success for improving chronic illness care that can be used to incorporate the patient, caregiver, and healthcare system in designing interventions [12]. In this model, focusing on self-management support, delivery system design, decision support, and clinical information systems is proposed to facilitate the development of systems in which informed, activated patients work collaboratively with prepared, proactive care teams. In a review of the evidence for the CCM, 32 of 39 studies examined found that interventions based on the CCM components improved at least 1 process or outcome measure when utilized for patients with diabetes [13]. Application of the CCM has demonstrated improvements in adherence in individuals with either diabetes or asthma [14, 15].

A clinician needs to evaluate the multiple factors affecting adherence for an individual patient. In this way, addressing non-adherence is a part of routine personalized medical care. Identifying the type of non-adherence for an individual, including a recognition and understanding of individual barriers, can guide an appropriate intervention strategy. As an example,

Table 26.2 Strategies to improve adherence

“SIMPLE” strategies	Behavioral approaches
Simplifying the regimen	Creating reminders Promoting self-monitoring Tailoring the regimen Developing contingencies and rewards
Imparting knowledge	Improving health education Assessing health literacy
Modifying beliefs	Health and behavioral feedback/coaching Cognitive behavioral therapy Motivational Interviewing
Patient communication	Problem solving Family therapy Social support
Leaving the bias	Addressing mental health Assessing individual barriers Assessing type of adherence behavior
Evaluating adherence	Asking open-ended questions Electronic monitors Pharmacy refill data

Adapted from [11]

for those with unwitting non-adherence, efforts to improve knowledge of the condition and its treatments could be the cornerstone for adherence interventions. An adolescent that only uses their asthma controller medication when they are feeling unwell could be educated about the chronicity of airway inflammation even in the absence of symptoms. In this type of case, the lack of immediate perceived benefits to chronic therapies also needs to be discussed as part of an adherence intervention approach. Similarly, reminder systems may provide a structure for those with unwitting non-adherence. Automated reminders such as mobile text messages align with the self-management support component of the CCM, and have led to improvements in adherence behaviors in varied populations, including individuals with asthma, diabetes, and HIV [16–18]. Messaging interventions can be designed as one-way or two-way, enabling communication between an individual and the healthcare system. Small studies of adolescents with asthma showed high satisfaction with tailored, individual messaging reminders targeting self-management [19]. However, these interventions alone, particularly in a complex therapeutic regimen for a youth with a chronic health

condition, likely would not lead to dramatic changes if not accompanied by a greater understanding of the global context of an individual’s day-to-day needs. For those with rationalized non-adherence, particularly those who identify time as a key barrier, reminders likely would not help as much. Interventions to address time pressures and competing priorities would be an appropriate strategy. Interventions would require more than simply reducing the number of prescribed therapies or shortening the actual administration of medications. Discussions would need to identify the reason that time is an issue and likely address the overall place of therapies in the context of an individual’s other daily routines. Examining family relationships, focusing on problem-solving skills, are robust targets for adherence interventions. Such interventions might best be implemented using techniques such as motivational interviewing [20].

Across all types of adherence interventions, developing a strong relationship with the clinical care team, particularly with respect to communication and respect, is a key driver of improved adherence. Recent opportunities for improving such interactions have entered the realm of health information technology. For example, a cell

phone support program for teenagers and young adults with CF was designed to provide CF information and social support [21]. Such technologies are likely to enhance existing care models and allow for innovative adherence interventions outside routine clinical visits. However, such programs would still need to promote structured knowledge, support, and shared decision-making while enabling youth to develop effective communication with their treating clinicians.

Since poor communication with clinicians has been associated with lower levels of adherence [8], enhancing communication efforts may lead to adherence improvements. One way to support communication is providing feedback on adherence data to clinical care teams. Such feedback can enhance patient-provider communication, alert clinicians to lapses in adherence in periods between routine clinical visits, and therefore aligns with the decision support and clinical information system components of the CCM. Feedback of adherence data to patients combined with counseling to overcome adherence barriers is increasingly being evaluated in other chronic health conditions (e.g., asthma, transplant, heart failure, hypertension, sickle cell disease) and has been shown to be superior to usual care or counseling alone in improving medication adherence [22–26]. Offering objective feedback of behaviors can be eye-opening for patients and, if provided in a supportive, patient-centered conversation, can encourage patients to play a more informed and activated role in their care.

Conclusion

In summary, youth transitioning from pediatric to adult-focused care, particularly those with chronic health conditions, may struggle with adherence to recommended therapies and care plans. Clinicians need to be able to identify non-adherence and differentiate the type of non-adherence behaviors that an individual patient may exhibit. They should also work with patients to identify their unique barriers and possible strategies to improve adherence.

Interventions to improve adherence need to be multifaceted, incorporating an understanding of barriers and behaviors. Technology, including monitoring and reminders, clearly has a role in adherence promotion, but needs to ultimately be coupled with personalized approaches tailored to the challenges facing each individual patient.

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