ABSTRACT

For patients with cystic fibrosis, adherence with lifelong treatment may be challenging, particularly as individuals enter into emerging adulthood (age 19–25 years). This article explores the various factors that are known to impact adherence, with a focus on the contribution of emerging adulthood on the major nonadherence typologies (erratic adherence, unwitting nonadherence, and intelligent nonadherence). Social support is considered critical to adherence, with practical support (eg, instrumental support, assistance, reminders, and organization), emotional support (eg, nurturance and empathy), and having a cohesive family all highly associated with treatment compliance. Patients who fall into one of the nonadherence typologies have a general higher risk of nonadherence as they enter adulthood because a major aspect of social support (parental involvement) begins to diminish. For example, patients with erratic adherence (understand and agree with therapy but have difficulty consistently maintaining regimens) may find it particularly difficult to adhere to regimens during emerging adulthood, in the face of variable college and sleeping schedules, work schedules, travel, alcohol consumption, and impromptu social opportunities. Also discussed in this article are reliable ways of measuring adherence (medication refill history and patient reports of nonadherence) and empirically supported adherence promotion techniques.

encounter, and to provide necessary counseling to treat or prevent nonadherence.

**FACTORS THAT IMPACT ADHERENCE IN EMERGING ADULTHOOD**

When exploring various factors that are known to impact adherence, it is important to consider why emerging adulthood might be a particular contributor to nonadherence. Characterized by a continuation of the adolescent exploration of identity, emerging adulthood (ages 18–25) is a time period that is marked by many role transitions, including college initiation and termination, choosing a career path, multiple changes in residence, the development of meaningful romantic relationships, and transitioning healthcare teams (eg, from pediatric to adult care). Although emerging adults are no longer children, neither they nor their parents perceive them as being fully adult. Many, however, are faced with greater autonomy in regard to financial and healthcare decisions, as well as the day-to-day management of their CF.

It is well established that social support is critical to adherence. One meta-analysis examining how different aspects of social support are associated with patient adherence to medical regimens found that practical support (eg, instrumental support, assistance, reminders, and organization) was highly associated with adherence. Emotional social support (eg, nurturance and empathy), although important, was not as significantly associated with adherence. Adherence was also considered higher among patients who came from cohesive families and lower in patients who came from families in conflict. Family structure (eg, married, living with someone, or living alone) was not strongly associated with adherence, most likely because it is not a certainty that living with a spouse is supportive. For example, one patient refused to administer treatments in front of his wife due to fear of appearing weak or sick; his adherence increased after he divorced and lived alone. Similar to social support, depression is repeatedly linked to nonadherence and poor health outcomes, as indicated by a meta-analysis that found the odds of nonadherence to be 3 times greater if a person is depressed. In CF, depression is also associated with poorer ratings on health-related quality-of-life measures, even after controlling for disease severity.

Beyond social support and depression, there are additional factors that may predict nonadherence. For purposes of simplicity, they can be summarized into 3 nonadherence typologies: erratic adherence, unwitting nonadherence, and intelligent nonadherence (Table 1).

**Table 1. Adherence Typologies**

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<thead>
<tr>
<th>Typology</th>
<th>Description</th>
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<tr>
<td>Erratic Adherence</td>
<td>Patient understands and agrees with therapy but has difficulty consistently maintaining regimen.</td>
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<tr>
<td>Unwitting Nonadherence</td>
<td>Patient and provider mistakenly believe that the patient is adherent.</td>
</tr>
<tr>
<td>“Intelligent” Nonadherence</td>
<td>Patient deliberately alters or discontinues therapy.</td>
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**NONADHERENCE TYPOLOGIES**

Patients who fall into the erratic adherence group understand and agree with therapy, but have difficulty consistently maintaining the regimen. These patients commonly report that they attempt to follow their regimen, but are overly busy, forgetful, stressed, lack medication supplies, or are overwhelmed by regimen complexity. Because parental involvement diminishes after adolescence, erratic adherence is likely to increase during emerging adulthood, particularly among young adults who have not developed the needed organizational or problem-solving skills. These individuals may find it particularly difficult to adhere to regimens in the face of variable college and sleeping schedules, work schedules, travel, alcohol consumption, and impromptu social opportunities.

In unwitting nonadherence, both the patient and the clinician mistakenly believe that the patient is adherent and knows how to correctly administer medication. This type of patient may claim, “I thought I was taking my medicine right,” but in truth may misunderstand the regimen due to educational barriers, language barriers, or cognitive defects (eg, attention deficit disorder or learning disabilities). Poor knowledge is a significant contributing factor in unwitting adherence, as demonstrated by a survey indicating that the average score on standardized measures of CF
knowledge was 79% for parents and 61% for teenagers. As an example, only 16% of parents and 19% of teenagers were able to answer correctly a question on whether fat, carbohydrates, or protein contain more calories. Therefore, a teenager or young adult may not know how to implement a recommendation to boost calories, regardless of their desire to gain weight. Similarly, administering medication in the intended order may be challenging, as exemplified by one patient who thought it would be efficient to administer his nebulized antibiotic while concurrently using his ThAIRapy vest (Hill-Rom, St. Paul, MN) and engaging in aerobic exercise. Poor device technique is also considered a significant factor in unwitting nonadherence. Studies of metered-dose inhaler and dry powder inhaler administration technique typically find that only 28% to 68% of patients exhibit sufficiently good technique to result in benefit from medication, and only 66% of most healthcare professionals (eg, physicians, nurses, and pharmacists) can correctly demonstrate the technique to their patients. Failure to coordinate the actuation of inhalation (eg, neglecting to exhale prior to inhaling or not holding breath long enough) is the most common error. Only one study has examined nebulizer technique and maintenance and found that only 78% of parents reported cleaning the nebulizer after every use.

The third adherence typology is known as intelligent nonadherence, where the patient deliberately alters or discontinues therapy. Although the patient knows what has been recommended, he has decided or rationalized that not following the recommendations is justifiable. Some of the rationalizations include belief that therapy will not significantly impact health or that medicine should only be taken when symptomatic, concern about side effects or drug resistance, and fear of addiction. Studies examining beliefs about asthma medication among parents of children and adult patients found similarities, as indicated by 33% of subjects claiming that “it’s hard to take medicine” when feeling fine and only 50% believing that the benefits of treatment outweigh the risks. Patients are more likely to comply if they feel threatened by their disease, with one meta-analysis indicating that the odds of patients being adherent is 2.5 times higher if they perceive their disease to be severe and potentially life threatening. Patients with mild CF may not notice any differences in their symptoms after administering treatment, may feel worse with treatment (eg, coughing), or may not be sensitive to small declines in lung function. Additionally, some patients have a high sense of fatalism, claiming that, “no matter what I do, I’m going to die young so I might as well have fun now.” Fear of drug resistance is salient in CF, with many patients concerned that present use of antibiotics will render them ineffective later in life. Patients also commonly believe that taking medication is a reminder of an illness they would rather forget.

MEASURING ADHERENCE

Taking into consideration the limited time during a clinical encounter, the first step is to appropriately identify nonadherence. Whenever possible, clinicians should utilize objective measures, such as medication refill history, which has been shown to be reliable and valid in relation to other measures of adherence. Unfortunately, most clinicians do not have the time or staff to obtain and summarize refill data into a useful adherence metric. Therefore, there is heavy reliance on parent and patient reports. Self-report has repeatedly been shown to significantly overestimate true adherence, as demonstrated by a study that compared self-reports with electronically recorded data and found that objectively measured adherence was lower than self-reported adherence. Moreover, objective adherence was found to decrease dramatically with increasing complexity of regimens (twice daily vs 4 times daily), whereas self-report adherence changed relatively little. It should be noted, however, that patient or parent report is highly specific for nonadherence—that is, patients are more likely to fake good adherence than to fake poor adherence. If patients report taking medication 50% of the time, clinicians can be highly confident that they are adhering to the regimen 50% of the time or less.

Although patient-reported adherence is not ideal, there are ways to improve accuracy, including using open-ended and direct questions. A poor question would be, “Any problems with your medication?” whereas a better question might be, “Which, if any, medications have you been taking and how do you take them?” Because many patients may intentionally lie to providers to avoid a lecture, it is important for clinicians to establish rapport and engage in nonjudgmental dialogue with patients to obtain honest responses (see Table 2 for tips on good communication and examples of open-ended questions). In listening to
patient responses, it is important to look for any hint of nonadherence and use it as an opportunity to resolve barriers, rather than admonish the patient to do better. Patient responses will help identify the appropriate adherence typology, which will help target the appropriate intervention. For example, it is an inefficient use of visit time to discuss how to remember to take medication if the patient is not convinced that the medication is needed.

**Empirically Supported Adherence Promotion Techniques**

Strategies used to improve adherence are most effective when geared toward the appropriate nonadherence typology (Table 1). For patients with erratic adherence, identifying barriers to adherence, teaching problem-solving skills, and simplifying or tailoring regimens specifically to patients’ lifestyles are often effective. For example, it may be helpful for a college-aged student with evening classes to administer evening doses in the late afternoon, prior to class. Behavioral strategies, such as self-monitoring (eg, patient diaries), cueing (eg, storing medication near toothbrush or pillboxes), reminders (eg, programmed into cell phones), and linking to established habits or pleasurable activities (eg, favorite television show in the morning and evening), are especially helpful for those with erratic adherence. It may also be helpful for clinicians to use positive reinforcement strategies with their patients, which can be as simple as offering praise or acknowledgment for small incremental changes in adherence. For emerging adults in particular, it is important to identify social support and emphasize that asking for help in following a treatment regimen is not a sign of weakness or over-reliance on parents.

For individuals with unwitting nonadherence, providing and reviewing treatment plans at each visit is critical, because patients may not read a handout given to them at the end of a visit. Another strategy involves asking patients to repeat instructions that were just provided (Table 2), because instructions and action plans are commonly misinterpreted. Reviewing device techniques, offering CF education (particularly pertaining to nutritional issues), and encouraging access to social support are also vital for those with unwitting nonadherence.

Patients in the intelligent nonadherence category are often the most challenging for clinicians, because a successful intervention is likely to require more time or more sophisticated counseling strategies than those used for other types of nonadherence. Using patient-centered communication and increasing patient inclusion in the decision-making process are effective approaches. Regardless of how scientifically rational a particular therapeutic strategy may appear, it is imperative for patients to agree that the plan is appropriate for their goals and values before they will adhere to it. In helping patients make decisions about treatment or level of adherence, it may be useful to discuss the health implications of each treatment choice, including doing nothing, as well as the relationship between adherence and health outcomes. For example, using graphs, charts, or pictures when discussing with patients the link between medication nonadherence and a decline in lung function, change in weight, or increasing exacerbations may be an effective way to succinctly provide complicated information to the patient. Some clinicians find it helpful to have patients use daily peak flow meters in order to link the results to adherence behavior, such as starting or ending a tobramycin cycle.

Another possible strategy involves providing CF education that extends beyond general facts and is tailored to

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<tr>
<th>Table 2. Patient-Clinician Communication Tips and Examples</th>
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<tr>
<td><strong>Tips for Good Patient Communication</strong></td>
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<tr>
<td>• Establish rapport</td>
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<tr>
<td>• Open-ended questions</td>
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<td>• Reflective listening</td>
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<tr>
<td>• Normalize nonadherence</td>
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<tr>
<td>• Identify motivation to change</td>
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<tr>
<td><strong>Ask Open-Ended Questions</strong></td>
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<td>• “I know we’re asking you to do a lot. How are you doing with fitting everything into your day?”</td>
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<td>• “If you’re running late in the morning or are particularly tired in the evening, what parts of your regimen are you likely to do and which are you likely to skip?”</td>
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<td>• “What are your thoughts about how (insert name of medication) is working for you?”</td>
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<td>• “What would have to change so you could take more of your medication?”</td>
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<td><strong>Ask Patients to Repeat Dosing Instructions</strong></td>
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<td>• “Can you please review with me what you’re going to do when you go home?”</td>
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<tr>
<td>• “Let’s go through our action items.”</td>
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individual perceptions and beliefs. For example, if the clinician’s goal for a female patient is weight gain, it may be essential to address her perception that thin is healthy and socially desirable before the patient will be ready to consume more calories. It is also important to link medication adherence and health status with patients’ personal goals and values. Some patients, for example, strive to be successful professionally by working long hours and consequently missing treatments. It may be beneficial to discuss whether this short-term solution will have long-term implications for the patient’s health, as well as career (eg, absenteeism and being healthy enough to continue working).

Turning points, which often occur during emerging adulthood, may positively or negatively affect adherence. These events, which may include first hospitalization, going away to college, beginning a new romantic relationship, or becoming a parent, result in a fundamental shift in life’s meaning, purpose, or direction. It may be important to elicit these events during a clinical encounter, because the clinician can use them as an adherence promotion opportunity—either to discuss how improved adherence would increase the positive aspects of the turning point or to provide anticipatory guidance for how the turning point may cause new barriers to adherence. Many adults with CF report a first hospitalization as a turning point, leading to the realization that they need to take responsibility for their own care. Similarly, teenagers with CF anticipate that their first hospitalization will be a turning point that triggers improved adherence.

CONCLUSIONS

Emerging adults with CF are at risk for nonadherence at a time of significant, yet normal, life changes, especially those affecting access to practical and emotional support. Using good communication techniques (eg, open-ended questions and reflective listening), clinicians should query patients about their adherence at every visit, bearing in mind that any report of nonadherence is likely true and requires some level of intervention. Identifying factors that contribute to nonadherence is critical for structuring counseling strategies to match identified barriers. With some effort and forethought, most of these strategies may be easily integrated into a clinic visit without a significant change in visit length. If attempts to counsel patients have not led to improved adherence, patients may be referred to mental health professionals, who generally have more time and skills to address intransient nonadherence. It is also important to realize that adherence is not static. Removing one barrier often results in another taking its place, especially during emerging adulthood when much of a person’s life is in flux. Adherence promotion is therefore a continuous process.

REFERENCES

14. Rand C. I took the medicine like you told me, doctor: self-


