# Chapter 4
# Developmental and Psychosocial Challenges for Self-Management and Maintaining Adherence to Chronic Therapies

**Jennifer L. Butcher**

## Introduction

The transition from pediatric to adult healthcare has traditionally been conceptualized as the development of a steady progression of skills leading to independence over a predictable time period, similar to walking up a smooth slope. However, more often, the transition process is like riding an amusement park attraction, with many ups and downs, curves and bumps, and sometimes even moving backward. Although uncertainty during transition is typical, there are common areas of expected challenge. These range from broad factors related to the adolescent and young adult (AYA)'s culture and access to healthcare services, to specialized individual skills such as the ability to schedule a medical appointment. Although social-ecological and systemic factors play an important role in the transition process [1], individual factors are the best understood [2] and potentially most modifiable [3]. Chief among these individual factors are the AYA's illness self-management knowledge, skills, and behaviors [4]. This chapter provides an overview of illness self-management and its role in healthcare transition, reviews the literature on self-management within chronic lung disease, identifies developmental and psychosocial variables impacting self-management, and provides recommendations for addressing these variables and promoting self-management during care transition.

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J. L. Butcher (✉)
Michigan Medicine C.S. Mott Children's Hospital, Ann Arbor, MI, USA
e-mail: jennbutc@med.umich.edu

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## Models of Illness Self-Management

Pediatric illness self-management can be defined as the "interaction of health behaviors and related processes that patients and families engage in to care for a chronic condition" [4]. Many models to explain these interactions exist including those that are disease-specific [5] and those that are more inclusive, including the classic Health Belief Model [6]. This model theorizes that appropriate self-management behaviors can be predicted by an individual's *perceptions of their illness* (view of illness severity and belief in the benefits of following the healthcare plan) in comparison to their perceived *barriers* to following this plan. Although widely cited, a criticism of this model is the challenge of translating this theory into intervention [5].

In contrast, the Transtheoretical Model of Behavioral Change [7] matches intervention strategies to each stage in the model and hypothesizes that individuals move through predictable *stages of change*, similar to developmental stages, when developing behaviors to promote their health. However, this model relies on an individual's ability to control and make changes independently and does not fully take into account systemic influences that are critical during the AYA period, such as the influence of caregivers.

A more recent model of illness self-management, the Pediatric Self-Management Model [4], takes into account *systemic influences* impacting AYAs, including individual, family, and community factors; while also categorizing influences into those that are considered fairly static (socioeconomic status) and those that are more *modifiable* (psychosocial distress). Categorizing influences into those that are challenging to change versus more amenable to change makes it easier to translate this model into targeted intervention strategies.

Although these models each focus on different influences on self-management, common among them is the understanding that successful illness self-management encompasses appropriate *knowledge* of the illness, including how to navigate challenges; and the engagement in recommended self-care behaviors or *medical regimen adherence* [8]. Illness-specific knowledge is generally best conceptualized as necessary, but not sufficient, in that it is the building block for independence, but knowledge in itself typically does not lead to significant change [9]. Interventions targeting both knowledge and medical regimen adherence have, to date, shown the strongest results [9, 10]. Medical regimen adherence is often defined as the extent to which a person's behavior matches medical or health advice [11]. Along with knowledge, it is perceived as a central part of illness self-management and is a modifiable factor that is often the target of behavioral intervention [10].

## Role of Illness Self-Management in Transition

Transition from pediatric to adult care is a multiyear process that is generally conceptualized as the time period when AYAs become more independent in their medical care while also receiving less support. However, this transition is often not a smooth process and, if poorly planned, can result in significant morbidity and mortality complications for the AYA [12]. Using knowledge of these potential complications, providers have developed best practices for promoting transition among individuals with chronic lung disease, including those with asthma [13], cystic fibrosis (CF) [14], and who are dependent on respiratory technology, such as receiving home ventilator support [15]. Best practice recommendations for transition specific to AYA post lung transplantation are limited [16], but best practices for transition among all solid organ transplant recipients have been developed [17].

Best practices generally stress the measurement of "transition readiness" among the AYA population [18, 19]. Illness-related "knowledge and self-management skills are the most common factors included in measures of transition readiness, suggesting a consensus regarding these issues as key contributors" [1]; thereby placing illness self-management in a central role for successful healthcare transition. To date, preliminary research has supported the role of illness self-management in the transition process. Measurement of transition readiness has been positively related to healthcare knowledge [18], self-management beliefs [20], and self-management behaviors [21]. Although there is preliminary evidence that participation in programs designed to promote transition readiness results in positive change [22], sustained evidence is lacking [23], and there are few current links between transition readiness and adult medical outcomes [22].

## Role of Illness Self-Management in Chronic Lung Disease

Transition theory and preliminary evidence support the integral role that illness self-management plays in successful transition to adult care, including among those with chronic lung disease. Unfortunately, illness self-management skills are often lacking, especially during the AYA time period when medical regimen adherence is generally the poorest [24].

Among all AYAs with chronic illness, medical knowledge has been correlated with medical regimen adherence [25], but education on its own has little evidence for prompting behavior change [10]. Further, having a cognitive deficit, especially impairment in executive function skills (organization, planning, working memory), may contribute to unique barriers to developing appropriate illness-related knowledge and skills [26].

Among AYAs with chronic lung disease, medical knowledge also plays an important role in illness self-management. There is some evidence that individuals diagnosed with asthma may be at greater risk for cognitive impairment, especially among executive function skills [27]. Further, poor health literacy (understanding of healthcare information) may negatively impact the ability to use asthma knowledge [28] and has been associated with poorer physical functioning [29]. In AYAs requiring invasive or noninvasive home ventilation, there is evidence of a cognitive impact, especially among executive function skills [30–33], but there is only preliminary evidence of the relationship between these impacts and illness-related knowledge

[31]. Among individuals diagnosed with CF, there is preliminary evidence of higher rates of executive function deficit [34], but it has not been related to treatment knowledge. Although understudied, no apparent cognitive impairment has been identified in individuals that are post heart-lung transplantation [35].

Strong evidence exists supporting the prevalence and impact of poor medical regimen adherence among all AYAs with chronic illness. Recent estimates have reported that only between 10 and 35% of adolescents across chronic illness groups can be classified as adherent to their medical regimens [10]. Poor adherence is associated with numerous negative outcomes including increased healthcare use [36], and interventions that improve adherence have shown positive benefits to health [9].

Evidence of medical regimen adherence difficulties in AYAs with chronic lung disease is also strong. Among those with asthma, adolescents have been found to take <50% of prescribed doses of daily medications [37], and similar results have been found for adolescents with CF (medication possession ratios of 45–50% per pharmacy refill data) [38]. For those receiving noninvasive home ventilation, there have been mixed results from findings that only 27% use support for >3 hours to 72% using support for 8 hours [39]. The medical regimen adherence among those using invasive home ventilation is largely unknown. Finally, adherence rates among adolescents who have received lung transplantation are understudied, but a recent article using a large dataset of pediatric heart and lung transplant recipients found that physicians reported evidence of nonadherence to immunosuppressant medications at the rate of 34% [40].

According to the Health Belief Model, understanding of barriers to medical regimen adherence is key [6]. A wide range of barriers are present during the AYA period making them more susceptible to nonadherence. These include barriers related to the family system, healthcare system, and the community. During transition of care, 53% of young adults with CF were found to have a gap in care with 12% having a gap of at least 1 year [41]. Gaps in care of 1 year or more were associated with younger age at transfer and having an adult center in a different city than the pediatric center. Further, socioeconomic status (SES) may play a role as lower adherence to airway clearance in CF has been demonstrated among those with lower SES [42]. Another criterial influence on adherence during the AYA period is family, and especially caregiver, functioning. Parental depression has been associated with poorer adherence in both CF [43] and asthma [44]. Less parental supervision is related to decreased adherence in CF [45], and intervention to improve family support improved adherence in asthma [46].

Unfortunately, societal and family influences on illness self-management can be challenging to overcome. Thus, as the Transtheoretical Model of Behavioral Change suggests, focus on individual behavioral change may be an effective intervention target [7]. Although many individual factors are also largely nonmodifiable (sex, age, cognitive functioning), as the Pediatric Self-Management Model suggests, focusing intervention on modifiable factors is key [4]. Finally, Models of healthcare transition have also highlighted focus on modifiable individual characteristics such as *treatment knowledge and medical regimen adherence* [1–3]. Familiarity with typical *adolescent development* can aid in understanding of how knowledge develops over time as well as the interaction between knowledge and behavior. Further, *psychosocial distress* is a modifiable factor impacting illness self-management [10].

## Adolescent Development and Illness Self-Management

Although developmental influences are largely nonmodifiable (except with time), familiarity with these influences can significantly increase understanding of the AYA and result in the development of practical intervention approaches. Physical development occurs rapidly in adolescence along with hormonal changes that can impact health functioning independently of illness self-management behaviors. For instance, earlier age at menarche has been associated with poorer adult lung function in epidemiological studies [47], and female sex hormones appear to play a role in CF pulmonary exacerbations [48]. Additionally, with rapid physical growth, appropriate drug dosing can become challenging during adolescence.

Along with physical changes, adolescents also experience cognitive changes, including the development of abstract reasoning, executive function skills, and metacognition (awareness of thought) [49]. However, these skills develop at different rates and, in certain cases, may be impeded in individuals with chronic lung disease as previously summarized. Importantly, impediments in cognitive skills have been related to worse illness self-management [26, 28, 31].

Traditional theories of adolescent development can be applied to increase understanding of how illness self-management behaviors form and change over time. Piaget's theory of cognitive development hypothesizes that adolescents move into "the formal operational stage" of cognitive development where they develop the capacity for abstract, scientific thinking [50]. During this time, adolescents begin to generate multiple solutions to problems and can solve abstract problems that they have never encountered in real life. Although there is some evidence that being in a family who is skillful at solving complex problems may aid an adolescent in adherence to a CF regimen [51], clinical interventions to improve problem-solving skills have not yet demonstrated improvement in adolescents' CF adherence [52].

It may be that the development of abstract thought initially impedes an adolescent due to negative side effects. This includes the development of argumentativeness, self-consciousness, and self-focusing [49]. Whereas during childhood, an individual with chronic lung disease might follow their treatment regimen with little resistance; in adolescence, the teen may debate a parent or question the need to complete the regimen. Additionally, self-consciousness increases in adolescence with the development of the "imaginary audience" belief where adolescents feel that they are the focus of everyone's attention [49]. This belief may result in an adolescent not wanting to disclose their illness or engage in medical care in front of others. Adolescents with CF have identified embarrassment and desire for social acceptance as barriers to adherence [53], and a study measuring asthma adherence in adolescence found that 53% of nonadherence episodes occurred while present with friends [54]. Another distorted cognition that results from self-focus is the "personal fable," where an adolescent believes that they are unique and invulnerable to the same penalties as others [49]. This has obvious consequences for illness self-management in that an individual who does not believe that nonadherence to their medical regimen will cause harm is more likely to demonstrate poor adherence. This is at the heart of the Health Belief Model [6] and may be especially relevant for treatment regimens that are burdensome [55].

Erikson's stages of psychosocial development is another classic developmental theory that can be applied to adolescent illness self-management [56]. Erikson theorized that the major personality achievement of adolescence is the development of "identity." This includes making decisions about what defines you, your values, and your life goals [49]. During this stage, adolescents move away from family and spend more time with friends, and peer support plays a central role. This has important consequences for medical regimen adherence because improved adherence in adolescence has been positively related to more parental involvement and shared treatment responsibility across a wide range of medical illnesses [10], including asthma [46] and CF [45]. In contrast, evidence whether peer support results in improved adherence has been mixed [10]. No changes in adherence to asthma controller medication were found in adolescents participating in a peer coping support group compared to the control group [57].

Although family involvement appears to play a critical role in illness self-management into adolescence, the development of supportive friendships and peer support is critical to achieving identity as theorized by Erikson [49]; and prosocial peer support may buffer against feelings of self-consciousness, indirectly promoting adherence [58, 59]. There is some evidence that individuals with chronic lung disease may have more social withdrawal and poorer friendship quality including among those with neuromuscular disease requiring home ventilation [31], CF [60], and asthma [61]. Further, peer rejection has been found to play a significant role in the increased risk for adolescent depression [62], which in itself is related to worse illness self-management [63, 64].

## Psychosocial Distress and Illness Self-Management

AYA psychosocial distress is another individual variable that negatively impacts illness self-management. Although psychosocial distress is typically modifiable, an AYA's exposure to life stress or "negative life events" is not and has important long-term consequences [65]. Specifically, stress exposure has been related to poor health outcomes in asthma [66]. Further, exposure to acute stress results in physiological symptoms, such as bronchoconstriction, that can be harmful to those with lung disease [67].

Chronic stress can also contribute to internalizing symptoms, such as mood and anxiety disorders. Adolescents with chronic illness are, as a group, at higher risk for depressive and anxiety symptoms [68, 69]. Among AYAs with chronic lung disease, higher rates of anxiety and depression symptoms have been identified in those with CF [70] and asthma [71]. Much less is known about internalizing symptoms among children requiring home ventilation. Preliminary data from one study suggests that 77% of children were rated by their parents as having "excellent" or "good" emotional adjustment and 82% were "seldom" or "only sometimes" depressed, although parent-reported symptoms of depression were significantly higher among adolescents than younger children [72]. Data among children receiving lung transplant is also limited. One study examined depression symptoms among children pre- and post-heart-lung transplant. They found that 31% of children were rated above the cutoff on a depression screener pre-transplant, which was significantly higher than populations estimate, while only 13% were rated above the cutoff post-transplant [73].

Internalizing symptoms play an important role in illness self-management for individuals with chronic lung disease. The presence of these symptoms has been identified as a barrier to medical regimen adherence in CF [63] and has been associated with increased asthma symptomology [74]. However, the role of anxiety symptoms has been mixed in that some studies have shown that increased anxiety among children is related to improvements in medical regimen adherence [75], including among those with CF [76].

Similar to internalizing symptoms, the presence of externalizing symptoms (disruptive behaviors) can impact illness self-management. Rates of externalizing symptoms among those with chronic lung disease may vary by disease type, and studies are generally focused on school-aged or younger children. Among children with CF, mean externalizing behaviors have not been found to differ significantly from community samples on broad-based measures such as the Child Behavior Checklist [77]. However, children with asthma have been found to have more disruptive behaviors than community samples [78]. Further, children with more severe asthma were found to be at higher risk for oppositional behaviors into later childhood and adolescence [79]. Rates of disruptive behaviors among those requiring home ventilation and who have received lung transplantation appear to be largely unknown.

Although rates of disruptive behaviors differ among chronic illness groups, illness self-management may be problematic for those demonstrating elevations [80]. Among school-aged children with CF and asthma, child oppositional behavior was the barrier most frequently cited by caregivers as impacting respiratory treatment adherence [81]. Further, direct observation of children with CF completing respiratory treatments found that child cooperation during individual treatments was related to higher respiratory adherence rates over 3 months [82]. These preliminary findings support that disruptive behaviors may be another important psychosocial variable impacting adherence and may be a useful intervention target.

## Best Practices for Assessing and Promoting Illness Self-Management in AYA

Taken together, the transition to independent illness self-management among AYA is a complex process full of potential developmental and psychosocial barriers. However, screening and assessment of these barriers, and clinical intervention focused on promoting knowledge and skill development, should be considered the best practice during the transition period [2]. Models of illness self-management suggest that key factors to the understanding of transition from pediatric to adult healthcare include recognizing that change happens in stages over time, involves systemic influences, and includes many barriers [4, 6, 7]. Further, focusing intervention on modifiable factors is optimal [4]. Models of healthcare transition suggest that aspects of illness self-management, including medical-related knowledge and medical regimen adherence, are modifiable individual influences that are crucial to optimizing transition readiness [1].

Although developmental change during adolescence is not modifiable, interventions can be tailored based on known developmental challenges for the purpose of improving knowledge and adherent behaviors. Education should be tailored based on the individual developmental level of the AYA while ensuring understanding through teach-back methods [83] and skill demonstration [84]. Further, independence and increased responsibility should not be granted based on age, but on behavior that is closely supervised by caregivers [45, 46]. Adolescent feelings of self-consciousness and the desire for increased peer engagement can be addressed through frank discussions of the adolescent's preferences regarding disclosure of illness and coaching on how to share this information [85]. An adolescent's belief in their uniqueness can be accommodated by ensuring that they are part of medical decision-making in a developmentally appropriate manner [86]. Finally, an adolescent's feeling of invulnerability can be addressed by careful screening of risk-taking behaviors [87] and ensuring that safety nets (typically caregivers) are in place while an adolescent is transitioning to independent self-management behaviors.

In contrast to developmental level, psychosocial distress in AYA is an area that is amenable to change. Empirically-supported treatment for adolescent mood and anxiety disorders includes cognitive-behavioral therapy; and treatment for disruptive behaviors includes behavioral management training and multisystemic family therapy [88]. Psychotropic medication evaluation by appropriate child pychiatric specialists should also be considered for mood and disruptive behaviors that are clinically significant [89]. Treatment of adjustment to illness and chronic life stress may include training in health promotion strategies and intervention to boost factors related to resilience [90].

Illness self-management should be routinely screened while meeting with AYAs without caregivers present. Screening should begin by assuming nonadherence and asking specific questions related to doses missed over a certain time frame. The best practice in medical regimen adherence measurement suggests that multiple methods and sources of information should be integrated, including self-report, medical variables, electronic methods if available, and co-informants such as caregivers [91]. Screening should also include assessment of common barriers such as avoidance, forgetting, and time management [92].

Depending on supports available in the clinic, optimal screening may also include screening for mood, anxiety, or behavioral disorders [93]. A number of national organizations supporting children with chronic illness recommend routine depression and anxiety screening beginning in adolescence, including the American Diabetes Association [94]; the North American Society For Pediatric Gastroenterology, Hepatology, and Nutrition [95]; and the Cystic Fibrosis Foundation [70]. The American Academy of Pediatrics also recommends depression screening in adolescence and points out that those with chronic illness, including asthma, should be considered higher risk [96].

Data obtained from screening methods can then be used to implement in-clinic interventions designed to promote AYA illness self-management behaviors. As previously reviewed, intervention should include education along with behavioral strategies. This may include reminders (including the use of technology), problem-solving, increased family involvement and monitoring, and follow-up/accountability on the part of the AYA [10]. In general, multicomponent interventions may be the most effective, although effect sizes for adherence interventions, to date, are generally small [97]. Interventions delivered in-clinic may be sufficient for some AYA, but for those that are experiencing multiple life stressors, clinically significant mood or behavioral concerns, or for whom poor illness self-management is a chronic problem, referral to a health psychologist is recommended.

## Conclusion

Developmental and psychosocial challenges to illness self-management during transition are common but unique to each individual patient. Understanding of common barriers can help providers know how to screen for and address self-management challenges. Additionally, focus on ensuring illness-related knowledge and bolstering medical regimen adherence throughout childhood into early adolescence may result in a smoother transition during AYA. Adding illness self-management screening and intervention strategies into clinical care can help an AYA's transition experience to be a thrilling, but ultimately successful, ride.

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