

The Transition of Health Care Responsibility From Parents to Youth Diagnosed With Chronic Illness: A Developmental Systems Perspective

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With improved health care, increasing numbers of children and adolescents with chronic illness and disability now live into adulthood. With this change, the health care community needs to address problems related to the transition from parents caring for their young children's needs to increasing health care responsibility being required of adolescents and young adults (AYA). The current article presents a conceptualization of relevant research related to the transition of health care responsibility from parent to AYA. Using a developmental systems perspective, representative literature on adolescent and dyad-level factors related to the transition of health care responsibility is reviewed to inform clinical practice and future intervention research. To identify the health care tasks that researchers have thus far considered as most important for successful transition, we review assessment measures in this area. The varying levels of agreement on transition of health care behaviors provide an index of current thought by experts in this field. Those behaviors consistently identified as key for successful transition of responsibility from parent to adolescent are outlined to inform future research and clinical practice.

Keywords: adolescent, chronic illness, developmental systems, transition

In the United States it has been estimated that one in six youth in the United States has a chronic medical condition or disability (Perrin, Bloom, & Gortmaker, 2007; Wise, 2007). Im-

proved survival rates necessitate the consideration of developmental phenomena that previously were not experienced or studied because of childhood death from chronic illness. In recent years, health care providers and researchers have become increasingly interested in the process of transition of health care (Fredericks et al., 2010; Gilleland, Amaral, Mee, & Blount, 2012; Pai & Ostendorf, 2011; Reiss, 2012; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). The transition of health care actually consists of two interrelated transitions in which youth with chronic illness experience a shift from parent to youth responsibility for illness management in addition to a transfer from pediatric to adult medical care providers (Rodrigue & Zelikovsky, 2009; While et al., 2004). Successful transition from parent to youth responsibility could be considered a necessary prerequisite to successful transfer from pediatric to adult health care providers, who may

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expect greater patient autonomy and provide less patient support. Although both are important developmental processes, the current article will focus on the transition of health care responsibility from parents to adolescents and young adults (AYA) within a developmental systems perspective.

The transition of health care responsibility from parent to AYA is an important developmental process in need of further attention for several reasons. For preadolescent children, parents are primarily responsible for all or most medical management including medication taking, disease knowledge, and appointments and communication with health care providers. As youth with chronic health conditions enter adolescence, however, they assume increasing responsibility for medical management with varying levels of guidance and support from their health care systems (Annunziato et al., 2007; Fredericks et al., 2010; Pai & Ostendorf, 2011; Sawicki et al., 2011; While et al., 2004). A survey of more than 18,000 AYA patients with health care needs indicated that pediatric health care providers “usually or always encouraged” more than 75% of patients ages 12 to 17 years old to take responsibility for their own health (Lotstein et al., 2009). Despite encouragement to assume increasing amounts of health care responsibility over the course of adolescence and emerging adulthood, these developmental periods have also been shown to be times of increased negative medical outcomes and non-adherence to medical regimens (DiMatteo, 2004).

Given that adolescents may be particularly at risk for negative health outcomes during the time period in which they are expected to assume responsibility for their health, a better understanding of factors associated with the transition of health care responsibility during the AYA developmental period is especially important. As modern developmental perspectives increasingly focus on emerging adulthood as a unique developmental period, the process by which emerging adults with chronic illness transition to greater health care responsibility will be of greater importance (Arnett, 2000). To date, both AYA and parent-AYA or dyadic level factors have been shown to be associated with the transition of health care responsibility process. The aim of the current article is to present an integrated conceptualization of the transition of health care responsibility within a

developmental systems perspective (see Figure 1). Transition-related variables identified in the literature that are most relevant to providing transition services to AYAs and their families were reviewed. These variables include AYAs’ age, adjustment, disease knowledge, self-efficacy, executive functioning, and autonomy, as well as families’ allocation of responsibility for health care, parental monitoring, and conflict. The compilation of an exhaustive list of all AYA and dyad-level variables that relate to transition of health care responsibility from parent to AYA is beyond the scope of the current article. Instead, we endeavor to present exemplars of clinically relevant variables that we believe can guide practice and research with AYAs in the health care setting. Readers interested in a consideration of additional factors are encouraged to refer to other recent reviews and models on the transition of health care responsibility (Pai & Ostendorf, 2011; Schwartz et al., 2011).

Adolescent- and Young Adult-Level Variables

Age

Adolescent patients’ chronological age has been repeatedly examined as it relates to the transition of health care responsibility from parent to AYA, oftentimes as a rough proxy for cognitive and emotional development (Reiss, Gibson, & Walker, 2005). However, the transition literature emphasizes the importance of AYAs’ reliable performance of prescribed health care behaviors over chronological age as being indicative of transition and transfer readiness (Bell et al., 2008; Gilleland et al., 2012). These conclusions are underscored by investigations with multiple illness groups including cystic fibrosis (Modi, Marciel, Slater, Drotar, & Quittner, 2008; $n = 103$), Type 1 diabetes (La Greca, Follansbee, & Skyler, 1990; $n = 40$), inflammatory bowel disease (Reed-Knight, Lewis, & Blount, 2011; $n = 90$), and solid organ transplant recipients (Fredericks et al., 2008; $n = 25$), which have consistently shown an inverse relationship between chronological age and medical regimen adherence, one of the primary health care responsibilities faced by AYA with chronic illness. These results suggest that although older adolescents are given more responsibility for their own health care, their

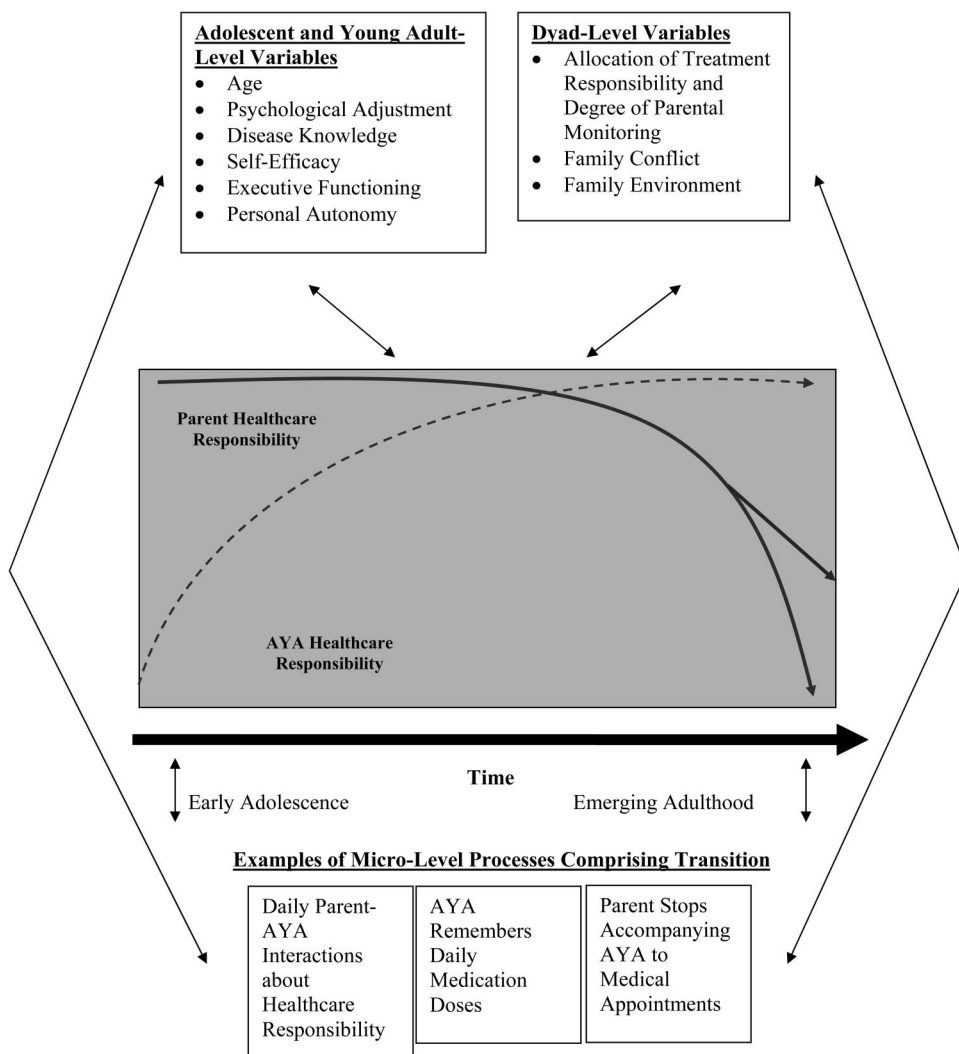


Figure 1. Conceptualization of the transition of health care responsibility from parents to AYA across the periods of adolescence and young adulthood. The macrolevel transition process is depicted in the large central box. At the top of the figure, factors that have been shown to influence transition are depicted with double-pointed arrows to represent the dynamic processes between these factors and the transition process. At the bottom, examples of microlevel processes that make up the ultimate transition of health care responsibility are given. Again, these microlevel processes are connected to the adolescent and dyad-level variables using double-pointed arrows. It is expected that parent health care responsibility would continue to decrease once the adolescent enters young adulthood and eventually adulthood.

health may actually suffer as they experience higher rates of nonadherence with increasing age. Failure to assume health care responsibility during adolescence and emerging adulthood may be an expected outcome partially attributable to the additional concurrent developmental

demands placed on AYAs including autonomy development, leaving their parents' home, and developing romantic relationships (Reiss, 2012).

Overall, results indicate that increasing chronological age is a poor indicator that an AYA

with chronic illness is prepared to take primary or sole responsibility for his or her own health care and that additional factors must be taken into consideration before transitioning responsibility from parent to AYA.

Psychological Adjustment

Adolescent and young adult psychological health has been found to relate to transition readiness and factors indicative of transition success. Within a sample of young females with diabetes, Bryden et al. (1999; $n = 76$) demonstrated a relationship between disordered eating and the misuse of insulin to control weight with extremely severe disease outcomes including mortality. In a later study of adolescents with Type 1 diabetes, the presence of externalizing symptoms, including antisocial and conduct-disordered behaviors, was predictive of worse disease functioning over the next eight years, which encompasses the period of AYA transition of responsibility and transfer to adult care (Bryden et al., 2001; $n = 76$). In adolescent recipients of kidney transplants, better parent-reported child behavior and fewer attention problems have been shown to relate to better medication adherence, an important indicator of transition success (Gerson, Furth, Neu, & Fivush, 2004; $n = 13$). In a recent study with adolescents diagnosed with inflammatory bowel disease, those experiencing higher levels of anxiety/depressive symptoms as well as barriers to adherence experienced the poorest adherence, suggesting that internalizing symptoms may be a risk factor for poor disease management above and beyond barriers related to poor organization, forgetting, and other behavioral and environmental difficulties with adherence (Gray, Denson, Baldassano, & Hommel, 2012; $n = 79$). Studies such as these indicate that adolescents' psychological health in terms of both externalizing and internalizing symptoms may influence the process of transition of health care responsibility.

Disease Knowledge

AYA knowledge of their disease and medication regimens is often regarded as a prerequisite for taking on increasing amounts of health care responsibility. Adult providers have identified disease and medication knowledge as highly important for successful transition but

oftentimes lacking in patients entering their care (Hait et al., 2009). Without increasing levels of knowledge of their health and disease process, it is hard to conceive of how AYAs could successfully transition to greater health care responsibility. Adolescents' perceptions of their medical regimen knowledge have not been associated with appointment or medication adherence (Fredericks et al., 2010; $n = 71$). High levels of disease knowledge can be demonstrated by AYAs who are not exhibiting high levels of health responsibility (Fishman, Bardse, Hait, Burdick, & Arnold, 2010; $n = 40$). Thus, disease knowledge appears to be necessary, but not sufficient for AYAs to assume health care responsibility and should not be considered a proxy for responsible health behavior.

Self-Efficacy

Often studied as it relates to health behaviors, self-efficacy refers to an AYA's perception of his or her ability to influence health outcomes, the environment, and health behaviors (Schwarzer & Luszczynska, 2008). Throughout the transition of health care responsibility, AYAs face an accumulation of health-related tasks requiring not only knowledge, but also skill acquisition and the necessity to function in unfamiliar environments and roles (e.g., communicating with health insurance staff, negotiating time-off from work or school). Adolescents with strong self-efficacy would be expected to feel capable of successfully meeting the challenges related to the transition of health care responsibility and to persist in effectively managing their health despite obstacles (Schwarzer & Luszczynska, 2008). Adolescents with higher health self-efficacy have been shown to be more likely to engage in health-promoting lifestyle practices (Jackson, Tucker, & Herman, 2007; $n = 162$).

In research specific to pediatric chronic illness, higher self-efficacy related to motivation and perceived control predicted better medication adherence in African American adolescent renal transplant recipients (Tucker et al., 2001; $n = 68$). In addition, adolescent medicine position papers have encouraged physicians and health care teams to promote self-efficacy in adolescents preparing for the transition of health care responsibility and the eventual transfer of

care through specially designed programming and care policies (Baldassano et al., 2002; Bell et al., 2008; Cooley & Sagerman, 2011; El-Matary, 2009). Such programming and care policies have not been described in detail and require further research. However, it is likely that self-efficacy specific to health care transition may be facilitated through operationalization of tasks to be completed, guided practice of health-related skills, and gradual responsibility acquisition.

Executive Functioning

Executive functioning is one facet of cognitive functioning and consists of many skills required for managing a complex medical condition including planning, problem solving, self-monitoring, organization, and working memory. Given the increasing requirements for AYA independence in managing health care related tasks and responsibilities across the transition period, executive functioning skills become increasingly pertinent. In adolescents diagnosed with Type 1 diabetes, better executive functioning as measured using parent-report on the Behavior Rating Inventory of Executive Functioning (BRIEF) was positively related to treatment adherence which in turn predicted glycemic control (McNally, Rohan, Pendley, Delamater, & Drotar, 2010; $n = 235$). Results suggest that parent-report measures are valid options for assessing executive functioning in the busy clinical setting. Similarly, Bagner, Williams, Geffken, Silverstein, and Storch (2007; $n = 130$) demonstrated a positive relationship between diabetes self-management and executive functioning, suggesting that cognitive skills related to planning, self-monitoring, and working memory may be important for successful disease management.

During the transition of health care responsibility, AYAs are required to integrate new information, acquire new skills, and to simultaneously monitor factors including physical symptoms, changes in medication regimens, and appointment scheduling. For an AYA with executive functioning deficits, the transition of health care responsibility may be especially challenging and require the addition of environmental and regimen modifications. For example, an adolescent with poor attention or planning may require a simplified medication

dosing schedule accompanied by external reminders, such as cell phone alarms, for health care-related tasks. Although executive functioning is beginning to be addressed in some areas of pediatric health care, as noted above, it has not been extensively studied in other important areas, such as how it relates to the transition of health care responsibility. Research on executive functioning may lead to methods for early identification of AYA patients who are at high risk for medication nonadherence and other problems completing health care tasks. In these cases, enhanced and sustained parental monitoring and assistance could be enlisted, and it is possible that patients may benefit from cognitive remediation training programs (Luton, Reed-Knight, Loiselle, O'Toole & Blount, 2011), as has been used in other areas of pediatrics. Behavioral health professionals working with AYA are uniquely trained to assess for executive functioning deficits and to provide cognitive remediation and problem solving for successful completion of health care-related tasks despite executive functioning difficulties.

Personal Autonomy

Researchers have examined how normative development in nonmedical aspects of the adolescent's life relates to the success of transition of health care responsibility. Interestingly, data have shown that adolescents who are expected to complete home-based chores despite their chronic illness are more likely to transition successfully to independent self-care (Blum, 1995). It is likely that the completion of chores and other everyday responsibilities helps prepare AYAs for medical-related responsibilities that must be completed on a regular schedule once they and their parents begin the transition process. For adolescents, simply feeling "tired of taking medicines" or "tired of living with a medical condition" have been shown to be significant barriers to medication adherence (Simons & Blount, 2007; $n = 78$). Chores and activities such as part-time jobs likely help the adolescent develop a generalized sense of self-efficacy for independently completing what may at times be challenging, tedious, and repetitious health care tasks. Similarly, normatively developing cognitive and social maturity, which may include AYAs assuming responsibility for meeting their own needs rather than

depending on others, have been described as important indicators of AYAs' readiness to assume increasing levels of health care responsibility (Fleming, Carter, & Gillibrand, 2002). Health care professionals can foster the development of personal autonomy by providing psychoeducation to families on the importance of setting age appropriate expectations regarding everyday responsibilities for AYAs including academic, home, and community involvement. Personal autonomy can also be fostered by helping AYAs envision a future in which they are primarily responsible for their own health care (Reiss, 2012). There is a dearth of research addressing the AYA's completion of activities of daily living and their mastery of health care responsibility.

Dyad-Level Variables

Allocation of Treatment Responsibility and Degree of Parental Monitoring

At the level of the parent–AYA dyad, allocation of treatment responsibility between parent and AYA is the primary factor shown to be related to the transition of health care responsibility (Pai & Ostendorf, 2011). Allocation of treatment responsibility is a term used to describe how the responsibility for chronic illness–related tasks is divided between the AYA and caregivers. Transition of health care responsibility from parent to child does not happen immediately or at predetermined times or ages. Shifting allocation of treatment responsibility throughout the span of adolescence is a more accurate portrayal of transition as a process rather than event. From our review of the literature and clinical experience, we assert that parents may inadvertently err by (a) giving responsibility too early, when the adolescent is ill prepared to assume it; (b) giving responsibility too late, thereby denying the AYA sufficient learning opportunities and practice; (c) giving responsibility with low ongoing parental monitoring in conjunction with graduated transition; (d) failing to provide a sufficiently supportive learning environment to train and undergird the AYA; or (e) failing to increase their responsibility should the AYA's performance of health care behaviors decline. In the ideal case, the shift of treatment responsibility is gradual, based on the

individual AYA's level of assistance needed, and supported by instruction, training, and problem solving that occurs as the AYA behaviorally demonstrates increasingly consistent success mastering the various health care management tasks.

Investigations into outcomes associated with varying patterns of parent and AYA allocation of treatment responsibility have used several different methodologies including self-report, daily diaries, and observations. Despite early clinical practice that was unguided by research and often advocated a complete transfer of responsibility at some predetermined age (e.g., 18 years old), investigations have consistently shown a relationship between child- or adolescent-only responsibility and poorer health outcomes (Kahana, Frazier, & Drotar, 2008; Pai & Ostendorf, 2011). Viewed from a different perspective, increased maternal involvement in adolescents' health care management has been shown to be related to improved outcomes including better medication adherence in several pediatric patient groups, such as those with inflammatory bowel disease (Reed-Knight et al., 2011; $n = 90$), cystic fibrosis (Modi et al., 2008; $n = 103$), and diabetes (La Greca et al., 1995; $n = 74$).

Modi et al. (2008; $n = 103$) conducted a study on the relationship between allocation of treatment responsibility and health outcomes in youth with cystic fibrosis. Although the study did not explicitly employ a developmental systems perspective, major tenets of the perspective were realized in the study. Modi and colleagues (2008) utilized a daily phone diary methodology to calculate the amount of time that adolescents spent on medical care alone, with their mother's help, and with their father's help over a 1-week period. This methodology allowed the researchers to examine dynamic activity patterns in the parent and adolescent caregiving system. As opposed to sole reliance on questionnaires, the daily diary method allowed for a better understanding of the interplay in the microlevel transition of health care responsibility between parent and child and how the transition is not a smooth linear process but one that changes daily. Results revealed that for the cross-sectional sample, parental allocation of treatment responsibility decreased across the preadolescent to adolescent period, which is likely an outcome of normal developmental

processes, with the lowest levels of parental involvement found for 15-year-olds. Interestingly, however, parental involvement was higher for the 16- and 17-year-olds in the sample than for the 15-year-olds. This shift may be attributable to the fact that the lowest rates of medical adherence were found for adolescents, suggesting that as parents were reducing their involvement in medical tasks, adolescents were not yet compensating by becoming more responsible. Perhaps parents realized that their young adolescents were becoming nonadherent and therefore increased involvement as their children progressed through adolescence. When predictors of adherence were examined using hierarchical regression, however, the strongest predictor of improved adherence was maternal supervision during the completion of medical tasks. Results suggest that although adolescents may be taking on increasing health care responsibility during the period of adolescence, parental monitoring and supervision remain important for increasing the likelihood of positive health outcomes.

Given the potential dangers, including increased morbidity and mortality, of premature allocation of treatment responsibility to a chronically ill adolescent (Annunziato et al., 2007; $N = 42$; Watson, 2000; $n = 20$), a prolonged, scaffolded transition of health care responsibility is supported. In this approach, concurrent adolescent responsibility and graduated parental supervision would be employed, similar to the manner in which adolescents learn to drive a car and acquire incremental driving privileges over time based on demonstrated abilities. Parental involvement and supervision might increase or decrease, depending on adolescents' monitored performance.

Family Conflict

Poorer teen–parent relationship quality was shown to be significantly associated with AYA report of decreased readiness to transition and more barriers to medication adherence among AYA kidney transplant recipients (Gilleland et al., 2012; $n = 48$). In a 4-year longitudinal study of adolescents with insulin-dependent diabetes and their families, adolescent-reported family conflict was found to be the strongest predictor of adherence to medical recommendations over the study period, with higher levels of

conflict predicting poorer adherence. Conversely, higher family cohesion was associated with better adherence (Hauser et al., 1990; $n = 52$). Although these studies were not designed to assess microlevel, day-to-day processes between members of the adolescent's family system, results from these and additional studies suggest that relationships within the family system are related to the adolescents' adherence to medical recommendations and health care responsibility during the period of health care transition (Hilliard, Guilfoyle, Dolan, & Hood, 2011; $n = 145$). Interventions to address family relationships have shown promise, with Behavioral Family Systems Therapy for adolescents with diabetes demonstrating improved family conflict and adherence after treatment (Wysocki et al., 2006; $n = 104$) as well as improved adolescent-mother communication and family problem solving (Wysocki et al., 2008; $n = 104$).

The associations between family relationships and AYA transition readiness and adherence may be attributable to several reasons. First, high-quality family relationships may support adaptive developmental processes including learning, growth, and independence in adolescence. Second, high-quality family relationships may also protect against factors that may interfere with the transition of health care responsibility including heightened adolescent rebellion, psychological distress, relational distress, and chaotic conditions. Third, relationship quality may affect AYAs' responsiveness to parental efforts to encourage processes related to the transition of health care responsibility, as well as parents' willingness to engage with AYAs regarding such issues.

Family Resources

Factors affecting the AYA and caregiver system including level of financial resources have the potential to profoundly affect the transition of health care responsibility. At the very time that AYAs are assuming greater health care responsibility, they may face terminations or gaps in health care coverage because of age or academic status (Willoughby et al., 2007). For AYAs experiencing limited or unpredictable financial resources and/or insurance coverage, successfully transitioning to greater health care responsibility may be especially challenging

and place them at risk for having limited access to medications and follow-up health care. However, in the age of health care reform, the Affordable Care Act (ACA) is believed to positively impact future transition outcomes for youth with special health care needs (McManus et al., 2013), and AYAs previously unable to continue with health care in emerging adulthood because of lack of insurance coverage may benefit from many of the ACA's provisions including Medicaid coverage expansion and eligibility to continue on parents' insurance coverage to 26 years of age. Behavioral health professionals should regularly assess how family resources and health insurance coverage may be affecting AYA's ability to engage with the health care system. Young adult patients also need ongoing education regarding insurance coverage and educational and vocational training opportunities.

Integrated Conceptualization of Transition of Health Care Responsibility

To use research to holistically inform pediatric clinical practice, we sought to pictorially represent the individual and dyad-level factors reviewed due to their clinical relevance to the transition of health care responsibility using a developmental systems perspective (see Figure 1). Within the central box, the transition of parents' health care responsibility is depicted as maintaining a high level throughout adolescence and decreasing into emerging adulthood, whereas adolescent's health care responsibility is depicted as increasing sharply with the passage of time through adolescence and into emerging adulthood. Parents' responsibility is not shown to decrease markedly during adolescence, as might be expected using an age-based rather than an empirically informed, performance-based understanding of the importance of parental supervision during the transition process for promoting positive health outcomes during teen years. The maintenance of high levels of parent health care responsibility also stands in contrast to previously published models of the transition of health care responsibility (While et al., 2004), which depict a substantial decrease in parental responsibility as AYAs move from pediatric toward adult focused care. Although a decrease in parent responsibility is to be expected and will likely occur by default

once the adolescent enters emerging adulthood, the current conceptualization is designed to highlight the importance of continued parental involvement across the period of adolescence to serve as a protective factor to increase the likelihood of adaptive and sustained positive health outcomes. Although the form of involvement may shift from performing tasks for the adolescent to monitoring to assure that they are done with supervision and training provided as needed, parental involvement should remain high to assure a greater likelihood of successful transition. Although to our knowledge the issue has not been addressed in the research literature, it also is probable that some degree of parental involvement may be beneficial after the transition into young adulthood, particularly for some young adults. Examples of potential needs for possible parental involvement, even with otherwise competent and responsible AYAs, include transportation for health care appointments, assistance with negotiating with insurance companies, assistance in making payments, and establishing working relationships with new health care professionals. We visually illustrate this by the terminal end of the Parent Health care Responsibility arrow ending in a potential range of parent involvement as needed, rather than a definite low point.

AYA- and dyad-level variables from the empirical and theoretical literature that are related to transition are depicted as interacting with the transition process via bidirectional arrows. For example, AYAs with more internalizing and externalizing problems or parent-AYA dyads with higher conflict are likely to find the transition process more difficult. Similarly, AYA oppositionality or unwillingness to assume more responsibility for their health care may result in more conflict within the parent-AYA dyad. Finally, examples of microlevel processes comprised by the transition process are given at the bottom of the figure to illustrate that the transition of health care responsibility occurs over an extended period and that the timing and nature of these processes is the result of everyday interactions between the parent and AYA.

Inclusion of the microlevel processes involved in the transition process is important for several reasons. First, the examples provided, such as an AYA remembering to take his or her daily medications, give clinicians a clearer operational definition as to the routine tasks that

make up the successful transition process. These individual health care responsibility tasks are discrete and teachable components of different facets of the composite transition process. Mastery of one microlevel component does not assume mastery of the other components. Second, the microlevel processes contribute to the transition process and to how the transition process influences the overall pattern of daily health care related tasks and interactions between parent and child. For example, within the separate domains of overall transition readiness, such as increasing responsibility for medication adherence and appointment making, parents and AYAs progress from adolescents being trained to perform simpler tasks and having less responsibility to performing more complex tasks in which they are increasingly responsible. Progression along this continuum would be guided by repeated demonstration of successful performance. Some microlevel tasks, such as medication organization and medication taking, seem to be tasks to be emphasized in day-to-day parent–AYA interactions, before attempting to address other less frequently occurring and potentially more complex tasks, such as scheduling health care appointments or negotiating with insurance companies. Similar to the interactions described by [Lichtwarck-Aschoff, van Geert, Bosma, and Kunnen \(2008\)](#) in their developmental systems model of adolescent identity development, parent–AYA interactions regarding the transition of health care responsibility are influenced by previous interactions so that the likelihood of ultimate transition success becomes increasingly constrained and more probable with each successful microlevel interaction.

Health Care Responsibilities Involved in Transition

A clear understanding of the factors related to the transition of health care responsibility aids in delineating and conveying the specific health care responsibilities involved in the transition so that AYAs, parents, and health care providers can have common expectations. One way to identify important health care responsibilities is to consider tasks that have been identified by multiple researchers in this area as integral health care responsibilities on measures of transition and transfer readiness and allocation of

treatment responsibility. This approach allows both for listing multiple transition readiness responsibilities, as well as a means for indexing the level of agreement regarding those behaviors considered integral for transition. There is variety in the settings, illness populations, and types of health care responsibilities with which measures have been developed. In [Table 1](#), we present sample measures pertinent to the transition of health care responsibility along with the constructs assessed. We did not seek to present a comprehensive list of assessment measures relevant to transition. Instead, we sought to identify a sample of generic and disease specific measures as examples to inform clinical practice and applied research.

In [Table 2](#), we present a more detailed description of the health care–related responsibilities most commonly assessed by each of the identified measures. The health care responsibilities assessed across the identified instruments essentially describe which responsibilities are considered to be integral for successful disease management. Many of the measures also assess additional responsibilities as well as attitudes or disease specific issues. Among the most frequently assessed responsibilities are taking daily medications, disease knowledge, scheduling medical appointments, and medication knowledge. Knowledge about insurance coverage and taking as-needed medications are less frequently assessed, though likely important tasks for successful transition of health care responsibility. Clearly operationalizing those health care tasks that have high agreement as being important across the various measures of transition of responsibility offers the possibility of great benefit. Such an approach could facilitate the development of guidelines for how to successively train AYAs on the various tasks, give necessary support, and increase the level of AYA responsibility based on repeated demonstration of mastery of those health care task goals. This is an area in need of additional research that could prove immensely useful for AYAs, their families, and the professionals working with them around issues of transition.

Implications for Intervention

Although there is increasing interest among researchers and clinicians in the process of the

Table 1
Transition of Health Care Responsibilities Assessment Measures

Measure	Disease group	Reporters	Constructs assessed	Citation ^a
Transition Readiness Assessment Questionnaire (TRAQ)	Any youth with chronic healthcare needs	AYA	Self-management, Self-advocacy	Sawicki et al., 2011
Transition Readiness Changing Roles for Families/Youth (TRCR)	Any youth with chronic healthcare needs	AYA; Parent	Knowledge of health issues/diagnosis, responsibility for management-related tasks, health insurance planning	National Health Care Transition Center, 2011
Cystic Fibrosis Readiness Questionnaire	Cystic Fibrosis	AYA	CF knowledge, AYA healthcare responsibility	Cappelli, MacDonald, & McGrath, 1989
Readiness for Transition Questionnaire (RTQ)	Kidney Transplant	AYA; Parent	AYA healthcare responsibility, parent healthcare involvement, perceptions of transition readiness	Gilleland, Amaral, Mee, & Blount, 2011
Transition Readiness Scale (TRS)	Liver Transplant	AYA; Parent	Self-management skills, Allocation of responsibility for health-related tasks, regimen knowledge, and psychosocial adjustment	Fredericks et al., 2010
Self-Care Independence Scale (SCIS)	Cystic Fibrosis	Parent	AYA Self-care autonomy	Patton, Graham, Varlotta, & Holsclaw, 2003
HIV Family Responsibility Questionnaire	HIV	AYA; Parent	Allocation of responsibility for medication-related and other HIV management-related tasks	Naar-King et al., 2009
Diabetes Family Responsibility Questionnaire (DFRQ)	Diabetes	AYA; Parent	Allocation of responsibility for regimen tasks, general health maintenance, and social presentation of diabetes.	Anderson, Auslander, Jung, Miller, & Santiago, 1990
Allocation of Treatment Responsibility Scale (ATR)	Kidney Transplant	AYA; Parent	Allocation of treatment responsibility for oral medication, clinic attendance, and laboratory attendance	Pai et al., 2010
Inflammatory Bowel Disease Family Responsibility Questionnaire (IBD-FRQ)	IBD	AYA; Parent	AYA and parent involvement in general health maintenance, social aspects, regimen management, and nutrition for IBD	Greenley, Doughty, Stephens, & Kugathasan, 2010

^a Please refer to references for further detail regarding measure development, psychometric properties, and indications for use.

transition of health care responsibility from parent to AYA, there is a dearth of research on how to promote successful transition through regular clinical practice. This conceptualization will hopefully serve to inform assessment and intervention aimed at the AYA and dyad-levels as well as at the microlevel processes that make up the transition process. At the AYA level, practitioners may encourage AYAs to assume developmentally appropriate levels of health care

responsibility. Chronological age may help inform the selection of developmentally appropriate tasks, but given past research that has shown increasing age to be a risk factor for poor outcomes (Fredericks et al., 2008; Modi et al., 2008), chronological age alone should not be used as a criterion for transitioning from parent to primarily AYA health care responsibility. Interventions may also work indirectly by increasing AYA's nonmedical responsibility tak-

Table 2
Assessment of Healthcare Behaviors Involved in the Transition of Health Care Responsibilities From Parent To Adolescent

Responsibilities	CF Readiness			HIV Family Responsibility						
	TRAQ	TRCR	Questionnaire	RTQ	TRS	SCIS	Questionnaire	DFRQ	ATR	IBD-FRQ
Taking daily medication	■		■	■	■	■	■	■	■	■
Taking as needed medications					■			■		■
Scheduling medical appointments	■	■	■	■			■	■	■	■
Managing medication refills	■	■		■	■		■		■	■
Remembering/Attending medical appointments	■	■	■	■	■		■	■	■	■
Knowledge about insurance coverage	■	■		■						
Disease knowledge		■	■		■	■		■		■
Medication knowledge	■		■		■	■		■		■
Routine self-care procedures (e.g., labs, physiotherapy)	■		■	■		■		■	■	■
Communicating with medical staff	■	■	■	■	■					■
Communicating with others about medical condition	■	■		■	■	■	■	■		■

Note. Black squares indicate that a healthcare responsibility is assessed via the measure.

ing such as promoting performance of daily household chores in order to teach responsibility, build general self-efficacy, and increase structure in the AYA's schedule. Adolescents and young adults should also be screened for psychological difficulties including both externalizing and internalizing problems so that existing problems can be treated with evidence-based mental health services. Reduction of psychological symptoms may lead to increased responsiveness and greater success in their assumption of health care responsibility.

At the parent-AYA dyad level, practitioners may target family conflict (Hauser et al., 1990), especially as it relates to the health care regimen. Most importantly, however, intervention likely needs to address the allocation of treatment responsibility within the home to help families operationalize and clearly define who in the family is primarily responsible for each of the required medical tasks and how levels of responsibility may shift over time. Given the

protective nature of parental involvement (Modi et al., 2008), treatment likely should not advocate for a complete removal or abdication of parental responsibility and should instead work to increase levels of AYA skills and responsibility while maintaining parental involvement and supervision as indicated (see Table 3). What our conceptualization recommends is a criterion-based training of different components of responsible health care behavior in AYAs, with more responsibility being given, and more complex skills being taught contingent upon sustained, demonstrated performance and mastery of prior health care tasks. Ongoing monitoring also allows for increasing parental involvement if the AYA's responsible health care behavior decreases, thus providing a safety net, as well as opportunities for further increasing AYA responsibility within a family-oriented context. Professional monitoring of the progress of AYAs and their parents, support, and intervention as necessary would undergird the family in this process.

Table 3
Strategies for Targeting Allocation of Treatment Responsibility to Promote Successful Transition of Healthcare Responsibility

Responsibilities	Examples of microlevel processes comprised by the allocation of treatment responsibility	
	AYA	Parent
1. Medication adherence	<ul style="list-style-type: none"> • Regularly uses pillbox • Takes on responsibility for filling pillbox weekly • Uses cell-phone alarm as a reminder for doses • Encounters barrier to adherence • Keeps “back-up” medication doses on hand (e.g., car, purse, bookbag) when away from home 	<ul style="list-style-type: none"> • Checks pillbox daily to insure medication has been taken • Teaches how to fill the pillbox then monitors accuracy of filled pillbox • Verbally checks-in after alarm to insure medication has been taken • Aids in problem-solving barrier with help of medical team • Secures permission/appropriateness for “back up” dose storage and checks-in via text as needed to confirm medications are taken
2. Medical appointments	<ul style="list-style-type: none"> • Stores numbers for physicians and clinics in personal cell-phone • Participates actively in medical appointments • AYA is seen independently from parent for portions of medical appointment 	<ul style="list-style-type: none"> • Teaches AYA how to schedule appointments • Helps AYA develop list of questions to ask at appointments • Attends appointments, shares concerns, and verifies information for providers
3. Prescription refills	<ul style="list-style-type: none"> • Stores pharmacy phone number in personal cell-phone • Stands in line at pharmacy and requests refills • Uses calendar to keep track of time to order medication refills 	<ul style="list-style-type: none"> • Teaches AYA how to call-in prescription refill and watches adolescent complete task • Monitors AYA and pays for refills • Reminds AYA to re-order to prevent running out of medications
4. Insurance coverage	<ul style="list-style-type: none"> • Carries insurance card in wallet and is knowledgeable about coverage plan and copays • Completes registration / check-out at appointments and pays co-pays 	<ul style="list-style-type: none"> • Instructs AYA about terms of coverage, copays, and how to access account details online • Supervises interactions and provides AYA with payment for care
5. Medical knowledge	<ul style="list-style-type: none"> • Demonstrates knowledge of medical history, medication information, and family medical history • Completes patient registration and medical history forms 	<ul style="list-style-type: none"> • Coaches AYA in accurate recall and presentation of medical history and treatment information • Oversees accuracy of information presented by AYA

Areas of Future Research

Using a developmental systems perspective to help design potential interventions would increase the likelihood of addressing the dynamic process of the transition of health care responsibility from multiple perspectives. A developmental systems perspective would advocate that instead of solely addressing AYA or dyad-level factors, the parent–AYA system must be addressed as a whole with interventions aimed at integrating treatment into the system while also highlighting and taking advantage of a family’s strengths. Such interventions might help parents and AYAs define the unique microlevel processes comprised by the transition process for their family such as the daily medication sched-

ule, appointment making, and obtaining prescriptions from the pharmacy, and then help families define the behaviors and sequence for the AYA progressively taking responsibility for each of the tasks (see Table 3). Once responsibility has been defined and delegated, the process of transitioning responsibility from parent to AYA with ongoing parental involvement can be planned. Such a process might concurrently treat relationship difficulties within the family system and AYA psychopathology, if present, or work to promote nonmedical responsibility for AYAs who do not have daily chores or routine responsibilities. Such a systems approach would target the transition of health care responsibility within the ongoing family context.

As increasing numbers of AYAs with chronic illness survive and develop from childhood into adolescence and then into emerging adulthood, the health care community will be increasingly affected by the need to address challenges related to the transition of health care responsibility from parent to AYA. Future research should continue to address additional factors related to the transition process including parent-level factors (e.g., maternal depression, health care knowledge), contextual factors (e.g., socioeconomic status, daily stressors) and health care system factors (e.g., insurance coverage, availability of transition services) to build a more comprehensive understanding of transition. As mentioned earlier, although adolescent medicine position papers have called on health care teams to promote AYA self-efficacy and to prepare patients for the transition of responsibility, research on effective methods for accomplishing these goals is needed. Research is also needed on the transition of a wider range of health care responsibilities, as the majority of current studies use medication adherence as the primary or only outcome. Future studies should examine how the transition of health care responsibility from parents to youth is related to AYAs functioning following the transfer to adult care. By comprehensively assessing and characterizing successful transition of health care responsibility using developmental theory and empirically validated measurement tools, clinicians and researchers can remediate a critical knowledge gap in supplying quality clinical outcome data. Utilizing a developmental systems perspective to inform future assessment and intervention research can move the field forward to most effectively serve the growing number of AYAs and families in need.

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