



Published in final edited form as:

*Nurs Clin North Am.* 2013 June ; 48(2): 305–317. doi:10.1016/j.cnur.2013.01.010.

## Health Care Autonomy in Children with Chronic Conditions: Implications for Self Care and Family Management

Barbara L. Beacham, PhDc, RN<sup>a</sup> and Janet A. Deatrck, PhD, FAAN<sup>b</sup>

<sup>a</sup>Doctoral Candidate, University of Pennsylvania

<sup>b</sup>Professor, University of Pennsylvania School of Nursing

### Synopsis

Health care autonomy typically occurs during late adolescence but health care providers and families often expect children with chronic health conditions to master self-care earlier. Few studies have examined the development of health care autonomy as it pertains to self-care and family management. This review will link the three concepts and discuss implications for families and health care providers. Case studies are provided as exemplars to highlight areas where intervention and research is needed.

### Keywords

Child; Development; Chronic Health Conditions; Family Management; Self-Care; Autonomy

More than half of all Americans have at least one chronic health condition,<sup>1</sup> and 1-in 5 households contain a child who has a chronic health condition.<sup>2</sup> Because the majority of these children now survive into adulthood,<sup>3</sup> their transition to self-care and eventually to adult health care is on the clinical, research, and policy agendas for many professional, advocacy, and governmental groups.<sup>4–6</sup> While common sense links child development, family issues, and the acquisition of self-care, a gap exists regarding how the components can be integrated into a model to guide nursing practice.

Health care autonomy is a developmental key that links family management and self-care. Autonomy is the ability to evaluate options, make a decision and define a goal, feel confident about those decisions, and develop strategies to meet the goal.<sup>7</sup> Health care autonomy, then, refers to the ability to evaluate options, make decisions and define health related goals, the confidence to stand by those decisions and to develop strategies to meet those health related goals. Autonomy in health care situations for children usually is one of the last contexts in which autonomy will be expressed, typically in late adolescence.<sup>8,9</sup>

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<sup>a</sup>Corresponding author for proof and reprints: Barbara L. Beacham, PhDc, RN, Doctoral Candidate, Center for Health Equity Research, University of Pennsylvania School of Nursing, Room 225 (2L) Claire M. Fagin Hall, 418 Curie Boulevard, Philadelphia, PA 19104, Phone: 215-898-0944, FAX: 215-573-9193 or 215-573-5925, blynne@nursing.upenn.edu. <sup>b</sup>Coauthor address: Janet A. Deatrck, PhD, FAAN, Professor and Co- Director, Center for Health Equity Research, University of Pennsylvania School of Nursing, Room 223 (2Lower) Claire M. Fagin Hall, 418 Curie Blvd., Philadelphia, PA 19104-4217, Phone: 215-898-1799, FAX: 215-573-9193 or 215-573-5925, deatrck@nursing.upenn.edu.

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The authors have nothing to disclose.

The general importance of autonomy is highlighted along with other factors, including family management and skills for self-management, within an ecological model of readiness to transition to adult health care for children with chronic conditions proposed by Schwartz and colleagues.<sup>10</sup> They explicitly indicate the importance of autonomy (developmental maturity), family management styles, and self-management to the transition process. The developmentally appropriate level of autonomy for the child is mentioned as a facilitator of the transition process. For all concerned (including the child and the family), family management goals that facilitate the child's autonomy and successful transition to adult care are necessary. More specifically, the family members and the family as a unit need to believe that the child is capable (i.e. child identity) and that the child will be able to care for themselves in the future (i.e. future expectations).<sup>11</sup> In addition, Schwartz points out that children who successfully transition must have disease self-management skills and parents need to be effective at supporting such skills.

The purposes of this paper are (1) to describe a developmental and family based model of health care autonomy that incorporates self-care and family management and (2) to apply the model to two case studies in order to highlight how it can be applied to nursing practice and possibility to nursing research.

## Development of Health Care Autonomy

The development of autonomy is integral to the development of self-care in children with chronic health conditions. As the model in the Figure depicts, health care autonomy, family management, and self-care provide the foundation for child health and well-being. Examining these concepts will provide a basis for understanding the challenges of incorporating management of a chronic condition into transitioning to young adulthood and how nursing care can best support this process.

The left hand side of the model depicts the key components required for development of autonomy. Autonomy readiness is assessed both by the parent and by the child, separately and based upon the feedback they get from one another. It is these individual assessments along with the interactions between the child and parent that provide the foundation for family management of the chronic health condition and the development of self-care within the child. The optimal outcomes of the process are health and wellbeing of the child and increasing health care autonomy.

Chronic health conditions can lead to decreased well-being for the child in terms of missed school days and opportunities for social interactions and activities, as well as lost productivity, poor health, lost wages, and increased medical expenses for parents.<sup>12,13</sup> Families of children with chronic health conditions face the challenge of managing all facets of the condition early in the child's life and then transitioning the management responsibility to the child. Therefore, by understanding the process of developing health care autonomy, and the key components for both the child and the parent, health care providers can help to maximize child health outcomes.

## Health Care Autonomy

Autonomy is a complex developmental construct which is instrumental in the transition from childhood to adulthood. Successful autonomy can be assessed by examining decision-making, relationships, influence upon others, and perception of competence, control, and responsibility.<sup>7</sup> It is often thought to be synonymous with independence and self-reliance.

Smetana et al, (2004) identifies four different domains of autonomy: prudential, conventional, multifaceted and personal in a study of decision-making autonomy.<sup>8</sup> Each

domain reflects a different context for autonomy development, with prudential (decisions regarding health and safety, e.g., when/if to smoke cigarettes, drink alcohol) and personal (decisions regarding the state of one's body, and privacy) being especially relevant to the child with a chronic health condition. Each domain deals with different issues and therefore autonomy develops in each domain over time but at different times and rates. The study also found that mothers and children had different perceptions about when the child should or did have increased autonomy in each area.

Children with chronic health conditions need to develop autonomy within these domains specifically related to the management of their chronic health condition. As was stated earlier, autonomy over health related issues (prudential) typically occurs late in adolescence,<sup>8,9</sup> but we often expect children with chronic health conditions to master these tasks earlier. Helping children master all the components of self-care requires a well-constructed plan over many years and requires the support and buy in of the child and family.<sup>5</sup>

## Family Management for Children with Chronic Conditions

Family management, how families actively organize, integrate, and accomplish tasks related to the chronic health condition in the child,<sup>11</sup> provides the health and well-being of the child. The three components and eight dimensions of family management identified by Knafl et al (2012) highlight the areas and issues families and practitioners need to consider. The family view of the child with a chronic health condition (child identity) and the view of the condition itself (view of condition) are two of the four dimensions of the conceptual component "Definition of the Situation" and are the foundation of family management.<sup>11</sup> Developing from this understanding, the parents also assess the ease or difficulty they have in carrying out the recommended treatments (management mindset) and the extent to which they have shared views of the child, condition and approach to condition management (parental mutuality). The second conceptual component, "Management Behaviors" identifies the parenting philosophy regarding condition management (parenting philosophy) and the ability of the parents and child to have a routine and strategies for condition management (management approach).<sup>11</sup> The third component, "Perceived Consequences" is comprised of two dimensions, the parents' assessment and satisfaction with how condition management has been incorporated into family life (family focus) and the parents assessment of the future for both the child and the family (future expectation).

Family management changes over the course of a child's life as the child develops the skills, cognitive ability and social confidence to manage their own health care activities. The authors of the model, developed primarily from the parents' perspective, have encouraged researchers to expand its use to other populations. A study of adolescents with spina bifida demonstrated the value of adolescents' perceptions of how they management their condition with their family.<sup>14</sup> The adolescents' description of condition management performed by themselves or their families was consistent with the dimensions and components within the family management model. In addition, self-management as well as the shared responsibility of care between the adolescent and the parent, was highlighted.

Moving the science forward will also require research regarding the children's perceptions about how their families manage within the context of their own self-care, as the child is both a recipient of family management and a participant with the family as they manage. Only then can we begin to examine the interplay of the family and child, recognizing that some of the components or dimensions of family management may remain stagnant and may not support the development of the child. Optimal family management would transition most

of the condition management to the child as they grow and develop, while maintaining health outcomes.

## Self-care for children with chronic conditions

Riegel, Jaarsma & Stromberg's, (2012) middle-range theory of self-care was created from experience with adults who have heart failure. The theory defines self-care as "a process of maintaining health through health promoting practices and managing illness".<sup>15(p195)</sup> The three components of the theory, self-care maintenance, self-care monitoring, and self-care management, delineate self-care and identify areas to consider when we are teaching children and their families.

Self-care maintenance are the behaviors used by patients with chronic conditions in order to maintain physical and emotional stability.<sup>15</sup> For children, the family, and health care provider, determining when the child is developmentally able to perform these behaviors is important when considering transitioning from an emphasis on parental agency in family management to child agency and self-care.

Self-care monitoring, the second component, is the process of observation or self-reflection in order to identify changes in signs and symptoms.<sup>15</sup> Again, the ability to attend to this process hinges on the child's developmental ability and self-awareness. As we will see, this component is most overlooked when considering a child's ability to perform self-care and may be a reason for a decline in outcomes during adolescence.

The third component of the model, self-care management, is defined as a response to the signs and symptoms when they occur.<sup>15</sup> Taking appropriate action requires knowledge of the options available, availability of the treatments required, and the physical ability and the psycho-social maturity to act. The child may have the knowledge, but not the maturity to act when faced with having to "show weakness" in front of friends or classmates. Both components of management are crucial when preparing the child for self-care activities.

This conceptualization of self-care provides a novel way to examine all the components of self-care that may be applicable for children with chronic health conditions and their families as they navigate the process of maintaining the health of the child. Table 1 demonstrates the way the original framework may be adapted to include children and families. This adapted model will be used as a template to examine care components families provide and transition to children over time.

Self-care for children with chronic health conditions is a joint effort between the family/parents and the child. Learning self-care practices begin as a parent/caregiver driven effort when the child is young, with the goal of transitioning to a child driven effort, as the child becomes a young adult. The process of transitioning can be seen in everyday self-care activities, such as oral care. When a child is born and throughout infancy, the parent/caregiver is responsible for maintaining the oral care. As the child develops the ability to handle a toothbrush, they are given a toothbrush; which they basically chew on. The parent perseveres and handles the actual tooth brushing while the child is learning about brushing his/her own teeth. The child observes and experiences the parents' tooth brushing and alters their own actions with each attempt. Once the child is able to brush his/her own teeth, the parent still follows up to ensure they are doing a good job. Over time the child proves they are able to brush her/his own teeth. Tooth brushing become a child driven self-care activity, although the parent may still handle making appointments and acute situations. Although physical ability is one component that drives the transfer of care from the parent to child, another is the child's ability to act autonomously.

The level of self-care a child is capable of depends on several factors. Knowledge of the disease and treatment regime, part of self-care maintenance, along with age of the child has been attributed to skill mastery.<sup>16</sup> But skill mastery is only one part of self-care. A study of children with asthma found that symptom recognition, the ability to identify changes early and intervene appropriately, is described by older children but not younger ones.<sup>17</sup> This study also found that older children with asthma were more adept at self-care management and were able to manage an asthma attack independently while younger children required assistance and all children lacked knowledge required to avoid asthma triggers and prevent an attack.<sup>17</sup> This finding is not surprising as symptom recognition is inherent in self-care monitoring and is a more sophisticated skill.

As children get older, studies have found that there is a decrease in self-care (medical adherence) for children with chronic conditions during adolescence resulting in decrease in well-being.<sup>18</sup> For example, a 4-year longitudinal study of children with diabetes found that age was related to a decline in metabolic control.<sup>19</sup> Additionally, self-care behaviors (maintenance) also declined over this period. Peer relationships were a risk factor for poor control. The authors posited that some of the deterioration may have been related to decreased parental monitoring, supervision and overall involvement in the diabetes management. In addition, parents may have decreased monitoring and direct involvement because their school-aged children appeared to be autonomous as they were compliant with self-care maintenance. Attempting to reestablish monitoring and parental agency or control with an adolescent often fails. What may not have been so obvious when the parent decreased monitoring is that the adolescent did not have requisite skills regarding health care autonomy which was evident in underdeveloped self-care monitoring and management. This exemplifies the dilemma faced by families during transition of responsibilities. Without adequate training, development and oversight, the child is not being prepared for success in all areas necessary for successful condition management. If parents totally abdicate and withdraw support and monitoring, trying to regain parental control may not be successful and outcomes may suffer. Therefore, the school-age period is an extremely important but delicate time of preparation and transition.

### **Self-care, Family Management, and Health Care Autonomy**

Thus, the ability to practice self-care is dependent upon the child's developmental stage. Just as the child needed the dexterity to hold a tooth brush and understanding not to swallow the toothpaste, children need the cognitive, physical, and psychosocial abilities to be autonomous with condition management. When children are too young (not developmentally able) to successfully handle all the demands of self-care, the family shoulders the condition management responsibilities. The family most optimally includes the child as an active participant and also allow them to observe the process used to make decisions. By actively participating in a developmentally appropriate manner, the child learns the thought processes, and can begin to understand the decision-making processes that are behind the skills and medical regimes they may already be doing.

In order for autonomy to develop, both the child and the parent need to be prepared. For the child, readiness to assume more autonomy for health related matters is dependent upon cognitive ability, physical maturation, feelings of competence or self-reliance and the perception of the parent/child relationship.<sup>20</sup> Somewhat independently, the parent is assessing the child's readiness to assume more autonomy, their own willingness to support autonomy development and relinquish management responsibility and their perception of the relationship with the child (see Figure).

The parent-child interaction determines the management activities and how those activities and decisions will be handled. Not surprising, the relationship between the child and parent, along with the family are important components in both the development of autonomy and self-care. Parental supports for the development of autonomy are those behaviors that provide autonomy support, that is, praise and encouragement,<sup>21</sup> as opposed to behaviors aimed at controlling the child or adolescent.<sup>22,23</sup> Maternal separation anxiety decreases as the child grows older, and this allows cognitive autonomy to increase.<sup>24</sup>

Although the child and parent relationship may be harmonious, the perception of autonomy is not always congruent between parents and their children. Butner et al found that adolescents rated their functional autonomy higher than their parents.<sup>25</sup> Although parents had less confidence in the adolescents' ability to act autonomously, they were willing to allow increased autonomy, even though outcomes declined.

Age also plays a role in the development of autonomy. In a study of children with diabetes, age of diagnosis was positively associated with child only responsibility and negatively associated with parent only responsibility.<sup>16</sup> Similar findings were made in an asthma study where older children showed more autonomous behaviors than younger ones, with parents being the primary decision makers for the younger child.<sup>17</sup> Setting may also be important for school-aged children, because regardless of the age, most of them informed an adult when they experienced an asthma attack in a social setting.

Years of experience with a medication or treatment may also influence autonomy. Children who had been using a pump for delivering their insulin, the more responsible they were regarding knowledge of diabetes management and the less parents were responsible for pump operations.<sup>16</sup> This study also reported a relationship between age of diagnosis and increased likelihood of child independent responsibility for CSII care.

Children mentioned behaviors that were autonomous included taking medications or telling someone when they were sick or having an asthma attack.<sup>17</sup> Taking medication is a multistep task and understanding what it means to the child is important to understanding the degree of autonomy they have. A child may say they take their medication on their own, but the parent provides the medication or reminds them to take it. It is also important to remember that it is the parent who most likely is still scheduling the doctor appointment and ordering the medication so it is available for the child to take. The larger task of obtaining the medication and ensuring it is available when and where the child needs it, is typically left up to the parent far beyond the school age years.

A closer look at what we know about the development of autonomy and its' relation to self-care, we can see that there are a couple of assumptions that need to be stated. For children, condition management involves interplay between health care autonomy, family management, and self-care. This relationship depends upon the child's development (physical, cognitive, psychological and social) as well as parent and child's assessment of readiness for assuming more responsibility and independence regarding condition management. If the child is to assume more responsibility, the parent must be ready to relinquish some of the control to the child. Relinquishing control, however, does not mean that the parents withdraw entirely from the process. The child needs to be supported in their attempts at autonomously assuming responsibility for self-care, coached through the trials of non-optimal condition management, encouraged to make good decisions, and appropriately monitored by their parents.<sup>26,27</sup> Family management optimally recognizes that the child needs to develop self-care in all three areas, maintenance, monitoring and management. Exploring the development of self-care in light of emerging autonomy and family management, we can see the areas where guidance, oversight, and monitoring may need to



continue, even as the child assumes more and more responsibility and autonomy. That is, developing self-care does not mean that there is not still assistance, advice and support from the family or others. Successful self-care is not a solitary endeavor and needs to be supported.

Table 2 represents the intersection of health care autonomy, self-care, and family management. Identifying the important factors across autonomy development that can influence the development of self-care can help us to guide parents and children under our care to ease the transitions and minimize changes in outcomes. Understanding how and where family management guides this process for the child identifies areas where support and interventions may be required. The case studies and discussion that follows were developed systematically from Table 2. They are meant to highlight some of the areas where families may need guidance and children support in light of the knowledge we have regarding autonomy, self-care and family management.

### Case study 1

Michael, a 12 year old boy, lives in a large, 4 bedroom house with his mother, father younger brother and pet dog. The father works outside the home and the mother maintain the home and coordinates all family activities. She believes the family has enough money to live comfortably and that the health insurance through her husband's job covers most of the medical expenses for the family. Michael does well in school; his favorite subjects are math and science. He has friends that he spends time with after school and on weekends. He's involved in sports, plays baseball and basketball and participates in scouts. He was diagnosed with diabetes when he was 6 years old and feels it's no big deal. Sometimes he gets frustrated when he has to stop doing something and check his blood sugar, but mostly it's okay cause, "Mom takes care of everything". She handles the daily dispensing of medications, draws up the insulin and gives Michael his injections. Michael says he tried to draw up his own insulin and give himself the injection when he as 9, but Mom said he didn't do it right so she has done it ever since. He thinks that when he's 15 he might be old enough to draw up the insulin and give himself the injections. He does prick his finger and use the glucometer, but reports the results to mom, who takes over from there. A chart on the refrigerator shows how much insulin is required for the glucose levels, but Michael isn't interested in checking it out, "Mom and dad tell me what to do and I just do it. It's easier that way".

### Case Study 2

Sam is a 12 year old girl with cystic fibrosis and asthma, and lactose intolerance. She does well in school, like to play with friends; takes dance lessons, and play the piano. She and her mother, father, older brother and sister live in a modest three bedroom row home in the city. She shares a bedroom with her sister and has her half of the room decorated in pink and has pictures of current pop musicians on the walls. Sam is able to identify the medication she takes and knows why she takes them. She is responsible for filling her weekly pill box on Sunday night and then her mom or dad checks it for accuracy. She has a small purse that she carries with her when she goes to a friend's home and brings along her enzymes and inhaler. She easily identifies when she needs to take extra enzymes when having a snack and when she has used her emergency inhaler. She usually doesn't ask or tell anyone about the enzymes, but if she needs to use her inhaler she usually informs her mom or other adult because, "sometimes it doesn't work and I need something else". She explains how she had chest PT when she was younger, which she liked and misses because it felt good, but now uses a vest twice a day. She was involved in discussions with the doctor and her mom regarding sleepovers and said she now uses the acapella® (Smiths Medical, St. Paul, MN),

“it’s easier to take with me and do at a sleepover”. She gets frustrated at school when the people in the cafeteria won’t let her have a certain food because they think I can’t have it. She tells her mom when she gets home and the mother calls the school. It works for about a week and then they go back to the old way. She doesn’t see a time when it will be different at school. She is learning to hook herself up to her nightly feeding tube and at first thought it was fun, learning something new. But now it’s kind of boring and she prefers when her parents do it as it interrupts her playing before bed.

Although both Michael and Sam are 12 years old, their families treat them very differently. Both children know about their condition, but Sam is a much more active participant in her daily care. She has assumed some responsibility in preparing her daily medications but Mom or Dad monitor the activity. She is fairly independent in taking her enzymes prior to meals and snacks and has autonomy over the activity when visiting with friends. She is being supported to learn new self-care skills, such as attaching herself to the feeding pump for overnight feeds, with the support and direction of her parents. Michael, on the other hand, has not progressed much from his initial task of checking his blood sugar. He is not responsible for recording the results or figuring out how much insulin he requires. He lacked support when he attempted to draw up his own insulin and self-inject, feeling that he wasn’t old enough to do it and estimates he’ll be having mom draw up and inject for another three years.

While Sam is involved in decisions regarding treatment options, Michael has not been involved and cannot explain his recent change in insulin. He has to be reminded to check his blood sugar before eating a snack at home, and required additional reminding to tell mom what his blood sugar was so she could get the insulin prepared.

Both parents admit to worrying about the children, but Sam’s mother says that Sam’s is going to grow up and have to take care of herself, and although they will always be there for her, she will have to take care of herself someday. They are working toward that day in slow easy steps. Michael’s mom also sees that Michael will need to take care of himself someday, but says that he will have to do it when he’s older, while I’m here and I can do it for him, it allows him to be more like a regular kid. “I take care of his diabetes so he doesn’t have to think about it”.

Although there are no absolutes, Michael’s parents are not providing him with the skills and understanding he needs as he grows up with diabetes. Without supporting his development, increasing his knowledge and teaching him the skills and decision making he will need to successfully manage his diabetes, Michael will one day be on his own and his health may suffer. He may be more dependent on his parents for guidance and direction regarding basic care issues he could have developed for himself over time.

Sam has been exposed to increasing responsibility for self-care. She has also been involved in making decisions regarding treatment options and has seen firsthand how her parents and the physicians, and her mom and the cafeteria staff work to resolve things. Although she may feel powerless with the cafeteria staff right now, Sam has been given a voice to express her needs regarding her treatment and with the continued support and guidance from her parents, will develop the self-care maintenance, monitoring and management required for optimal outcomes.

## Conclusion

In order for self-care to be successful, all three components, self-care maintenance, self-care monitoring, and self-care management must be developed with increasing capacity for health care autonomy. Children with chronic health conditions may learn basic maintenance



skills, and look very competent, but unless attention is paid to teaching them monitoring and management, as they mature and the expectations are placed upon them, they will not be successful. Paying attention to the components of self-care, as well as the family management style and the developmental abilities of the child will help nurses assess the care status and help to create a plan to assist the child and family with the care transitions.

Further research is needed regarding incorporating health care autonomy, self-care and family management. Studies aimed at testing interventions to improve child health outcomes throughout adolescence and into young adulthood may prove to assist children and families as they progress through this challenging transition.

## Acknowledgments

This work was supported by Grant Nos. F31NR11524 and T32NR007100 from the National Institutes of Health, National Institute of Nursing Research and by a Grant from the Sigma Theta Tau Xi Chapter, University of Pennsylvania.

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### Key Points

- Autonomy in health care situations usually is one of the last contexts in which autonomy will be expressed, typically in late adolescence
- Self-care for children with chronic conditions incorporates self-care maintenance, self-care monitoring, and self-care management.
- Current care guidelines stipulate that health care providers and family caregivers need to ensure that children with chronic conditions master developmentally appropriate knowledge and skills regarding their disease.
- School-aged children between the ages of 8 and 13, with chronic conditions are becoming more knowledgeable about their disease and acquiring more skills to support their management activities.
- The development of health care autonomy requires appropriate family management as self-care develops from parent-focused care, to joint/cooperative/shared care, to child determined care.
- Supporting the development of health care autonomy in school-aged children with chronic health conditions also supports the development of self-care and more optimal outcomes throughout adolescence.
- During adolescence children with chronic health condition may experience a decline in management outcomes

### Recommendations for the family

- When communicating with partner and other family members remember the importance of helping the child become able to take care of himself/herself overtime and a plan to do so.
- When communicating with the child remember to support self-reliance/self-competence. Increased use of guidance and monitoring as opposed to authoritative style of parenting.

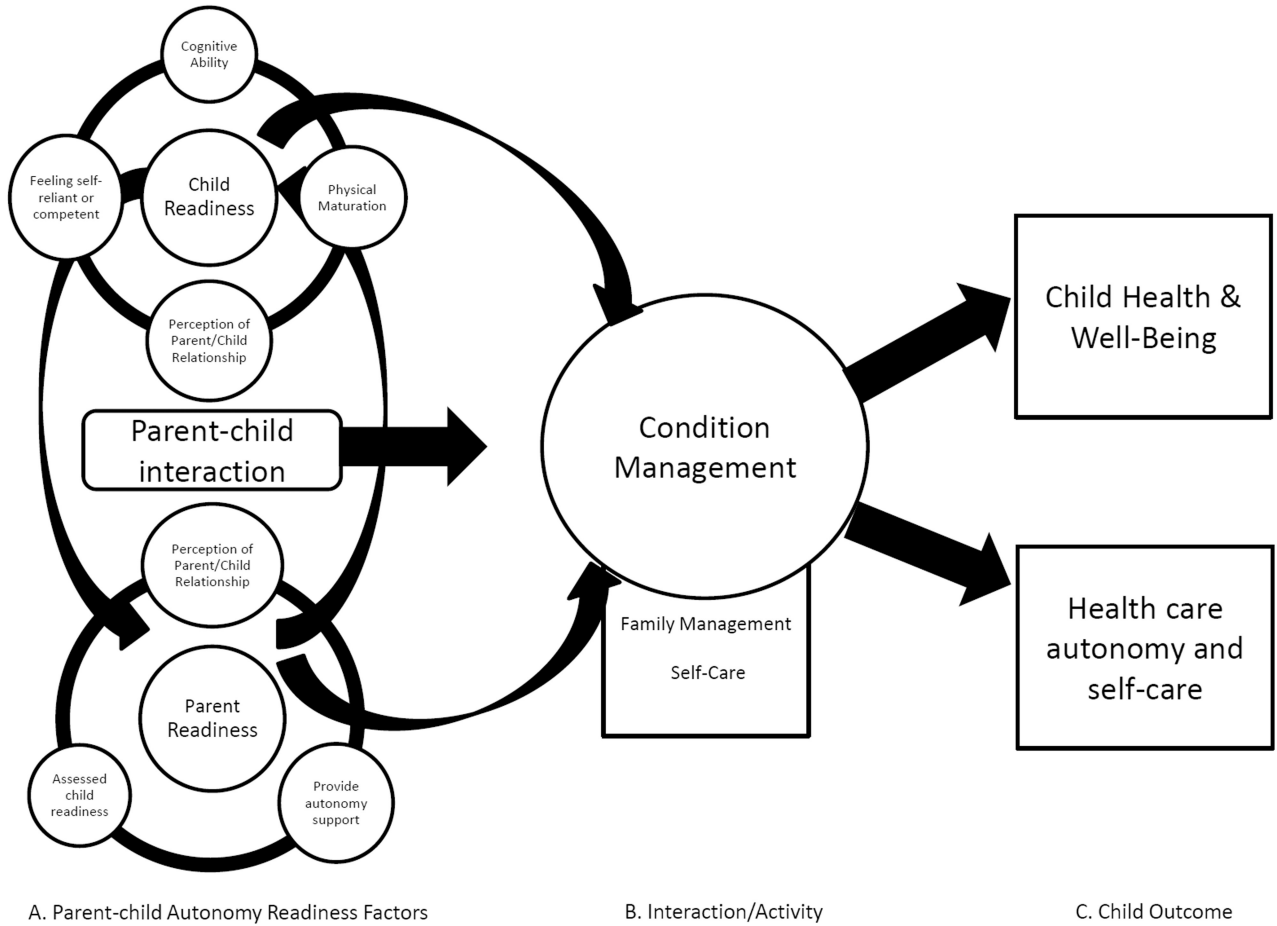
Retain appropriate parental agency throughout school-aged years into adolescence that allows for the development of health care autonomy but enables safety and adherence for the child.

Develop skills in parental monitoring to encourage adherence and safety, especially during self-care transitions; that is, continue monitoring and involvement throughout school-aged years into adolescence even when the child appears able to perform basic skills independently as reinvolvement during adolescence will be difficult.

### Recommendations for the Provider

#### Interventions to develop self-care need to consider

- assessing child readiness for self-care including developmental stage, self-reliance, physical, cognitive and psycho-social ability and the parent-child relationship;
- assessing agency: who is driving the condition management (parents, shared, or child) and determination as to appropriateness based on child's development;
- teaching skills for parental monitoring that are developmentally appropriate; and
- assisting the family and child with culturally appropriate interventions to transition to self-care, including responsibilities for self-care maintenance (behaviors), self-care monitoring (body listening), and self-care management (evaluation).



**Figure. Development of Health Care Autonomy**

- A. Parent-child Autonomy Readiness Factors include those areas the child and parent assess independently and in interaction with one another to determine readiness to increase child health care autonomy for condition management.
- B. Interaction/Activity considers the condition management, both from the family and child.
- C. Child outcome examines the child health and well-being as well as the child autonomy and self-care.



**Table 1**

## Adaption of Self-Care Model

Self-care	Definition <sup>a</sup>	Adaptation for Child/Family	Examples of Self-care in Action
Self-care	Process of maintaining health through health promoting practices and managing illness	Family management to maintain health promoting practices and managing illness; believes that the child will be or is capable and expects the child to care for self in the future	Transition from parental agency and family management to child agency and self-care
Self-care maintenance	Behaviors performed to improve well-being, preserve health, or to maintain physical and emotional stability	Behaviors performed by the child and/or family to improve well-being, preserve health, or to maintain physical and emotional stability	Daily flossing and brushing teeth. Reduced sugar intake. Biannual checkups
Self-care monitoring	Process of routine, vigilant body monitoring, surveillance, or "body listening"	Process of routine, vigilant body monitoring, surveillance, or "body listening" by the child and family	Awareness of tooth and gum status, sensitivity to hot/cold, bleeding, pain, need to brush teeth after eating and food sticks to your teeth or between
Self-care management	Involves evaluation of changes in physical and emotional signs and symptoms to determine if action is needed	The evaluation of changes in physical and emotional signs and symptoms by the child and/or family to determine if action is needed	Evaluation of tooth/gum pain and deciding to call the dentist, brush or floss as needed in addition to twice a day

<sup>a</sup>Definitions from Riegel et al<sup>15</sup>(pp195–196)

Table 2

## Intersection of Autonomy, Self-Care and Family Management

Autonomy Requirements	Self-Care Maintenance <sup>a</sup>	Self-Care Monitoring <sup>a</sup>	Self-Care Management <sup>a</sup>	Family Management <sup>b</sup> Component
Developmental Stage	Consider all developmental areas, especially cognitive and psycho-social, Maslow's hierarchy of Needs.			Child Identity Parenting Philosophy Family Focus
Self-Reliance	Is the child confident he/she can do the tasks at hand?	Is the child able to identify sign and symptom of condition change and communicate as needed?	Is the child able to decide on the intervention required and take the necessary steps?	Child identity View of the condition Parenting Philosophy Management Mindset Management Approach Future Expectation
Physical Ability	Does the child have the strength, dexterity, physical attributes necessary to perform the task?	Is the child self-aware of her/his own body to recognize the signs and symptoms of condition change?	Does the child have the strength, dexterity, physical attributes necessary to perform the task?	Child Identity
Cognitive Ability	Does the child have the cognitive ability required to perform the tasks?	Does the child have the cognitive ability to recognize the change in signs and symptoms?	Can the child make decision regarding condition management?	Management Mindset
Psycho-social Ability	Does the child have the support systems in place and the emotional maturity to maintain self-care?			Child identity View of condition Parental mutuality Parenting Philosophy
Perception of Parent/Child Relationship	Does the child feel supported and trusted by the parent while they transition and assume more maintenance responsibility?	Is the child listened to when they perceive a change in condition that requires intervention of some sort and are they supported in decision making?	Is the child supported during management attempts and allowed to reflect on different possible courses?	Child Identity View of Condition Management Approach Family focus Future Expectations

<sup>a</sup>Adapted from Self-Care model, Riegel et al<sup>15</sup>

<sup>b</sup>Adapted from Family Management Styles Framework, Knafel et al<sup>11</sup>