

Illness-Specific Risk-Taking in Adolescence: A Missing Piece of the Nonadherence Puzzle for Youth With Type 1 Diabetes?

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■ ABSTRACT

Risky behavior is often at its lifetime peak in adolescence. Chronic illness creates additional opportunities for risk because nonadherence behaviors can jeopardize adolescents' health. Adolescents with type 1 diabetes could engage in risky behavior around insulin administration that would put them in danger of severe health consequences. It is possible that some nonadherence behaviors observed in adolescents with type 1 diabetes may result from youth taking risks with their medical treatment. Illness-specific risk-taking behaviors are not captured in most assessments of adherence, which primarily focus on frequency of adherence behaviors. This article reviews current models of general risk-taking and their implications for diabetes management. The authors argue that illness-specific risk-taking may be an important, understudied aspect of illness management that can inform future studies and treatment of nonadherence in adolescents with type 1 diabetes.

Across chronic health conditions, adolescence—roughly the period between puberty onset and the completion of brain maturation in the mid to late second decade of life (1)—is singled out as the developmental stage in which adherence and self-management problems escalate. Adolescence is a time of dramatic physical, behavioral, social, and neurodevelopmental changes (1,2) that significantly complicate diabetes adherence, which has been defined as “the extent to which a person's behavior coincides with medical or health advice” (3). It is estimated that nonadherence (the extent to which a person's behavior does not coincide with medical advice) affects 50–75% of youth with chronic conditions (4).

Many developmental and individual factors have been found to contribute to nonadherence, including transition of responsibility for medical treatment from parent to child (5), increased family conflict

(5,6), less frequent parental monitoring (7,8), increased involvement with peers (9), lower socioeconomic status (10), and minority ethnic/racial background (11,12). Although all of these factors contribute to the increase in nonadherence in adolescence, they do not fully explain it, suggesting that adherence in adolescence is extremely complex (3). We propose that risk-taking behavior is another, previously understudied, factor in adolescent nonadherence.

Adolescents tend to take more risks than either children or adults. For example, adolescents are more likely to engage in health risk behaviors such as binge drinking, unprotected sex, and reckless driving, and these behaviors contribute to an increase in morbidity and mortality in youth (13). Given the propensity for risk-taking in adolescence, it is possible that some nonadherence may be the result of youth taking risks with their medical treatment. In fact, this

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hypothesis has been proposed previously by several researchers (14–19).

Most of the literature on risk-taking in youth with chronic illness has focused on *general* health risk behaviors (e.g., smoking, alcohol/drug use, and unprotected sex) (14,15,20–26), and findings are mixed. For example, researchers have found evidence of an association between general risk-taking and nonadherence (14,15,23,24,26,27). There is also evidence that having a chronic illness may act as a buffer against adolescent risk-taking (28,29) or may increase the chances of general risk-taking (25). In addition, researchers have hypothesized ways in which general risk-taking behaviors may have more severe health consequences for youth with chronic illnesses (22). However, to our knowledge, no previous studies have examined nonadherence as a risk-taking behavior in itself. In this article, we develop the hypothesis that *illness-specific* risk-taking behaviors may be a related, but unique, factor in the health of youth with chronic illnesses, and specifically those with type 1 diabetes.

Type 1 diabetes provides a good example through which to illustrate the ways in which risk-taking may have an effect on adherence. Management of diabetes is extremely complex, intrusive, and aversive, and adolescence is known to be an especially challenging time for people with type 1 diabetes (30). Adolescents assume increasing responsibility for diabetes care (5), with decreasing parental supervision (7,8), at the same time they face many physical, psychosocial, and developmental changes. Furthermore, it is well documented that adherence and glycemic control typically decline in adolescence (5,31,32). If complex diabetes management tasks are not completed accurately and blood glucose levels are not adequately controlled, the risk for severe and life-threatening health consequences increases. Short-term consequences include seizures resulting from severe hypoglycemia and

life-threatening diabetic ketoacidosis associated with chronic hyperglycemia. Long-term consequences include retinopathy, nephropathy, neuropathy, cardiovascular disease (33), and cognitive late effects (34).

In the following sections, we first review the recent literature on general adolescent risk-taking and studies that have examined risk-taking in youth with chronic illness. These findings and current theories of general risk-taking are used to develop an integrated working model of adolescent risk-taking. We then propose and define a construct of “illness-specific risk-taking.” We apply the risk-taking model to type 1 diabetes as an example, drawing on clinical experience and behavioral research in diabetes. Finally, we discuss clinical implications of the model and suggest directions for future research.

General Risk-Taking in Adolescence

During adolescence, an increase in novelty-seeking and risk-taking behavior occurs in most mammals, including humans, and it has been surmised that these are adaptive behaviors that promote independence and reproductive success (35). From this perspective, risk-taking can be thought of as normative behavior that is driven by biological motivations (36,37). Common motivators include rewards such as sexual intercourse, food, and social approval, all of which activate the brain’s dopaminergic reward system and all of which are associated with health risk behaviors (such as having unprotected sexual intercourse). Risky behavior may also be motivated by avoidance of harm and unpleasant states such as when youth decide to take their chances driving drunk rather than tell their parents they have been drinking.

Current models suggest that risk-taking can reflect both planned and impulsive aspects of behavior. The Prototype Willingness model (38,39) posits that risk can arise either from a reasoned consider-

ation of costs and benefits or from an unplanned reaction to circumstances. The *reasoned pathway* (39) reflects calculated risk arising from a decision process of weighing costs against benefits (e.g., engaging in unprotected sex after deciding that the odds of pregnancy are relatively low) (40,41). At the same time, experience tells us that much risk-taking is unplanned—a spur-of-the-moment response to a situation or opportunity (e.g., impulsively getting into a car whose driver has been drinking). This sort of impulsive response, which has been termed the *social-reactive pathway* to risk (39), is, as the name implies, much more likely in social situations.

Many researchers (e.g., Steinberg [42]) have suggested that adolescents are more likely to act in risky ways because they are more impulsive and have poorer self-control than adults, an assumption that finds support in the neurodevelopmental literature (see below). However, some researchers (notably Reyna and Farley [43]) have argued that developmental differences exist in reasoning that might also predispose youth to more risk-taking. Specifically, they note research suggesting that youth may be more likely to weigh costs and benefits of risky behaviors (such as having unprotected sex), whereas adults are more likely to consider such high-risk behaviors “not worth thinking about.” Thus, developmental differences in both the reasoned and social-reactive pathways might account for the increase in adolescent risk-taking (44).

Dual Systems Models: Neurodevelopmental Findings

Consistent with the hypothesis that there are separate processes that lead to risk-taking behavior, neuroimaging studies have revealed two distinct brain systems that appear to be implicated in risk-taking. The first, which has been called the *social-emotional system* (42), reflects activity in the ventral striatum, which is

involved in reward processing and approach behaviors, and the amygdala, which is involved in emotion processing and avoidance (36). The social-emotional system is thought to be fast, reactive, and largely automatic (i.e., not under conscious control). The second system is an *executive or cognitive control system*, which is largely instantiated in the prefrontal cortex. This second system tempers the first by inhibiting initial reactions, evaluating social-emotional inputs, and weighing behavioral options before initiating an action (45,46).

Dual systems models (e.g., Steinberg [42], Casey et al. [47], and the triadic model of Ernst et al. [36]) posit that adolescent risk-taking largely reflects the interaction between the social-emotional system, which motivates risk-taking behavior, and the executive control system, which tempers it. Importantly, these two systems mature at different rates. Starting at puberty, the social-emotional system begins to show significantly heightened activity and responsiveness, peaking in activity in mid-adolescence (48,49). Associated with this peak in activity, adolescents show an increase in sensitivity to reward (49), tend to value immediate reward more highly than delayed reward, have greater difficulty than adults with delayed gratification (2), and engage in more sensation-seeking behavior (50). In comparison, development of the executive control system lags, not reaching maturity until the third decade of life (51).

It has been argued that this “maturational imbalance” (47) between reward sensitivity and self-control accounts for increased risk-taking behavior in youth (42). One might also infer that risk-taking would spike in mid-adolescence, when the maturational gap is at its widest, but risk-taking behavior actually does not peak until the early 20s (52,53). The reason for this seems straightforward. Although sensation-seeking may slowly decline from middle adolescence to early adulthood, op-

portunities to engage in risky behavior increase as adolescents gain greater independence from their parents (54,55).

Changes in Social Context

Older adolescents experience many social changes that increase the likelihood of risk-taking behavior. Parental monitoring, a major moderator of risky behavior (7), declines at the same time youth begin to spend more time with friends. Compared to adults, adolescents are more likely to show an increase in risk-taking behavior in social situations (56). Youth drive more recklessly with peers (57) and are more likely to drink alcohol or experiment with drugs (58). As adolescents leave their parents’ homes, they often experience frequent changes in residence and life circumstances without yet having many of the constraints of adult social roles (52), further increasing opportunities for risk.

Illness-Specific Risk-Taking:

A Proposed Part of Nonadherence

The research reviewed above leads to some general conclusions. First, the increase in risk-taking in adolescence reflects normal development, resulting from changes in the social-emotional system that outpace the tempering ability of the immature executive control system (42). Second, social situations activate the social-emotional reward-seeking system and make risk-taking more likely. Third, adult supervision reduces the likelihood of risk, but supervision decreases during the adolescent period; by early adulthood, risky behavior is at its height. Perhaps not coincidentally, nonadherent behaviors also increase over the course of adolescence and peak in early adulthood (52), a concern that was recently highlighted in a position statement of the American Diabetes Association (59).

These observations have led us to hypothesize that some adolescent nonadherence may be a specific type of risk-taking in youth. We define illness-specific risk-taking as a type

of risk-taking in which youth engage in nonadherence behaviors that put them at risk for poor health outcomes (Figure 1). By viewing nonadherence through the lens of risk-taking, we can apply the risk-taking literature to develop hypotheses about this subsection of nonadherence behaviors.

To better apply current knowledge of risk-taking to youth with chronic illness, we first outline a working model of general risk-taking (Figure 2). Control factors that mitigate risk are represented in the top row, whereas the bottom row delineates motivational factors that increase the likelihood of risky behavior. The columns show how control and motivational factors are in opposition to each other within the individual (column 1) and social contexts (column 2). The likelihood of engaging in risk-taking behavior is conceptualized as resulting from the interaction of control and motivational factors at both the individual and contextual levels, which interact with each other and with situational specifics to determine whether a risky behavior is initiated.

This model is most applicable to risky behavior on the social-reactive pathway, given the well-documented relationship between the dual systems model, social context, and impulsive risk-taking (e.g., Steinberg [42]). It is less clear how the model might relate to risk-taking on the reasoned pathway.

Youth who take risks with their diabetes management may be especially likely to experience short- and long-term negative consequences. For example, an adolescent with type 1 diabetes may risk a severe hypoglycemic event by taking more insulin than instructed because she is frustrated by a high blood glucose reading that will not come down. Table 1 provides additional examples of diabetes-related risk-taking. The type of illness-specific risk-taking in which this adolescent is engaging is not discussed in the literature as a part of general risk-taking (e.g., alcohol or

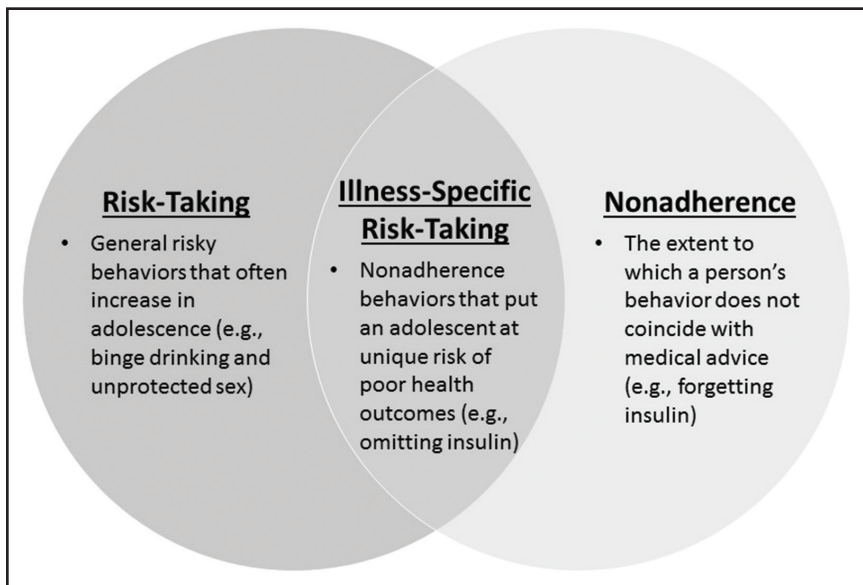


FIGURE 1. Illness-specific risk-taking in youth with chronic illnesses.

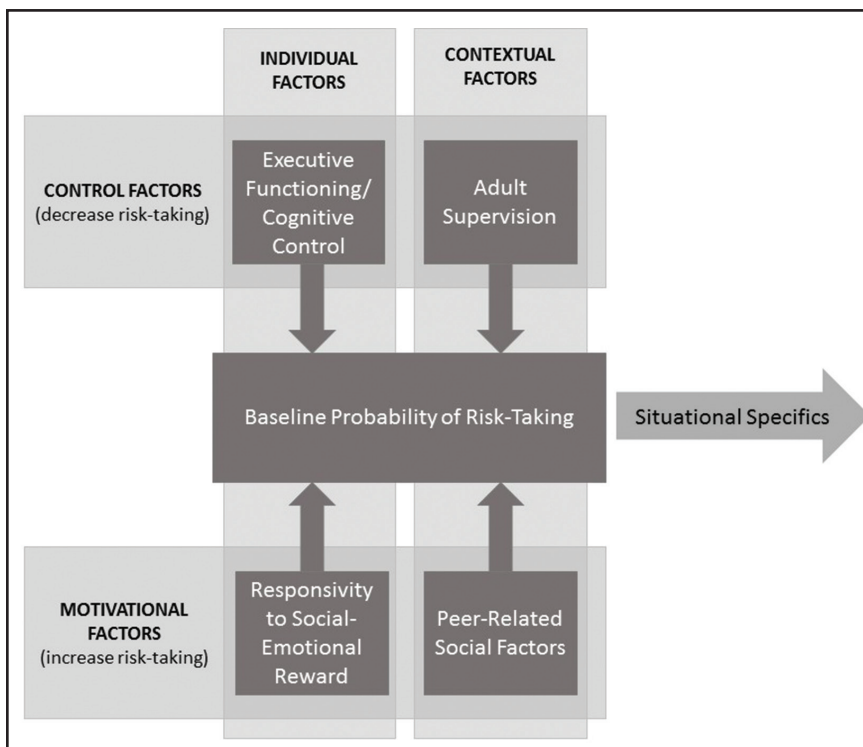


FIGURE 2. Working model for general risk-taking behaviors in adolescence.

drug use). Moreover, illness-specific risk-taking behaviors are not captured in most assessments of adherence, which primarily focus on frequency of adherence behaviors. Because there is no precedent for conceptualizing nonadherence as risk-taking, we can apply the risk-taking literature to inform our understanding of this new concept.

To identify behaviors that fall under the construct of illness-specific risk-taking, we apply the idea that risk-taking is an adaptive behavior fueled by biological motivations or avoidance of harm. As mentioned above, common biological rewards include sexual intercourse, food, social approval, and excitement. There are many ways in which adolescents

with type 1 diabetes might take risks with their medical treatment to seek such rewards. For example, because sexual intercourse is a powerful, biological reward, an adolescent with type 1 diabetes might forgo a pre-sex blood glucose check and risk hypoglycemia despite awareness that he or she should check blood glucose before any physical activity. Similarly, because food is another inherent biological reward, an adolescent may risk high blood glucose levels by eating without first checking blood glucose or taking insulin because the immediacy of the food is a stronger motivator. Adolescents with type 1 diabetes may also engage in illness-specific risk-taking to avoid punishment or harm. For example, an adolescent might avoid changing his or her insulin pump site to avoid pain.

Individual Differences and Illness-Specific Risk-Taking

Applying the risk-taking model (Figure 2) to illness-specific risk-taking leads to a number of testable predictions regarding nonadherence behaviors. The model suggests that individual differences in the development of executive control, impulsivity, and sensation-seeking would all make an adolescent more or less likely to engage in illness-specific risk-taking. Specifically, the dual systems models may have important implications for illness-specific risk-taking behaviors, especially when adherence behaviors have a delayed effect on health and well-being. There are some chronic illnesses for which treatment provides immediate and recognizable rewards (e.g., pain relief medication). However, in type 1 diabetes, there is usually no immediate reward from taking insulin. Instead, taking insulin is needed to prevent serious life-threatening complications that may occur in the future. The dual systems models posit that adolescents in particular have increased sensitivity to rewards and greater difficulty with delaying gratification. Thus, adolescents with type 1 diabetes may have

TABLE 1. Examples of Illness-Specific Risk-Taking Behaviors in Type 1 Diabetes

- Taking more insulin than needed to bring down a stubborn high blood glucose level
- Eating without first checking blood glucose or taking insulin
- Manipulating insulin to see what a low blood glucose level feels like
- Lying to parents about checking blood glucose or taking insulin
- Refraining from checking blood glucose to stay in a soccer game
- Omitting checking blood glucose before or after intercourse to avoid interrupting the moment
- Deciding not to check blood glucose when at a friend's house
- Taking an insulin pump off to go out for the night with no plan of using shots in the meantime
- Avoiding rotating insulin pump insertion sites because of pain

difficulty prioritizing their medical treatment when other, more exciting and immediate rewards are present. For example, if an adolescent typically goes to the restroom to take insulin shots when eating out, she may forgo the insulin shot and risk higher blood glucose to stay at the table with her friends.

Contextual Factors and Illness-Specific Risk-Taking

The contextual factors outlined in the risk-taking model (Figure 2) suggest that illness-specific risk-taking would be more likely in social situations and when adult supervision is low. Reduced parental supervision is clearly associated with a decline in illness control across a range of pediatric conditions (18). In contrast, adolescents who experience more parental involvement, monitoring, and collaborative teamwork in diabetes management tend to have better adherence (7). For youth with type 1 diabetes, parents often transition responsibilities for medical tasks during adolescence (5). Thus, adolescents are provided greater freedom and opportunities for risk-taking in their everyday lives, as well as with their medical tasks, giving them more opportunities for illness-specific risk-taking. For example, many parents allow children with diabetes to manage their own insulin and blood glucose monitoring; thus, adolescents could go several days or weeks without a parent realizing that they had been taking too little insulin.

Over the course of adolescence, youth tend to spend increasing amounts of time with peers and are more likely to take risks when they are with peers (56). Thus, it is possible that adolescents would engage in more illness-specific risk-taking when they are with friends than when they are alone or with adults. Although this idea has not been empirically evaluated, it has clinical support, as families often say that adolescents have a harder time checking blood glucose and taking insulin when they are out with friends (60). Also, it has been demonstrated that health-promoting peer support is an important factor in adolescent adherence in social settings (61).

Reasoned/Reactive Pathways and Illness-Specific Risk-Taking

Theories of risk-taking suggest that there may be different ways to arrive at the same illness-specific risk-taking behavior. Youth may weigh the costs and benefits of engaging or not engaging in an adherence behavior (the reasoned pathway), or they may engage in nonadherence as a result of their reaction to circumstances (the reactive pathway). In both of these situations, adolescents could engage in the same illness-specific risk-taking behavior, but the way in which the behavior comes about is different. The reasoned versus the reactive pathway hypothesis may be particularly useful when examining causes or antecedents of illness-specific risk-taking behaviors.

Implications for Interventions and Future Research

The literature reviewed here suggests that some degree of risk-taking is normal adolescent behavior driven by maturational changes in the brain that interact with social and family contexts. Diabetes risk-taking behaviors such as omitting glucose monitoring or insulin would therefore seem to be more or less expected in adolescence, especially in social contexts and in contexts with immediate rewards. Thus, it may be important for health care providers and parents to be aware of illness-specific risk-taking behaviors and to discuss and assess their frequency. Although we used the example of type 1 diabetes to illustrate the concept of illness-specific risk-taking, there are likely other risk-taking behaviors that are unique to other chronic illness populations. The current model provides a framework for identifying illness-specific risk-taking behaviors. We hope that this model will allow clinicians and researchers to identify and conceptualize illness-specific risk-taking behaviors not only for youth with type 1 diabetes, but also across other chronic illness groups.

Further research will be necessary to examine the frequency of illness-specific risk-taking and determine which behaviors may be most important to routinely assess in clinical care. Once illness-specific risk-taking behaviors are identified, measures can be developed for use in both research and clinical practice. Measures of general risk-taking

(e.g., Vrouva et al. [62] and Centers for Disease Control and Prevention [63]) and risk-taking propensity (e.g., Lejuez et al. [64]) may be helpful in developing and validating illness-specific measures. Research is also needed to investigate the association between general risk-taking and illness-specific risk-taking, as well as between illness-specific risk-taking and health outcomes. In particular, it may be of interest to learn which diabetes-specific risk-taking behaviors are most likely to cause negative health outcomes (e.g., hypoglycemic events, diabetic ketoacidosis, or glycemic variability). Determining the level of risk associated with these behaviors would allow clinicians to focus their assessments and interventions on the specific risk behaviors that are most likely to result in serious health complications.

Family communication and problem-solving skills may be especially important in addressing illness-specific risk-taking. The more involved parents are with medical tasks, the fewer opportunities adolescents have for taking risks, but the greater the opportunity is for family conflict. The existence of developmental differences in reasoning about risk (43) suggests that adolescents and adults might assess and approach illness-specific risk-taking differently. For example, an adolescent might weigh the costs/benefits of omitting insulin for 24 hours, whereas an adult would not even consider it because the risk of a severe health consequences would not be considered worth any benefit. If adults and youth reason differently about illness management, parents (and caregivers) may not understand and empathize with adolescents' decisions to take risks with medical tasks. Clinical intervention to improve family communication and manage conflict might reduce risky behavior by helping parents and youth develop a shared understanding of youths' adherence behaviors and allow par-

ents to better guide youths' reasoning around treatment decisions.

Risk-taking is also likely to be an important consideration in clinically referred samples of youth with type 1 diabetes and mental health concerns. For example, depression is associated with both risk-taking and nonadherence (14). Youth with attention deficit hyperactivity disorder engage in significantly more general risk-taking behaviors (65–67), suggesting they likely also will exhibit more illness-specific risk-taking. However, in some cases, the relationship between psychosocial functioning and risk-taking may be more complex. For example, anxiety is associated with general risk avoidance (68,69), as well as with reduced adherence (e.g., frequency of blood glucose monitoring [70]). Parsing the different contributions of risk-taking, risk avoidance, and adherence is an important area for future research.

Adolescence is a crucial time to intervene to prevent or reduce illness-related risk-taking. Illness-related risk-taking is a likely extension of the increase in general risk-taking that occurs as a part of normal adolescent development. The period of adolescence affords great opportunity for risk-taking behaviors to be at their peak. Moreover, there is evidence that a negative developmental trajectory around diabetes management during adolescence may persist into early adulthood, accelerating the risk of long-term medical and psychological complications of diabetes (71). This research underscores the importance of optimizing adherence and reducing illness-related risk-taking during the challenging developmental period of adolescence. More research is needed to determine how to assess the developmental trajectory of illness-specific risk-taking behaviors. In addition, clinical interventions designed to reduce illness-specific risk-taking during this opportune period of development will need to be evaluated. Of course, not all youth engage in significant risk-taking behavior.

Identifying and reinforcing the resilience factors that help protect youth against risky behavior in general may also help minimize diabetes-specific risk-taking.

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Duality of Interest

No potential conflicts of interest relevant to this article were reported.

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