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A Framework for the Youth with Type 1 Diabetes during the Emerging Adulthood Transition

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Abstract

Emerging adulthood, a developmental period from late adolescence to the late twenties, is a critical transition for youths with type 1 diabetes. This article proposes a framework for emerging adults with diabetes during this transitional time, integrating theoretical writings on transitions and emerging adulthood with empirical findings from younger adolescents with diabetes, about whom more is known. Key health, developmental, and behavioral outcomes are proposed as well as key influential personal and environmental characteristics. Influential transitional events for this age group are also discussed relative to these outcomes and to personal and environmental characteristics. This framework provides a guide for longitudinal studies on the transition to young adulthood among emerging adults with type 1 diabetes. Identifying key times and influential factors will provide information for designing future effective interventions to improve glycemic control and quality of life for these youths as they transition to adulthood.

Transitions in general are of interest to nursing, [1] and the developmental transition of emerging adulthood[2, 3] is particularly critical for the health of youth with type 1 diabetes. During this transition, these youth will need to assume primary responsibility for their diabetes care, [4] and failure to do so will place their health at risk. For youth with type 1 diabetes the primary health risk is related to glycemic control, which tends to worsen during the early years of emerging adulthood.[5, 6] Good control is essential to reduce the likelihood of future serious long-term health consequences.[7] Quality of life is also a key outcome, specifically because diabetes management often interferes with the social lives of youth with diabetes.[7] These outcomes of glycemic control and diabetes-related quality of life are the most salient outcomes for youth with diabetes since they experience minimal psychological,[8] social,[9] or developmental[10] consequences from the diabetes condition. This is in contrast to the life skills needs of youth with other special health care needs and chronic illnesses.[11,12] Although emerging adulthood is a critical transitional time for those with diabetes, empirical findings are few and fragmented for this age group; more is known about younger age groups, particularly early and middle adolescents. Thus, the purpose of this article is to propose a framework for youth with type 1 diabetes to specifically predict the primary diabetes-specific health outcomes of glycemic control and diabetes-related quality of life during the developmental transition to emerging adulthood.

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A Framework for Emerging Adults with Type 1 Diabetes

Major sources for this framework are the writings on transitions[1] and emerging adulthood development.[2,3] A transition is a process with movement from one state to another.[1] One type of transition is developmental[13] and is considered to be normative, dynamic, and complex.[14] Emerging adults are in the process of becoming young adults, and in fact emerging adulthood has recently been recognized as a developmental period or life stage[2, 15] This period is primarily from late adolescence (18 years of age) to middle and, for some, even late twenties.[2, 3] Another type of transition for these youth is situational, which is an event associated with relocations;[16] these co-occurring events are also proposed to be influential[17] in relation to health and well-being.[16] Situational transitions or events are particularly important for this developmental period known for its instability.[2]

A successful transition is indicated by outcomes such as subjective well-being and mastery of behaviors and roles.[1] This mastery may be especially salient for emerging adults, who often delay taking on the commitments and responsibilities of adulthood.[2,3] Such delays, especially in relation to daily functioning, can be a particular problem for those with diabetes who have daily care requirements. These outcomes are influenced by personal and environmental characteristics.[17] Personal characteristics are important because emerging adulthood is a time known for great freedoms[3] and therefore these youths must rely more on their own resources. The specific environmental characteristics in this framework are relationships with parents and peers because they are primary influences on youth development. [18]

Related to these theoretical concepts are specific concepts for the emerging adult with diabetes. The main theoretical concepts and relationships as well as the key concepts for the emerging adult with diabetes are delineated in Figure 1 and discussed below. The concepts were chosen because in general they are amenable to interventions. For example, gender has been associated with glycemic control,[5] but it as well as other demographic variables are not included in Figure 1 because they cannot be changed. Within the context of emerging adulthood, it is proposed that changes in most of these key concepts occur over time.

Key Concepts

Key Outcomes

The specific outcomes for these youths are organized within three domains: (1) health (glycemic control and diabetes-related quality of life); (2) developmental (primary diabetes care responsibility); and (3) behavioral (diabetes management, alcohol use, and weight control behaviors). Two major assumptions underlie the choice and conceptualization of outcomes in this framework. First, because an interest is in the process of developing primary responsibility for diabetes care, it is viewed as a separate concept from management.[19] This differs from the views of some experts who see diabetes care responsibility as part of diabetes self-management.[20] Furthermore, because the interest is in the transition toward adult status, another assumption underlying this framework is that emerging adults' primary responsibility for diabetes care is the outcome of interest. This is in contrast to findings with younger adolescents that parent-adolescent shared responsibility may be preferable since it is associated with better management and glycemic control.[21, 22]

Health Outcomes—The focus is on diabetes health outcomes of glycemic control and diabetes-related quality of life. *Glycemic control* indicates how well the diabetes has been managed and it is routinely assessed at clinic visits.[7] Glycemic control tends to worsen in the early years of emerging adulthood, around 18–19, and to improve around 22–24 years of age.[5, 6] It is likely that instability during this transitional period [2,3] contributes to difficulties

with diabetes management and, subsequently, to poor glycemic control. *Diabetes-related quality of life,* specific to the diabetes, refers to the impact of health or illness as well as treatment on one's life.[23] It is a particular issue for these youths because diabetes management may be burdensome for them, interfering with social aspects of their lives.[7] For example, youths with diabetes may find it difficult to interrupt time with friends to check their glucose level. However, it is not clear how emerging adulthood interfaces with diabetes-related quality of life, with mixed findings in studies that have included late adolescents and emerging adults; there was no association between diabetes-related quality of life and age in some studies [6, 24] whereas some found better diabetes-related quality of life [25] and others found poorer diabetes-related quality of life.[26, 27]

Developmental Outcome—The developmental outcome is *primary diabetes care responsibility,* which involves autonomy or independence in behaviors and decision-making related to diabetes care with a goal of ownership for diabetes care.[19] This is important because, according to experts, it is expected of emerging adults with diabetes,[4] who usually cannot delay taking over tasks important to maintaining glucose control. With the greater freedoms that emerging adults experience[2, 3] parents may not be readily available to assist them, and these youths have to adapt their plans for dealing with such tasks as managing hypoglycemic events. However, emerging adults may be able to gradually take on responsibility for less critical tasks such as making appointments with health care providers and keeping track of needed supplies such as glucose-testing materials. Although older adolescents are known to have greater diabetes care responsibility,[21, 28–31] and late adolescents were reported to be independent in diabetes care in one qualitative study,[32] it is not known when, on average, emerging adults assume primary care responsibility.

Behavioral Outcomes—Diabetes management, alcohol use, and weight control behaviors are particularly salient outcomes for youth with diabetes because these behaviors have the potential to affect their glycemic control. *Diabetes management* involves daily activities such as glucose testing, meal planning, exercise, insulin administration, and management of hypoglycemic events. Although some of the same diabetes management tasks are involved in both management and responsibility, in this framework they differ in that management refers to how well the tasks are performed and responsibility refers to autonomy or independence in doing them. Further, they differ in their goals; the goal of management is to maintain glycemic control,[20] whereas the goal of responsibility is ownership of diabetes care.[19] Although little is known about emerging adults, it is well known that adolescents have difficulties with diabetes management.[7] *Alcohol use* is a health-compromising behavior among emerging adults[33] and is proposed to be related to developmental issues in this group.[34] It is a particular risk for those with diabetes because it interferes with glycemic control.[7] Estimates are that 19% to 39% of adolescents with diabetes have used alcohol.[35, 36] *Weight control behaviors* are actions undertaken to lose weight, and unhealthy ones such as diet restriction, skipping meals, and self-induced vomiting[37] are used by up to 60% of youth with diabetes.[37–39] In addition, up to 57% of youth with diabetes are estimated to be involved in a particularly unhealthy weight control behavior-- intentional insulin mismanagement.[38–42] It is not known how weight control behaviors change during emerging adulthood for those with diabetes; however, this time period is considered particularly risky for unhealthy weight control behaviors in the general population.[43]

Key Personal and Environmental Characteristics

Specific personal and environmental characteristics related to outcomes for emerging adults with diabetes have been identified from empirical findings, predominantly in adolescents with diabetes since little research has been conducted with emerging adults. In the context of

this framework, these concepts are from the perspective of the individual emerging adult. The assumption is that the emerging adult's view is paramount as he or she moves toward achieving adult status, with more independence in activities and living arrangements. Changes over time are proposed in these personal and environmental characteristics; during developmental transitions, changes occur related to self and others.[44]

Personal Characteristics—Personal characteristics proposed to be related to outcomes are diabetes-specific self-efficacy, fear of hypoglycemia, perceptions about primary diabetes care responsibility, depressive symptoms, and impulse control. *Diabetes-specific self-efficacy*, that is, beliefs about one's abilities to perform certain behaviors[45] specific to diabetes management, has been identified as a key concept for diabetes studies.[46] *Fear of hypoglycemia*, the concern about the occurrence of low blood glucose levels, is important because hypoglycemia is a common complication of diabetes treatment, leading to fear of hypoglycemia and, in turn, to maintaining high glucose levels for adolescents and children with diabetes.[7] Perceptions about diabetes are well known to be associated with diabetes management,[47] and in this framework *perceptions about diabetes care responsibility*, that is, emerging adults' subjective view of the advantages and disadvantages of assuming diabetes care responsibility, are particularly important. Among adolescents with diabetes, perceived advantages of assuming responsibility have included gaining confidence in their abilities, preparation for the future, and freedom and independence, whereas perceived disadvantages of assuming responsibility involved views about adolescents' burden of care as well as adolescents' view of their parents' concerns about loss of control and of their parents' stress and worry about the consequences of poor management by their son or duaghter.[48] *Depressive symptoms* or depression are important because they peak around 21 years in emerging adulthood,[49] reported to be 23%–35% in those 18–28 years of age.[50] *Impulse control*, the ability to plan and monitor one's behavior, delaying immediate gratification to achieve goals,[51] is important because it corresponds to an important biological change in the prefrontal cortex, which is immature into emerging adulthood.[52]

Environmental Characteristics—Environmental characteristics shown to be related to outcomes in this context include two key components: (1) parent–adolescent relationships (warm and caring relationship and parent-youth conflict) and (2) involvement of significant others (support for autonomy development and support received from family, friends, romantic partners, and health care professionals). Parental relationships are important because they are related to outcomes for emerging adults.[53] One aspect of parent-adolescent relationships is having a *warm and caring relationship;* this has long been known to be important for positive development of adolescents.[54] This factor is expected to be fairly stable because there is continuity in parent-adolescent emotional ties from earlier developmental periods.[54] Another aspect of the parent-adolescent relationship is *parent-youth conflict,* that is, communication expressed as disagreement.[55] Youths' conflicts with parents in the general population are around such areas as independence and responsibility,[56] and as such, conflict around diabetes care responsibility is salient for youths with diabetes. For emerging adults with diabetes, conflict may decline since it declines in emerging adulthood in the general population,[57] or it may increase during this transitional time when issues arise as emerging adults fully take over responsibility for their diabetes care from their parents.

Significant others' involvement in diabetes care is another key environmental characteristic. Most writings have been on parental involvement and suggest that variations exist, with over-involvement an adaptive response for good management of chronic conditions, but not a way to foster development of self-responsibility.[58] Thus, supportive behaviors are conceptualized as: (1) those with the goal of maintaining good diabetes management and (2) those with the goal of facilitating development of youths' diabetes care responsibility.

Because behaviors reflect goals,[59] behaviors to maintain diabetes management may be different from those to facilitate development of diabetes care responsibility.

Facilitation of the development of responsibility is primarily seen in *parental support for development of autonomy*, that is, parental behaviors that are responsive to youths' perspectives and needs, provide choices, encourage initiative, and involve reasoning about rules.[60] This type of parental involvement is important because it is well known to encourage adolescents' development of autonomy,[61] is positively associated with well-being among emerging adults,[53] and has been described by parents and adolescents as helpful for adolescents' assumption of diabetes care responsibility.[62] Parental support for autonomy development may be especially salient during early adolescence, a time known for autonomy strivings;[63] such support decreases with adolescents' increasing age.[64] However, this type of support may also be salient for a subgroup of emerging adults whose parents have not prepared their sons or daughters earlier in adolescence for this transition. Although most of the evidence is for parental support for autonomy, autonomy support from health care professionals also has been shown to be important among young adults with diabetes.[65]

To maintain good diabetes management, youths need to receive *diabetes- specific support* from family, friends, romantic partners, and health care providers. This "instrumental support" is the help received related to ordinary responsibilities and the provision of resources.[66] Important support persons for youth with diabetes are parents[67] and peers,[68] and it can be assumed that romantic partners would be another source of support for emerging adults with diabetes since they are important persons for emerging adults in general.[3] Support from family, friends, and romantic partners would be expected to change over time; parental support decreases with increasing age, [67] and peer support is greater for adolescents than for children with diabetes.[69] In addition, health care professionals also provide resources that are important for youth with diabetes.[7]

Key Situational Transitions or Transitional Events

Transitional events are included in the framework because emerging adulthood is characterized by immense and diverse changes[70] that are often associated with problem behaviors among emerging adults.[71] Transitional events, or life events, are occurrences that require adjustments and, whether evaluated as positive or negative, are assumed to be stressful and thus have the potential to negatively influence health.[72] Some transitional events such as marriage and the death of a relative or close friend are not specific to emerging adult development,[72] whereas others such as graduating from high school,[73] enrolling in college,[15] joining the workforce,[15] and moving out of the parental home[15] are specific to this age group. Indeed, up to 56% of emerging adults in the general population live independently of parents.[74, 75] Another important event for youth with diabetes is the transition from pediatric to adult care providers.[76]

Relationships among Concepts

Based upon the writings from transition and developmental theory and from empirical evidence, there are two inter-related paths of influencing variables to the two main health outcomes of glycemic control and diabetes-related quality of life (See Table 1). The main path of influence for glycemic control includes behavioral outcomes of diabetes management, alcohol use, weight control behaviors; personal characteristics of diabetes self-efficacy, fear of hypoglycemia, depressive symptoms, and impulse control; environmental characteristics of a warm and caring relationship, diabetes-specific parent-youth conflict, and diabetes-specific support; and transitional events. The main path of influence on diabetes-related quality of life includes the developmental outcome of primary diabetes care responsibility; the personal characteristics of diabetes-specific self-efficacy, perceptions

related to diabetes care responsibility, depressive symptoms, and impulse control; the environmental characteristics of a warm and caring relationship, diabetes-specific parent-youth conflict, and parental support for autonomy development; as well as transitional events. These are proposed to be the predominate influential variables for these health outcomes; however, there are complex inter-relationships among these variables, and one could even argue that almost all of the influencing variables at least indirectly affect both glycemic control and quality of life.

Summary

This framework provides a way of viewing changes in key outcomes among emerging adults with type 1 diabetes as influenced by personal and environmental characteristics as well as transitional events within the context of a major developmental transition. Key outcomes are glycemic control and diabetes-related quality of life (health-related); diabetes management, alcohol use, and weight control behaviors (behavioral); and primary responsibility for diabetes care (developmental). Key personal characteristics posited in the framework are diabetes-specific self-efficacy, perceptions about diabetes care responsibility, fear of hypoglycemia, depressive symptoms, and impulse control. Key environmental characteristics are a warm and caring relationship with parents, diabetes-specific parent-youth conflict, support for development of autonomy, and diabetes-specific care support. Finally, key transitional events are related to living, work, education, and health care provider situations as well as other life events such as marriage or death of family members. A major proposition is that during the developmental period of emerging adulthood changes occur in these outcomes as well as in personal and environmental characteristics. A second major proposition is that these health, developmental, and behavioral outcomes are inter-related. Thirdly, specific personal and environmental characteristics are proposed to influence specific outcomes. Finally, transitional events are proposed to influence the outcomes as well as personal and environmental characteristics.

It is important to recognize the assumptions underlying this framework. First, because the interest is in understanding what influences the development of independence in performance as well as what influences the quality of management, diabetes care responsibility is assumed to be a concept separate from diabetes management. Second, primary responsibility is the concept of interest in this framework because emerging adults need to be autonomous in their diabetes care as they become more independent in their activities, live independently from their parents, and achieve adult status. Third, the perspective of the individual emerging adult is paramount because he or she is the predominate actor in the transition.

Limitations of this framework need to be considered. First, because there is little empirical evidence about emerging adults with diabetes, the concepts and propositions are based upon theoretical literature and upon empirical evidence for youths in general or for younger adolescents with diabetes. The framework needs to be tested to see if it holds true for older youths. Second, this framework's focus is on the individual and not on health care systems, whether transition care models in general[110, 111] or those specific to youth with diabetes.[112] Thirdly, the focus is limited to specific health outcomes in the context of youths with diabetes and is not meant to be generalized to other populations where there is likely to be a different array of needs.[11–12, 113–114] Finally, this framework includes variables that have the potential to be modified and therefore does not include demographic and diabetes-related characteristics. For future testing of the framework, some of the latter variables may indeed need to be controlled since they are known to influence outcomes.

Identifying key times and influential factors could provide information essential for designing future effective interventions to improve glycemic control and quality of life among these youths during this transition. When empirical evidence becomes available, and if it supports this framework, clinicians can use the information to identify emerging adults who are having difficulties with this developmental transition as well as the most likely times for difficulties. Identification of key influential factors could guide skill-building interventions [114–116] for this population of emerging adults.

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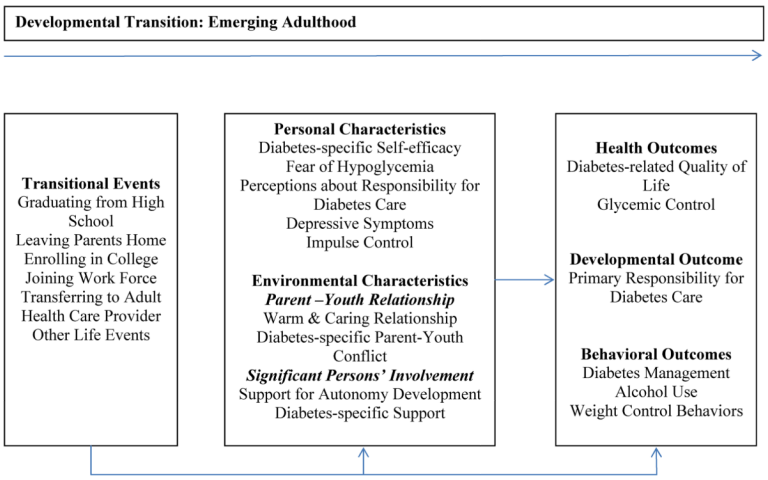

Figure 1.
A Framework for Youth with Type 1 Diabetes during Emerging Adulthood

Table 1

Relationships among Key Concepts

Relational Statements	Support for Relational Statements
Health, developmental, and behavioral outcomes are inter- related.	
Glycemic control is influenced by diabetes management, alcohol use, and unhealthy weight control behaviors influence.	Diabetes management,[77] alcohol use[7] and unhealthy weight control behaviors[37] have been found to influence glycemic control.
Diabetes-related quality of life in influenced diabetes care responsibility	Parents having greater diabetes care responsibility is associated with poorer diabetes-related quality of life.[78]
Glycemic control is associated with diabetes-related quality of life.	Better glycemic control is associated with better health-rated quality of life[25, 41] and with physical health.[79] Glycemic control has been associated with psychosocial aspects of diabetes-related quality of life,[21, 26, 80] although some studies found no relationship between these factors.[25, 27]
Diabetes management often leads to poor quality of life.	Diabetes management interferes with the social lives of youth with diabetes.[7]
Personal characteristics influence outcomes.[17]	
Diabetes management is influenced by diabetes-specific self-efficacy, fear of hypoglycemia, depressive symptoms, and impulse control.	Diabetes management mediates the relationship between diabetes self-efficacy and glycemic control.[31, 81] Fear of hypoglycemia is associated with poorer management.[82] Depression is linked with poor glycemic control among adults[83] and youth,[22, 84] and blood glucose management mediates the relationship between depression and glycemic control.[85] Low impulse control is associated with behaviors that are risky among youth in general.[86]
Depressive symptoms and impulse control influence alcohol use and weight control behaviors.	Alcohol use and weight control behaviors are associated with depressive symptoms among youth in general[87, 88] Low impulse control is associated with behaviors that are risky among youth in general.[86]
Diabetes-related quality of life is influenced by diabetes-specific self- efficacy, perceptions about responsibility, depressive symptoms, and impulse control.	Diabetes self-efficacy is associated with diabetes care responsibility [22] and psychosocial diabetes- related quality of life.[89] Greater responsibility is associated with greater perceived advantages to assuming responsibility, whereas more disadvantages were associated with less responsibility.[90] Depressive symptoms are negatively associated with diabetes-realted quality of life.[91] Good self-control is associated with better well- being among adolescents in general.[92]
Diabetes management and primary diabetes care responsibility are linked through self-efficacy.	Diabetes-specific self-efficacy mediates the relationship between primary responsibility and management.[31]
Environmental characteristics influence outcomes.[17]	
Diabetes management is influenced by diabetes-specific support.	Diabetes-specific support, with an aspect of instrumental support, received from family is associated with better management and glycemic control,[31, 67, 93,94] and such support from peers is associated with better diabetes management.[22, 68, 94]
Diabetes management, alcohol use, and weight control behaviors are influenced by a warm and caring relationship and by diabetes-specific parent-youth conflict.	A warm and caring relationship is associated with better diabetes management[67] and less involvement in alcohol use among youth in general.[95] Diabetes-specific parent-youth conflict is associated with poorer management and glycemic control,[21, 69, 96,.97 and poor relationships with parents are associated with alcohol use[98] and unhealthy weight control behaviors.[99]
Diabetes care responsibility and diabetes-related quality of life are influenced by parental support for autonomy development, a warm and caring relationship, and diabetes- specific parent-youth conflict.	Parental support for autonomy development is associated with diabetes care responsibility among younger adolescents.[64] Parental support for autonomy is associated with well-being[53] among emerging adults in general and among adolescents with diabetes, and parental behaviors that include parental facilitation of autonomy are associated with quality of life.[78100] A warm and caring relationship is associated with a better diabetes-related quality of life[101] and most likely is associated with diabetes care responsibility; adolescents, in general, best develop their autonomy within close, warm relationships with their parents.[102] Parent-youth diabetes-specific conflict is associated with poorer quality of life.[93,96,78,103]

Relational Statements	Support for Relational Statements
Situational events influence outcomes[16] as well as personal and environmental characteristics.	
Transitional events influence glycemic control, diabetes-related quality of life, diabetes management, alcohol use, weight control behaviors, diabetes- specific self-efficacy, and parental diabetes-specific support.	Life events are associated with poorer diabetes management and glycemic control.[104] Life events are often associated with poorer quality of life.[94] College enrollment and/or living independently of parents are associated with more alcohol use[105] and unhealthy weight control behaviors[106] among emerging adults in general. Decreased clinic attendance, an index of problems with the transitional event of transferring from pediatric to adult care providers, was associated with poor glycemic control in one study, [107] although these variables were not associated in another study.[108] Transitional events lead to new experiences; according to Bandura, [45] successful experiences lead to greater self-efficacy whereas unsuccessful experiences lead to lower self-efficacy Among adolescents in general, lower levels of family support occur for those who moved out of the home.[108]