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Moving the journey towards independence: Adolescents transitioning to successful diabetes self-management

Elizabeth K. Babler, PhD, ARNP, CDE and

University of Washington School of Nursing, Psychosocial & Community Health, Box 357263, Seattle, WA, USA 98195-7263, Phone: 01-360-620-2268, Fax: 01- 414-229-6474, babler@uwm.edu

C. June Strickland, PhD, RN

University of Washington School of Nursing, Psychosocial & Community Health, Box 357263, Seattle, WA, USA 98195-7263, Phone: 01- 425-747-7268, Fax: 01- 206-685-9551

Abstract

Purpose—To gain a greater understanding of adolescent’s experiences living with Type 1 diabetes mellitus (T1DM) and create a theoretical paradigm.

Methods—Grounded theory as described by Glaser was used. Fifteen in-depth interviews were conducted with adolescent’s ages 11 to 15 with T1DM. Symbolic interactionism is the theoretical framework for grounded theory. Data were collected; transcribed, coded, and analyzed simultaneously using constant comparative analysis and findings were grounded in the words of participants.

Results—A theoretical model was created with the concept of “**normalizing**”. Normalizing was defined as the ability to integrate diabetes into one’s daily life to make diabetes ‘part of me’. Phase four of the model, and the focus of this manuscript was “**Moving the Journey towards Independence**” and included: 1) taking over care, 2) experiencing conflict with parents, and 3) realizing diabetes is hard. The major task for adolescents in this phase was separating from parents to independently manage diabetes. The normalizing task for this phase was: “**taking on the burden of care**”. Adolescents described challenges with independent care and increased parental conflict including: fearing needles, forgetting insulin, feeling embarrassed and believing that diabetes was a burden in their life. Additionally, juggling the multiple responsibilities of home, school and work along with managing a chronic illness during adolescence is challenging.

Conclusions—Transitioning to diabetes self-management is a challenge for adolescents. This model advances understanding of the moving processes in adolescents transitioning; additionally,

Correspondence to: Elizabeth K. Babler.

¹Present address - University of Wisconsin – Milwaukee, College of Nursing Cunningham Hall, Office 475 P.O. Box 413 Milwaukee, WI, USA 53201-0413

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hypotheses are presented that may be used for developing interventions to promote success in self-management.

Keywords

self-management; Type 1 diabetes; adolescent; conflict; parent

Introduction

Transitioning to diabetes self-management (DSM) is a challenging time for most adolescents (Ingerski, Anderson, Dolan, & Hood, 2010). Many adolescents take on increased independence in their diabetes management tasks as early as age 9–10 with the majority of care being done by the adolescent by age 11–13 (Dashiff, McCaleb, & Cull, 2006; Ingerski et al., 2010). As adolescents take on more of their own care, hemoglobin A1C (A1C) rises and blood glucose self-monitoring decreases (Rausch et al., 2012; Ziegler et al., 2010) leading to increased risk for diabetic ketoacidosis (DKA) (Ziegler et al., 2010). Transition is difficult for both the parent and the adolescent and a greater understanding is needed to assist families during transition to DSM. While a number of research studies have been undertaken to address diabetes management with adolescents, none have focused on developing a paradigm from the perspective of the adolescent that help to predict, describe, and explain behaviors (Channon et al., 2007; de Wit et al., 2008; Lehmkuhl et al., 2010; Mulvaney, Rothman, Wallston, Lybarger, & Dietrich, 2010; Svoren, Butler, Levine, Anderson, & Laffel, 2003; T. Wysocki et al., 2007) as was the aim of this study. The purpose of this research project was to gain a greater understanding, of the adolescent's perspective, of their experiences in living with diabetes, and associated challenges and management issues they may face. Findings are of value to families and adolescents, nursing practice, as well as the advancement of nursing science in the understanding of adolescent management of diabetes.

Adolescents with type 1 diabetes mellitus (T1DM) learn to self-manage their diabetes gradually starting in childhood. The first steps of DSM are often learning the tasks of blood glucose monitoring and giving insulin injections (Hanna & Decker, 2010). Diabetes self-management is very complex with over 600 tasks needed to manage diabetes effectively (Coffen, 2009) and include not only the physical tasks needed for glycemic control, but emotional adjustment to having a chronic illness. DSM also includes needed skills in decision making, and problem solving (Wysocki et al., 2008). The adolescent's perception of their self-efficacy has been shown to be an important factor in not only DSM but also glycemic control (Berg et al., 2011; Iannotti et al., 2006). In adolescents and parents with a good relationship there is better adherence to diabetes care and metabolic control than for those with poor relationships (Berg et al., 2011). Despite this, collaboration with parents drops off dramatically between ages 14 and 15 while problem solving skills increase throughout the adolescent period (Keough, Sullivan-Bolyai, Crawford, Schilling, & Dixon, 2011). Risk factors for poor adherence to care include increasing age, single-family homes, lower socio-economic status (SES), high family conflict, poor family communication and problem solving skills, and poor social skills and coping methods (Wysocki, 2006). Adolescent females tend to have better communication than males with their parents, their

friends, and their providers about their diabetes (Keough et al., 2011). While there are several theories that describe self-management of chronic illness and the risk and protective factors that improve outcomes it is difficult for adolescent's to achieve successful self-management of their diabetes during these transition years (Grey, Knafl, & McCorkle, 2006; Ryan & Sawin, 2009). Parents have described frustration and worry over their adolescent's self-management of their diabetes but state that reminding their adolescent and granting more freedom are helpful during this time (Dashiff, Riley, Abdullatif, & Moreland, 2011).

There is an increase in psychological distress during these years including poor self-esteem which is correlated with poor quality of life (Abolfotouh, Kamal, El-Bourgy, & Mohamed, 2011), increased parental conflict (C. Dashiff, Vance, Abdullatif, & Wallander, 2009; Ingerski et al., 2010), higher rates of depression and anxiety (Hoey, 2009; Insabella, Grey, Knafl, & Tamborlane, 2007). Adolescents believe their parents are overbearing and controlling (Carroll & Marrero, 2006; Hoey, 2009; Leonard, Garwick, & Adwan, 2005), and often do not want their parents involved (Hanna, Juarez, Lenss, & Guthrie, 2003) despite the benefits shown from increased parental support (Leonard et al., 2005). These adolescents often struggle with peer relationships (Buchbinder et al., 2005) and do poorly in school (Northam, Lin, Finch, Werther, & Cameron, 2010).

In summary, the changes in supervision of care as well as the emotional distress associated with the adolescent years leads to a dramatic decline in blood glucose monitoring (BGM) with poor A1C's during this stage with only 17% of adolescents meeting the national recommendation for A1C < 7.5% (Cengiz et al., 2013; Professional Practice Committee, 2015). Despite the multitude of interventions that have been done with adolescents with T1DM no lasting changes have been made in improving glycemic control (Channon et al., 2007; de Wit et al., 2008; Lehmkuhl et al., 2010; Mulvaney et al., 2010; Svoren et al., 2003; Wysocki et al., 2007). This understanding of the adolescent's perspective of how they live and manage their diabetes gave a unique understanding of their challenges and allowed for the development of a theoretical paradigm on "**normalizing**" (Babler & Strickland, 2013). This paradigm provides information from the perspective of the adolescents on their experiences of living with diabetes.

In this manuscript, the focus is on one portion of the research, "moving the journey towards independence". This particular portion of the research contributes to a greater understanding of the transition to DSM for adolescents and thus is of value to health providers, parents, and adolescent's as they struggle with the challenges of addressing DSM at this important stage of adolescence. The theoretical model developed in this research also advances the science in DSM.

Methods

The purpose of this study was to gain an understanding of the adolescent's experiences in living with diabetes, their challenges and management issues, and to build a theoretical paradigm to create future interventions for adolescents with T1DM. In this manuscript, phase 4 of the theoretical model developed, "moving the journey towards independence" and

separating from the parent was the focus. Further details of the methods, data analysis, and the full model are available and have previously been described (Babler & Strickland, 2015).

Study Design

This was a qualitative study utilizing traditional grounded theory as described by Glaser (Glaser & Strauss, 1967). Symbolic interaction is the theoretical framework for grounded theory (Blumer, 1969). Grounded theory was the most appropriate method for this study because it was congruent with the aims of the study which were to understand the experiences of adolescents with T1DM management, to build a theoretical paradigm, and to generation hypothesis for future interventional studies. Understanding more about the conditions that are present with certain behaviors assists in the design of interventions (Glaser, 1978; Glaser & Strauss, 1967).

Study Sample

The sample for this study was chosen from Caucasian adolescent's ages 11 to 15 years that had T1DM from western Washington State. There were 3 boys (27.3%) and 8 girls (72.7%) with a mean age of 13.9. The participants had an average A1C of 8.2% (7.2–9.2) as reported by their parents. The majority of families were middle class with 9.1% earning <\$20,000, 27.3% earning \$21–50,000, 36.4% earning \$51–75,000, and 27.3% earning \$76–99,000.

Process

In home interviews were digitally recorded and lasted approximately 60 minutes. The first 3 interviews used purposeful sampling followed by 12 interviews using theoretical sampling to provide needed information for data saturation. Three of the participants were re-interviewed to obtain further clarification of certain codes to achieve data saturation. Sampling, coding, and data analysis were done simultaneously using gerund coding, theoretical coding, and constant comparative analysis to form a theoretical paradigm as described by Glaser (Glaser, 1978; Glaser & Strauss, 1967). Themes and their relationships were reviewed with adolescents during the interview, memos were written, and a focus group was conducted near the end of the study to assure credibility, fittingness, and auditability of the study (Denzin & Lincoln, 2005; Lincoln & Guba, 1985).

Study Questions

Study participants were asked open ended questions initially and included: 1) *Let's discuss your experiences of living with diabetes.* 2) *Let's talk about taking care of or managing your diabetes. Can you tell me about that?* Additional questions were asked based on information provided in the interviews (Babler & Strickland, 2015).

Human Subjects

IRB approval was obtained through the University of Washington and the local study site. Parents signed consents to participate and the adolescents signed assents.

Results

In this manuscript, the focus is on Phase 4 “**Moving the Journey towards Independence**”, a stage in the larger picture and understanding of normalizing of diabetes management for adolescents with T1DM – see Figure 1. Phase 4 is an important step for adolescents as they begin to take on more independent care of their diabetes and learn the steps that are needed to successfully keep their blood glucose levels balanced. It included the following major codes: taking over care, experiencing conflict with parents, and realizing diabetes is hard. The major task of this phase for adolescents is separating from parents to independently manage diabetes and the normalizing task is “taking on the burden of care”.

Moving the journey towards independence was defined as the ability of the adolescents to successfully transition to independence from their parent by taking on primary responsibility for their diabetes management tasks. Regardless of the age of the child at diagnosis, at some point they reach the age of adolescence. During this phase of their life they begin the normal developmental tasks of early and middle adolescence that greatly influences their diabetes management. The adolescents begin to deal with some of the emotional challenges of the adolescent years by becoming more aware of others around them and wanting to spend more time with their peers than with their parents and wanting to be more independent.

In an earlier phase of normalizing adolescents valued their privacy and realized they were different. In this phase the adolescents begin the process of seeking independence from their parents in their daily life as well as with their diabetes care. The primary task of normalizing during this phase was ‘**taking on the burden of disease**’. As the adolescents take on more of the diabetes management, they also begin to realize that managing diabetes independently is a challenge and sometimes frustrating. Adolescents’ interactions with their parents are difficult as they strive to become more independent and do not want their parent’s involvement in their diabetes care. During this stage (Phase 4-moving towards independence) three codes that will be discussed include: **(a) taking over care, (b) experiencing conflict with parents, and (c) realizing diabetes is hard**. The major task in this stage is **separating from parent and independently managing diabetes**.

Taking over care is defined as adolescents wanting to independently manage their diabetes. Transitioning to self-care of diabetes is a slow process that usually occurs over time. One of the challenges in taking over care from the parent is the willingness of the parent to let go of the care and for the parent to not transition before the adolescent is ready. Steps and identified codes in the data that are part of taking over care include: transitioning from parental care, independently monitoring the blood sugar, taking over administration of insulin, managing diet independently, and managing activity independently.

Transitioning from parental care was defined as the steps adolescents took as they endeavored to become independent in their life. Included in this transition were: depending on your parent, taking over some responsibility gradually, needing to separate from parent, and assuming full responsibility.

“when I was a child my mom mostly took care of it, so she was always watching my blood sugars, I think it was about when I was about 10- 12 maybe between that time frame that I started doing it on my own” Interview #4 p.1

Needing to separate from parent was when adolescents described their parents as too overbearing, and they would like to have more independence in their own care. The adolescents struggled with how to take care of themselves when their parents want to be so involved. They also shared that their emotional turmoil during this time of conflict with their parents made it difficult for them to want their parent involved in their care and they often do not want to do the care just because of their parents’ constant reminders.

“she doesn’t want to give up and let go but I’m not just going to let her do it either, I’m not going to let her take care of me because I need to be able to function as a normal person” Interview #11 p. 15

Assuming full responsibility was where adolescents described they finally believed they would have complete control of their own care. Some adolescents stated they do not believe this will happen until they are able to move out of the house. They say they were worried their parent will be calling to check in on them once they are on their own.

“I think the only way I’m actually going to be able to do it (diabetes) full on my own is by leaving so I mean like when I start my freshman year at college and they drop me off, then I can assume full and all responsibility, but I’ll probably still get the phone calls at like 2:00 in the morning” Interview #11 p. 13

Conditions when the adolescents are able to transition from their parent include: (a) when the parents are willing to let go, (b) when the adolescents have the skills to take over care, (c) when the adolescents are older, and (d) when the adolescents are emotionally ready to take on diabetes management. Conditions when the adolescents are not able to transition from their parent include: (a) when they are too young, (b) when the parents are not able to let go of care, (c) when the transition happens too rapidly, and (d) when the adolescents do not have the knowledge to manage their own diabetes and make appropriate care decisions. A hypothesis is helping the adolescent and parent work through the transition process together will decrease conflict and improve care.

Independently monitoring the blood sugar was defined as being able to do a blood sugar reading on one’s own and knowing what that number means, and what to do with that blood sugar number. During this phase the adolescents have some skills for caring for their diabetes but are taking on the additional step of learning to do the care independently from their parents and incorporating the decision making that is necessary. Steps needed to independently monitor blood sugars include: reaching independence in blood sugar monitoring, remembering/forgetting, and creating strategies for remembering.

“mostly on like really stressful days when I really have a lot to do sometimes it will like just totally skip my mind and it’s just that like a few hours and I’m like, oh no I didn’t do my BS, and then it’s like that time that I will usually go high or low ‘cuz I’m not like paying

attention to like what I'm eating, when I'm eating and when I'm doing my BS" Interview #4 p.4–5

Strategies that help the adolescents remember include the following: keeping a log, setting an alarm, using app on iPod touch or phone, keeping a schedule, and using a planner.

"I have a schedule so like I get up at the same time every day, test at the same times every day, come home test, go to practice, test, eat dinner, test, so the school year it's fairly easy, in the summer it's a challenge because I just want to go off and do things" Interview #10 p. 8

Conditions when the adolescents were able to independently manage their blood sugars included: (a) when they feel they know what they are doing, (b) when they have an insulin pump, and (c) when they have someone reminding them. Conditions when adolescents were not likely to independently manage their blood sugars included: (a) when they forget to test and (b) when they do not want to. A hypothesis is by creating strategies the adolescents like to help them remember their blood sugar tests will improve adherence to care.

Taking over administration of insulin was defined as adolescents being able to independently give their own insulin. Steps in this process included: determining amount of insulin needed, giving the insulin, remembering to give the insulin, experiencing high blood sugars, developing strategies to address issues, and seeking assistance from others. This step includes the important aspects of making sure that appropriate equipment is available as needed to manage blood sugars. Learning to do insulin administration independently from the parents and common strategies that adolescents believed were helpful were creating a schedule and carrying a bag with their supplies.

Conditions present when the adolescents independently gave insulin include: (a) knowing how to use their supplies, and (b) when they have their equipment available. Conditions present when the adolescents are less likely to independently take insulin include: (a) not caring if you give the insulin, (b) forgetting to give the insulin, and (c) having others check to make sure insulin is given correctly. A condition that is a barrier to independent care is when the adolescents are afraid of giving their own injection or replacing their own pump site.

"it is time to change your site and I'm like I'm not doing it, I'm not doing that nope, like I just started crying and everything and I don't know why...I was like 12 or 13 and I was old enough that I didn't need to be crying over that but it still wasn't fun" Interview #7 p. 14

A hypothesis is that insulin pump use increases independence and improves care for adolescents and that use of the alarm feature can help adolescents remember to do their own blood sugars and insulin. Also helping adolescent's overcome fear of giving injections and developing strategies to support giving insulin, such as carrying a bag may also be expected to further contribute to taking over administration of insulin.

Managing diet independently was defined as being able to independently count the carbohydrates, make appropriate food choices, and calculate insulin dosing. Adolescents describe multiple strategies used to manage their diet including: learning to identify foods

with carbohydrates, learning to identify amount of carbohydrate in products, learning to add the total carbohydrates, calculating the correct dose of insulin for carbohydrates, learning from blood sugar results how food affects the body, learning how to create a balanced diet, remembering to take insulin for food, and developing strategies for carb counting. Adolescents share steps in identifying the amount of carbohydrates that include: using a scale, using a measuring cup, looking up information in the book, eyeballing the food, using hand values to estimate amount of carbs, memorizing certain foods, and eating prepackaged foods. The adolescents describe a number of steps they take to help in adding the total carbohydrate intake including: using the calculator, creating a log, and writing amounts on a sheet.

“I got this really cool book that had like every chain restaurant and everything in there so I could look at that and it pretty much had like every food on the planet so like if I would go get a milkshake I could look it up in there...it had the amount of food – like 1 cup of cereal – that is 23 carbs for cheerios or whatever” Interview #12 p. 2

Adolescents state they have trouble remembering their insulin for their food, especially when snacking or when they are out with others.

“I wouldn’t remember that it was there and that I needed to take insulin ‘cuz I was just like, oh well does it matter, it’s just a little bit of food” Interview #4 p. 5–6

Conditions when the adolescents were able to manage their diet independently included: (a) when they understand how to carb count correctly, (b) when they are able to learn how much insulin to give for their food, (c) when they understand the effects of their diet choices on their blood sugar, and d) when they structure their eating times and choices. Conditions when the adolescents were not able to manage their diet independently included: (a) when they guess at their carbohydrate totals, (b) when they are not able to understand the process of how to identify and count the foods they are eating, (c) when they are out with others, and (d) when they eat foods that they are not familiar with. A hypothesis is that by helping the adolescent to feel comfortable with appropriate carb counting methods, and once they have developed the skills needed for carb counting, they will be more successful in giving the correct dose of insulin. Further investigation is needed on being unable to stay on track with food when they are out with others; it is recognized that it is part of normalizing and not wanting to be different.

Managing activity independently was defined as learning to assess effects of activity on the blood sugar values and make appropriate adjustments to insulin or food. Adolescents shared two things they do to help manage activity including: assessing effects of activity and managing insulin dosing for exercise.

“I have found that I go high right after I exercise...my first reaction is oh, my BS is high and I need to give myself insulin but if you give yourself insulin then you are going to hit the low from the exercise and then you are going to go really low so exercise is like really hard for me” Interview #11 p. 11

Conditions when the adolescents were able to independently manage their activity included: (a) understanding the effects of exercise, and (b) having the ability to make a judgment on the amount of insulin to be given to keep their blood glucose levels balanced. Conditions when the adolescents were not able to independently manage their activity included: (a) when they are not monitoring their blood glucose with their activity, and (b) when they do not understand the effects of how activity affects their blood glucose control. A hypothesis is that by developing an awareness of the effects of activity on blood sugars adolescents will then learn to better manage their blood sugars when active.

The major goal of the adolescents in taking over care was to become independent in their diabetes management tasks. As the adolescents took on more of these tasks they simplified their regimen to maintain as much normalcy in their life as possible. In trying to accomplish normalcy and independence, the adolescents began to experience more conflict with their parent as they made choices about how they were going to manage their diabetes that may not fit with the parent's view of maintaining their health.

Experiencing Conflict with Parents was defined as the parent and adolescents not agreeing on diabetes management or arguing over care being done. Codes included: struggling for independence, experiencing nagging from parent, and building trust. Adolescents shared that they began experiencing increased conflict with their parents as they tried to transition to independent care of their diabetes. The adolescents and parents had disagreements about their care, what was expected from them, and how to help their parent trust their abilities to care for themselves.

Struggling for independence was defined as trying to take on more independent care by having parents too involved or checking in too often was a struggle. Adolescents shared that while they were attempting to become independent from their parent, they felt like they were in a tug of war with their parent wanting to retain control over the diabetes management. Adolescents stated that they believed they were doing their own care, but their parents were constantly trying to stay involved. On the other hand, once the adolescents were older they began to understand that this was a difficult transition for their parents, and their parents want them to stay healthy. Additionally adolescents discuss worrying about the reaction of parents or others. An example of struggling for independence follows.

"it is the tug of war that happens when you have a sick child that you have been taking care of since she has been like an infant and I completely understand...but it's just hard for her but at the same time it kind of just needs to be like a Band-Aid - just rip it off quick, I mean and just let me go" Interview #11 p. 15

Worrying about the reaction of parents or others was defined as worrying about the parents' reactions to blood sugar values. Adolescents shared that as they perform care independently, they have high blood sugars at times and worry about what to tell their parent or doctor to avoid getting into trouble. They sometimes lied about their blood sugar value or did not test ketones with high blood sugar just to avoid conflict.

"we had installed the fear that if like you don't have a perfect number you were going to get yelled at and like I still have that fear 'cuz even now if I have a high number and I know

mom is going to get on me I might be like just tell her it's a little lower even though I am like going to take care of it" Interview #7 p. 10

Experiencing nagging from parent was defined as when the parents ask them over and over again about their blood sugars and always wanting to check in with them about how their blood sugars are doing. The adolescents relayed how at times the nagging caused them to not want to do their blood sugars and that as they get older they just ignore the nagging more. Codes include: avoiding testing from nagging, wanting to be 18 to not deal with parent nagging, understanding parent means well, getting used to parent nagging, and experiencing the parent not nagging.

"I can actually remember myself doing the calculations and finding out just how many days till I turned 18 so I didn't have to deal with mom or dad nagging on me anymore, I mean all the time" Interview #6 p. 4

Conditions when the adolescents experience less nagging from their parents include: (a) when they are older, (b) when they believe their parent is trying to help, and (c) when they know they need reminders from their parent. Conditions when the adolescents are more likely to experience nagging from their parent include: (a) when they are young adolescent age (10–12), (b) when they first are doing more on their own, (c) when the parent repeatedly asks about diabetes management, and (d) when the adolescents do not believe the parent trusts them to make a good decision. A hypothesis is by decreasing nagging between adolescents and their parent the adolescents will be more willing to do their care. Providing parent and adolescent education to address the behaviors and concerns that result in a sense of being nagged may be expected to be of value in this transition to independence.

Building trust is defined as having a relationship with their parent that allows the parent to trust that the adolescents are able to independently manage their diabetes. The adolescents share that building trust is part of the process in decreasing conflict with their parent. Codes that are part of building trust include: demonstrating care being done, affirming care is done, having a conversation with parent, demonstrating truthfulness in care, and showing parent you are doing well.

"you just need to have the conversation with your parent that like if my number is like 425 because I had a bag of chips and I didn't bolus for it you will just have to trust me that I am going to get that number down because I know what it's like to be sick and I'm not going to do that to myself...I guess some points they lose trust but you just have to let them know that you know how to handle it...you know what you are supposed to be doing" Interview #7 p. 10

Conditions when the adolescents are able to build trust include: (a) when they are doing their care, (b) when their parent is monitoring the adolescent and assuring care is done, and (c) when they are communicating with their parents. Conditions when the adolescents are not able to build trust include: (a) when they lie to their parent, (b) when they do not test or take their insulin when their parent asks, and (c) when they are younger. A hypothesis is that when parents trust the adolescents they are more likely to allow the adolescents independence with providing their own care and adolescents are more likely to be truthful in

sharing information. An important part of building the trusting relationship is to address communications and learn strategies for building trust.

The goal for the adolescents during this step is to decrease the conflict and nagging from their parents by building trust in their ability to manage their diabetes. Part of the struggle for the adolescents as they are trying to find a sense of normalcy and balance in their life is the realization that diabetes is hard, and finding they often experience the management tasks as a burden on their life that leads to problems in maintaining blood sugar control.

Realizing diabetes is hard was defined as struggling to manage diabetes independently all day every day, not having blood sugars respond as expected, and the emotional burden of having diabetes and just wanting to give up. Adolescents share challenges they had in managing their diabetes independently once they began to separate from their parents and realized they are different from their peers. They stated that when their blood sugars were out of control was when they feel diabetes was hard and when their blood sugars were in control they are better. Codes included: experiencing burnout, juggling diabetes with other responsibilities, getting frustrated, getting annoyed, and getting stressed.

“Sometimes it is kind of hard, you just have those days where like it seems like everything is harder than it really is, when you are young and when you have those days, basically when you have diabetes it’s like you just want to give up” Interview #4 p. 13

Experiencing Burnout was defined as the adolescents not being able to focus on doing their diabetes care in an appropriate way due to their feelings about having diabetes and feeling it is a burden in their life. Codes include: realizing that diabetes is a pain, believing diabetes is a burden, and experiencing trouble taking care of diabetes.

“living with diabetes is definitely and interesting experience... it’s almost like continually riding a bike and you cannot stop or else...it’s just a pain, I will put it that way, it’s definitely a pain” Interview #6 p. 1

Believing diabetes is a burden was defined as the adolescents believing that diabetes was something they have to deal with that is very difficult and time consuming to manage. Adolescents shared how feeling diabetes is a burden leads to their not always managing their diabetes as they would like to. Steps of believing diabetes is a burden includes: not checking blood sugars, lying about blood sugar numbers, running out of insulin, acting lazy, and needing a break.

“you have to check your blood every hour or two hours, and you have to give injections or change your sites or fill your reservoirs, or if you get sick you have to go to the hospital, or the feeling of when you’re sick of how nauseous you are, it’s a burden any disease is a burden” Interview #7 p. 2

Not checking blood sugars was defined as when the adolescents were tired of the day to day work in managing their diabetes and do not always do their blood sugar checks in a way they know will help them to control their diabetes. They state they also are trying to fit in with their peers.

“like not checking your blood, like some days I check my blood like twice I know that is horrible... you realize you are different from everyone else and you are trying to fit in...if you are going to a movie to eat popcorn... you don’t want to be hold on I’ve got to check my blood” Interview #7 p. 3

Lying about blood sugar numbers was defined as when the adolescents know they are not doing what they are supposed to and do not want others to find out their blood sugars are not in the range they would like them.

“we are in the car and mom is like did you check your blood and like if I do I will say it was 125, I could lie about that number she is not going to go check my meter some days she does and some days she doesn’t” Interview #7 p. 10

Running out of insulin was defined as when the adolescents were not keeping up with their diabetes and did not make sure they had insulin in their insulin pump which leads to DKA.

“one of the biggest things for me is like I will go to bed and forget that my reservoir is empty and I’ll be like so comfy and I will be like you just need to get up, I did that last night, I mean I do that all the time and it is like the biggest bummer” Interview #7 p. 12

Acting lazy was defined as not doing what you are supposed to be doing to manage your diabetes because some days you just are not as motivated to take care of it, which leads to poor blood sugar control.

“I obviously know when I’m not like checking my blood enough and I know when I’m being lazy with it but I’m like a teenager and teenagers are lazy and I know that I’m not supposed to be lazy but I think that is a natural human habit to be lazy when you are a teenager but I know it’s not an excuse...I know there is nothing drastically wrong with me I’m just lazy” Interview #7 p. 3

Needing a break was defined as just wishing you could have one day when you do not have to take care of your diabetes, and so some days you do not do all the care to give yourself a break.

“you do get burnt out, you get tired of doing the same thing every single day, you want to know take a break from it even though you know you can’t and so I guess you try to just get around it” Interview #7 p. 3

Experiencing trouble taking care of diabetes was defined as not being able to keep up with doing the blood sugars and giving the insulin resulting in a rise in A1C. The adolescents shared that when their parents stopped helping them as much they had, more problems keeping their blood sugars controlled.

“I started doing it on my own and for the first few years my A1C went up a bit but it was still ok, then maybe a year or two ago it actually started becoming harder for me to be able to keep up with you know doing blood sugars and insulin” Interview #4 p. 1

Juggling diabetes with other responsibilities was defined as the adolescents trying to maintain balance in their daily life. This balance includes their school work, chores, friends, sports, and their relationships, yet still being able to manage their diabetes.

“I’m overwhelmed trying to juggle school, and sports and diabetes and stuff” Interview #10 p. 17

Getting frustrated was defined as the adolescents not feeling successful in their management of diabetes and trying to manage their blood sugars while keeping up with their other responsibilities. The adolescents view diabetes as hard when they have problems managing their blood sugars.

“if I’m really, really high or something...if it’s just one of those days that I’m not in a good mood and then my BS is off and it just kind of like piles up like one thing after another, I mean maybe they are just little things but... if my BS are way off then it just makes it worse (frustrating)” Interview #10 p. 12

Getting annoyed was defined as being irritated when others were always checking in on them because of their diabetes, as well as when caring for diabetes was interfering in their day.

“suffocating...smothering...It’s annoying honestly and she knows it... I just don’t think she’s physically capable of stopping -what’s your BS now what’s your BS now” Interview #11 p. 4

Getting stressed

Getting stressed. Adolescents discuss how stressed out they get from diabetes, from life, from all the responsibilities they have, and how that makes it hard to juggle everything and the effects on their blood sugar from stress.

“I have been stressed out about family things and school things especially with fast pitch because I have been practicing all day... then coming home and doing my chores and my homework and it’s hard and then it just stresses me out so then my blood sugar goes high and that’s pretty much why my blood sugar goes high lately” Interview #2 p. 3–4

Conditions when the adolescents felt that diabetes was not hard included: (a) when they have more parental assistance, (b) when their blood sugars are in better control, (c) when they are older, and (d) when they do not believe diabetes is a burden. Conditions when the adolescents felt that diabetes was hard included: (a) when they are having difficulty controlling their blood sugars, (b) when they want to fit in with their peers, (c) when they feel like they need a break, (d) when they are younger adolescents, and (e) when their parent is not helping as much. A hypothesis is if adolescents were able to take a break from diabetes for a few hours or a day when they feel it is a burden they will be more in control on other days. Education programs to help adolescents recognize and address burn out and develop strategies for coping with burn out such as taking time off, may be expected to result in better blood sugar control.

Emotions are an important part of phase 4 of normalizing - moving the journey to independence. Negative emotions that adolescents discussed on their journey to independence included: feeling worried, feeling sad/depressed/suicidal, feeling not recognized by their parent and feeling overwhelmed. Adolescents discussed how they wish they could just forget they had diabetes and their struggles with having to worry about their blood sugar all the time.

The adolescents described **feeling depressed** about having diabetes, having an overwhelming sadness that causes them to wonder what the point is, and stating they think about suicide.

"I don't even know what I'm sad about anymore, you just get to the point that it's like what is the point of being sad, you know? You know what I'm talking about right, committing suicide" Interview #6 p. 4

Adolescents describe **feeling not recognized** by their parents; they would like approval from their parents instead of always hearing negative comments.

"I want to please my parents and mom's not exactly the person to come to and say oh wow! It's great! She will say well that looks nice, but ... you missed this... sometimes I don't feel recognized by mom for being mature" Interview #6 p. 5

Adolescents discussed feeling **overwhelmed** about their diabetes and how their parents respond to events that happen with their diabetes. Adolescents share how they have to say they are fine just to calm their parents down.

A key component for adolescents in normalizing during this phase is how they are able to manage '**taking on the burden of care**'. The process of taking over care from their parents and becoming independent, the conflict they experience with their parents, as well as when they have difficulty controlling their blood sugars leads them to feel very frustrated and out of control. Adolescents share that diabetes is hard, a burden, and they experience burnout while trying to juggle all the responsibilities they have in life which just adds to this burden of care and their ability to normalize during this crucial time of moving to independence. The provision of adolescent emotional support groups might be of value in helping adolescents address the emotions they experience in transitioning to the management of diabetes.

Discussion

During this fourth phase, the axial code '**moving the journey towards independence**', the major codes included taking over care, experiencing conflict with parents, and realizing diabetes is hard. The major task adolescents were attempting to achieve was separating from parents to independently manage diabetes with the normalizing task of "**taking on the burden of care**". Some of the key conditions that prevented adolescents from achieving the major task during this phase included: (a) fear of needle pain, (b) forgetting to give insulin, (c) making judgments on insulin dosing affects outcomes, (d) feeling self-conscious or embarrassed about doing care in front of others, (e) experiencing conflict with parents

occurs more when they are frequently asking about blood sugars, (f) the rate of transition affects how the adolescent does (too soon, too slow), and (g) feeling that diabetes is hard when adolescents just want to fit in with peers.

Key hypotheses included: (a) insulin pump use increases independence and improves care for adolescents and the alarm feature can help adolescents remember to do their blood sugars and insulin, (b) creating strategies to decrease needle fear and help adolescents achieve success in administering their own insulin and placing their own pump sites will enhance independent care, (c) an awareness of the effects of activity on blood sugars will help the adolescents to learn to manage their blood sugars better when they are active, (d) creating strategies the adolescents like to help them remember their blood sugar tests will improve adherence to care, (e) helping the adolescents to feel comfortable with appropriate carb counting methods, they will be more successful in giving the correct dose of insulin, (f) decreasing nagging between adolescents and their parents, the adolescents will be more willing to do their care, (g) helping the adolescents to have appropriate knowledge and assisting the parent and adolescents in a smooth transition will decrease conflict and improve care, (h) when the adolescents do not feel diabetes is a burden, they have less emotional trouble with managing their diabetes and (i) creating a climate of trust between adolescents and their parents may reduce lying about blood sugar numbers.

In this research adolescents have provided information about the challenges they face as they journey toward independent DSM. They have also provided many important details and steps about how they are able to meet these challenges of benefit for researchers as they plan future interventions with this population to improve health outcomes. There are many emotions that the adolescent deals with as they work towards independent DSM. These emotions, along with the tasks needed for managing diabetes, often become overwhelming and thus are perceived as a burden.

These research findings are similar to previous research findings. Other researchers have described the conflict with parents during this transition process that is often detrimental to care (Dashiff et al., 2009; Ingerski et al., 2010). Researchers note that adolescent's feel that parental support is beneficial to them but more needs to be understood about how to facilitate helpful supportive parental behaviors instead of non-beneficial nagging (Hanna & Guthrie, 2001; Kyngas & Rissanen, 2001; Leonard et al., 2005). This research advances understanding in that it provides rich details about the processes and conditions under which conflicts occur. In this study adolescents not only describe the worry about the reactions from their parents but also the effects of parental nagging on their ability to self-manage.

Adolescents' also described steps they took to build trust with their parents and how this was important for them in decreasing parental support and nagging. In this research, it is hypothesized that working with parents and adolescents on communication skills during transition and teaching how to share information about diabetes in a way that is beneficial to both parties may be beneficial in promoting self-care as well as self-esteem. Poor self-esteem is encountered often during these years and interventional work is being done to improve self-esteem and coping to enhance diabetes glycemic control (de Wit et al., 2008; M. Grey, Boland, Davidson, Li, & Tamborlane, 2000; M. Grey et al., 2009). This research

provides concrete examples and offers hypotheses to address self-esteem. Gaining approval from others for doing a good job and good communication has been recognized as important to the adolescent and issues such as how parents handle the loss of control when the adolescent takes on more self-care have also been discussed (Hanna & Guthrie, 2000; Hanna et al., 2003). This research adds to that understanding in that specific behaviors have been identified and conditions under which behaviors occur that contribute to the formulation of interventions to address the issues.

In this study adolescents note that they find managing diabetes hard and overwhelming. They have trouble with burnout and describe burden in detail and relate information on some of their behaviors during this time such poor blood glucose (BG) monitoring, lying about BG numbers, running out of insulin, being lazy and just wanting to take a break. These findings advance the understanding of the reactions that adolescents have when diabetes is overwhelming; it also contributes to the understanding of burn out and the development of strategies to address burn out and the transition of care. These strategies may ultimately result in a slower transition to self-management and the adolescent feeling comfortable seeking more parental help or support in blood glucose management.

Transition of care is also important not only in how the adolescent learns to perform the skills needed to control BG levels but also make complex decisions about insulin adjustments, diet and exercise. In this model adolescent's describe many conditions that are beneficial to them in learning to control their BG and remembering to do their care when needed. It is recognized that transitioning the adolescent to more self-care happens early, as they are able to learn tasks, but it is not known if parents back off prior to adolescent's having the required skills or if adolescent's push parents away in their quest for independence (Davidson, Penney, Muller, & Grey, 2004; Ingerski et al., 2010). This research provides further detailed information about this transition process.

Conclusions and Recommendations

In this study we found that providing support for the adolescent during this time of transition is critical in helping them to complete the tasks necessary for successful DSM. Understanding the strong emotions they feel during this period in taking on care and learning to, not only do the tasks associated with testing blood and giving insulin, but learning all the components that influence glycemic control. Future intervention studies might focus on helping adolescent's and parents set up frequent meetings to discuss care and learn how to communicate about diabetes in a healthy way. Additional work can be done in building coping skills and decreasing stress for adolescent's that allow them to ask for assistance when they are feeling overwhelmed. Grounded theory is a qualitative research method in which the aim is to generate hypotheses for future intervention work. It is important in grounded theory research to carefully describe the sample since that information describes the population for whom the future intervention work is most applicable. Qualitative research such as grounded theory is not intended to be generalized; assuring confirmability and trustworthiness is the priority with qualitative research. Thus, limitations of this work include that these findings may only be applicable to this age group of adolescents and further investigation should be done to see if this paradigm is useful for

other ages of children, adolescents and young adults with T1DM or others with chronic illness. This was also a small sample of adolescents who were primarily female and additional work could be done to assess more males to see if additional information would be obtained.

Recommendations for diabetes educators and providers include: **Individual and group counseling** on coping skills and fostering motivation, and working with parents on how to decrease nagging and provide supportive feedback for adolescents and encouragement for positive reinforcement. Developing programs that assist adolescent's in building trust with their parents, teachers, and nurses around the skills they know allows for more independent care with less supervision and oversight needed. **System and policy changes** that would be beneficial during diabetes transition include: allowing adolescent's to keep supplies needed at school or sports practices so they always have equipment available when needed and working with policy makers to support the mental health needs of adolescents with diabetes in a way that does not make them feel stigmatized or different will be important as they seek help and support.

In summary, this paper focuses on the one phase of normalizing "**Moving the Journey Towards Independence**", which was part of a larger grounded theory study on adolescent perspectives of managing their diabetes. In the larger study and model on normalizing, the major task that the adolescents were working on were identified and the major codes, stages, and related conditions. This model of normalizing includes hypothesis that were generated based on the data and included recommendations for future interventional research to test this model. In this manuscript, one phase or stage in this larger model, "moving the journey towards independence" was the focus. Rich information was provided about this phase of transition to DSM for adolescents that create a deeper understanding of how they learn self-management and barriers they face. This framework is important to advance the science in DSM for adolescents with T1DM hopefully utilizing some of these strategies that were discussed.

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Highlights

- Adolescents increasingly take on responsibility for diabetes self-management.
- Conflict with parents is often high in this stage of self-management.
- Parental nagging was seen as a barrier to a successful transition.
- A trusting parental relationship was important in decreasing conflict.
- Adolescent's often feel diabetes is a burden and experience burnout.

Major Task: Separating from parent and independently managing diabetes

1.0 Taking over care

1.1 Transitioning from parental care

- 1.11 Depending on your parent
- 1.12 Taking over some responsibility gradually
- 1.13 Needing to separate from parent
- 1.14 Assuming full responsibility

1.2 Independently monitoring the blood sugar

- 1.21 Reaching independence in blood sugar monitoring
 - 1.211 Knowing how to use the equipment
 - 1.212 Keeping up with the equipment
 - 1.213 Doing the blood test
 - 1.214 Interpreting the result
 - 1.215 Understanding when blood sugar testing needs to be done
- 1.22 Remembering/forgetting
- 1.23 Creating strategies for remembering
 - 1.231 Keeping a log
 - 1.232 Setting an alarm
 - 1.233 Using mobile device application (app) on iPod touch or phone
 - 1.234 Keeping a schedule
 - 1.235 Using a planner

1.3 Taking over administration of insulin

- 1.31 Determining amount of insulin needed
- 1.32 Giving the insulin
 - 1.321 Knowing how to use the equipment
 - 1.322 Keeping equipment available
 - 1.323 Giving insulin independently
- 1.33 Remembering to give the insulin
- 1.34 Experiencing high blood sugars
 - 1.341 Addressing high blood sugars
- 1.35 Developing strategies to address issues
 - 1.351 Creating a schedule
 - 1.352 Carrying a bag
- 1.36 Seeking assistance from others

1.4 Managing diet independently

- 1.41 Learning to identify foods with carbohydrates
- 1.42 Learning to identify amount of carbohydrate in products
 - 1.421 Using a scale
 - 1.422 Using a measuring cup
 - 1.423 Looking up information in the book
 - 1.424 Eyeballing the food
 - 1.425 Using hand values to estimate amount of carbs
 - 1.426 Memorizing certain foods
 - 1.427 Eating prepackaged foods
- 1.43 Learning to add the total carbohydrates
 - 1.431 Using the calculator
 - 1.432 Creating a log
 - 1.433 Writing amounts on a sheet
- 1.44 Calculating the correct dose of insulin for carbohydrates
 - 1.441 Memorizing the scale (for insulin dosing)

- 1.442 Using the insulin pump
- 1.45 Learning from blood sugar results how food affects body
- 1.46 Learning how to create a balanced diet
 - 1.461 Using the plate plan
 - 1.462 Cooking for yourself
- 1.47 Remembering to take insulin for food
- 1.48 Developing strategies for carb counting
- 1.5 Managing activity independently
 - 1.51 Assessing effects of activity
 - 1.52 Managing insulin dosing for exercise
- 2.0 Experiencing Conflict with Parents
 - 2.1 Struggling for independence
 - 2.11 Worrying about the reaction of parents or others
 - 2.2 Experiencing nagging from parent
 - 2.21 Avoiding testing from nagging
 - 2.22 Wanting to be 18 to not deal with parent nagging
 - 2.23 Understanding parent means well
 - 2.24 Getting used to parent nagging
 - 2.25 Experiencing the parent not nagging
 - 2.3 Building trust.
 - 2.31 Demonstrating care being done
 - 2.32 Affirming care is done
 - 2.33 Having a conversation with parent
 - 2.34 Demonstrating truthfulness in care
 - 2.35 Showing parent you are doing well
- 3.0 Realizing diabetes is hard
 - 3.1 Experiencing Burnout
 - 3.11 Realizing that diabetes is a pain
 - 3.12 Believing diabetes is a burden
 - 3.121 Not checking blood sugars
 - 3.122 Lying about BS numbers
 - 3.123 Running out of insulin
 - 3.124 Acting lazy
 - 3.125 Needing a break
 - 3.13 Experiencing trouble taking care of diabetes
 - 3.2 Juggling diabetes with other responsibilities
 - 3.3 Getting frustrated
 - 3.4 Getting annoyed
 - 3.5 Getting stressed

Figure 1. Moving the Journey towards Independence

Phase 4 from “Normalizing my life with diabetes during adolescence” (Babler & Strickland, 2013)