Review Article

The eight psychological treatment schemas for adolescents diagnosed with type 1 diabetes

Roger W. Apple, Rebecca A. Rausch, Anna N. Holowicki

Division of Pediatric Psychology, Department of Pediatric and Adolescent Medicine, Western Michigan University, Homer Stryker M.D. School of Medicine, Kalamazoo, MI, USA

Contributions: (I) Conception and design: All authors; (II) Administrative support: All authors; (III) Provision of study materials or patients: RW Apple; (IV) Collection and assembly of data: RW Apple; (V) Data analysis and interpretation: RW Apple; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

Correspondence to: Roger W. Apple. Division of Pediatric Psychology, Department of Pediatric and Adolescent Medicine, Western Michigan University, Homer Stryker M.D. School of Medicine, 1000 Oakland Drive, Kalamazoo, MI 49008, USA. Email: roger.apple@med.wmich.edu.

Abstract: The eight psychological treatment schemas for adolescents diagnosed with type 1 diabetes were originally identified from a qualitative study are discussed in this manuscript. The original study sought to describe the factors that influence the diabetes treatment regimen for adolescents diagnosed with type 1 diabetes. The study used a qualitative phenomenological method of inquiry in order to gather data from a first person perspective. Using qualitative methodology is very useful in identifying phenomena that have multiple unknown variables. Most would agree that treatment compliance for adolescents diagnosed with type 1 diabetes is very complex and potentially life threatening making a qualitative approach to help clarify these complexities very useful. The use of qualitative methodology in the original study resulted in multiple layers of analysis and resultant data. Part of the data analysis revealed the following eight psychological treatment schemas: treatment tasks, affective, relationship, personal uniqueness, treatment integration, acceptance, cognition, and intentionality. These treatment schemas were illuminated through data analysis, reduction, and theme development and provide an organized glimpse into the complex phenomenon of how adolescent perceive the factors influencing their treatment. This manuscript provides a brief overview of the eight psychological treatment schemas for adolescents diagnosed with type 1 diabetes and discusses the implications for adolescents and the team of providers.

Keywords: Diabetes; adolescents; treatment; adherence

Received: 22 February 2022; Accepted: 29 December 2022; Published online: 14 February 2023.
doi: 10.21037/pm-22-7
View this article at: https://dx.doi.org/10.21037/pm-22-7

The following eight psychological treatment schemas for adolescents diagnosed with type 1 diabetes were developed as part of a phenomenological qualitative study (1) (*Table 1*). The schemas were developed based on the adolescents' first person account of diabetes treatment adherence, which is somewhat rare in the literature. Below the eight treatment schemas are reviewed and provide an overview to understanding diabetes treatment adherence from adolescents' perspective and followed by implications for providers.

Treatment tasks schema

The "treatment tasks schema" in adolescent diabetes treatment was original coined in a qualitative study looking at adolescents with type 1 diabetes perceptions of treatment adherence (1). The treatment tasks schema is conceptualized by all of the treatment regimen tasks, identified by the adolescents, to maintain normal blood sugar levels and control of their diabetes treatment. These tasks were reported to include: checking blood sugar as

Table 1 The eight psychological treatment schemas (1)

Treatment schema	Description
Treatment tasks	• Checking blood sugar as often as recommended • Counting carbohydrates • Calculating the correct insulin dose • Precision of treatment • Pain and time of insulin injections • Unpleasant taste of glucose tabs • Accessibility and ease of use of equipment and supplies • Physical activity • Healthy diet
Affective	Affective themes • Empathic understanding • Confusion about treatment • Self-esteem • Enjoyment Specific affective characteristics: anger, anxiety/worry, depression, awkwardness, sense of balance in life, feeling blamed or judged by others, feeling comfort or accepted, embarrassment, peer pressure/avoidance—not wanting to appear different, enjoyment, fear, frustration, honesty, hopelessness/helplessness/worthlessness/discouragement, level of motivation, overwhelmed, self-awareness, self-esteem, stress, nuisance
Relationship	The relationship schema describes the social interaction between the adolescent and the following factors: • Family and friends • Medical team • School • Emerging independence
Personal uniqueness	The factors influencing adherence to the diabetes treatment regimen are unique to each adolescent and are often a dynamic inter-relation of the following influences: • Treatment tasks • Environmental • Cultural • Psychological • Social • Unique personal characteristic of each adolescent
Treatment integration	• Integrating diabetes treatment regimen into normal routines of everyday life is essential for maintaining good blood sugar control • Treatment integration was viewed as an essential factor to live a normal life by those doing well with treatment • Treatment integration was almost nonexistent or outright rejected for those struggling with treatment

Table 1 *(continued)*

Table 1 *(continued)*

Treatment schema	Description
Acceptance	• Acceptance is a process that occurs slowly over the course of several years as maturity and independence increase • Acceptance, treatment integration, and level of self-esteem appear to be inter-related • Acceptance tends to increase as adolescents mature and transition into adulthood • Treatment usually declines during the transition into adulthood and then improves
Cognition	Cognition is impacted by many variables including: • Attitude toward treatment • Worldview relating to optimistic or pessimistic outlook • Belief system (faulty or functional beliefs about treatment) • Coping skills • Cognitive ability
Intentionality	Intentionality refers to the adolescents making purposeful (intentional) decisions about their treatment. Examples include: • Purposefully sacrificing treatment • Restricting the amount of insulin to avoid pain, bruising, and lumps • Restricting food intake to reduce the size of insulin injections • Accepting personal responsibility for level of treatment success • Making health their number one priority • Choosing to eat a healthy diet • Choosing to make diabetes treatment and integrated part of life

often as recommended, calculating correct insulin doses, accurately counting carbohydrates (2), and administering the correct dose of insulin at the appropriate times. In qualitative research (1) studying a specific phenomenon, it is helpful to ask about all aspects of treatment (3).

It was noted by the participant in the study (1) that all aspects are critically important in managing diabetes or a negative chain reaction of events could occur. They noted that in addition to the tasks of treatment precision with those tasks is highly important to making those tasks effective and also identified pain, time of injections, and taste of glucose tabs as factors getting in the way of treatment tasks. Adolescents also emphasized factors that help facilitate the treatment tasks are equipment and supplies that are easy to use. Some report insulin pumps make treatment tasks easier while others stated they did not want to be attached to equipment. Interestingly, those doing well with treatment reported exercise and a healthy diet as part of the treatment task schema; those with poor treatment did not.

Affective schema

The "affective schema" was also one of the results of the qualitative study looking at adolescents with type 1 diabetes perceptions of treatment adherence (1). The affective schema refers to a combination of affective themes, emotions, and feelings that emerged from the qualitative analysis and include: empathic understanding, confusion, self-esteem, and enjoyment with empathic understanding (4) repeatedly referring to the medical teams' lack of understanding the individual experience of diabetes or lack of conveying that understanding to the individual adolescent. Confusion occurred across several areas of treatment including many of the areas in the treatment tasks schema causing an overall ambiguity about what makes managing treatment so challenging. Self-esteem (5) was an interesting aspect of this schema as those adolescents

with low levels of self-esteem reported more problems with treatment adherence while those with higher levels of self-esteem reported fewer challenges with treatment adherence. Lastly, enjoyment was highlighted within this schema and the adolescent noted that they would pay better attention to their treatment management if it helped them enjoy something, however, if treatment got in the way of enjoying something they would pay less attention to their treatment.

Relationship schema

The "relationship schema" is another schema developed by the qualitative study mentioned above (1). Family and friends emerged as a tremendous factor in this schema with most adolescents reporting that caring and healthy relationships; particularly those with significant parent involvement (6), are important in most aspects of treatment. Conversely, those with poor relationships, particularly those with parents, report more challenges with treatment. Also, within the family and medical teams dynamics (7) is the adolescent's growing sense of emerging independence. This can cause significant stress between parents who are trying to protect their child and adolescents wanting to manage their treatment on their own. An additional source of stress is that emerging independence can occur at different times between parents and the medical team.

The concept of "relationship" also emerged as quite important in relationship to the medical team so much so that the adolescents in the study reported that if they perceived a "non-caring" relationship with the medical team they would be more likely not to listen to their recommendations.

The school environment also was highlighted in the relationship schema. Unfortunately, the school environment was often reported as a difficult place to effectively manage treatment for most adolescents; however, it was noted that if a good relationship was developed with a staff member (usually office staff), the adolescents reported that they were much more likely to have a positive experience at school. Also, many factors that cause stress (8) can significantly impact treatment. However, if a good relationship did not exist with a school staff member around diabetes treatment the adolescents reported numerous barriers to treatment such as frequent disagreements with teachers, unwanted attention, and inability of school staff to be helpful.

Personal uniqueness schema

Each individual with diabetes is unique and their needs are idiographic. This was reflected within the qualitative study discussed above (1) as evidenced by the "personal uniqueness schema" emerging from the data. This points to the fact that for each adolescent, there was a complex combination of different factors that impacted their treatment regimen and no two individuals were the same when it came to obstacles (or facilitators) to the implementation of their care needs. While this may complicate treatment and support for these individuals, it should not be surprising for those who are involved in their care teams. Multiple treatment schemas arose from the interviews conducted in the qualitative study looking at adolescents with type 1 diabetes perceptions of treatment adherence (1), and while these were found throughout all the interviews for participants, each had their own view, interpretation, or perspective. This is consistent with the idea of egocentrism during adolescence as discussed by David Elkind (9) which commonly concentrated on the personal fable and imaginary audiences. Adolescents both under-differentiate their concerns from those of others, while over-differentiating their feelings as unique, leading to the feeling that others cannot understand how they feel (9).

In a previous qualitative study, children/adolescents with type 1 diabetes and those who care for them expressed that health care professionals who did not have diabetes could not understand what it is like to live with it (10). Participants in the qualitative study looking at diabetes treatment adherence from the perspectives of adolescents (1) also spoke of feeling that their medical team did not understand what it was like to have diabetes and this impacted the way they perceived their treatment interactions. In 2017, 20 patients diagnosed with type 1 diabetes during adolescence were interviewed about their "lived experience". Many participants discussed their experiences (and problems) with health care professionals they worked with, such as not being treated as individuals by health care professionals, having the discussions be with parents instead of the participants, and having trouble discussing non-diabetes related issues during visits (such as sex and smoking) (11). It is clear that the participants from the study where the "personal uniqueness" emerged (1) spoke of many complex factors that contributed to their personal treatment adherence that were not only specific to diabetes tasks, such as psychological, social, and cultural influences.

Treatment integration schema

For adolescents, management of diabetes can be challenging as it necessitates intricate daily tasks to be carried out (12). Living with a chronic illness can impact many areas of an individual's life, and this was reflected in the interviews from the qualitative study looking at adolescents with type 1 diabetes perceptions of treatment adherence (1) resulting in the "treatment integration" schema. Consistently discussed by participants who reported doing well with their treatment recommendations, it appeared that having their diabetes treatment regimen integrated into their day-to-day life and routine was necessary to help maintain recommended blood glucose levels. Indeed, for this age group greater automaticity for diabetes self-management may help to support better management of diabetes on a day to day basis (13). Further, participants interviewed in the qualitative study discussed above (1) felt that integration was required and actually facilitated being healthy and living "normal" lives. This finding was also reflected in interviews with a sample of adolescents with well-controlled type 1 diabetes with the emerging theme, "living with diabetes becomes a way of life." While acknowledging that it was a developmental process that took time, adolescents in this study indicated that diabetes management was routine and part of who they are (14).

Young adults (aged 15–25) may find diabetes to be disruptive to their lives, leading to minimization of diabetes through neglect of self-management (15). Rejection of integration was also seen in the adolescent sample interviewed during a qualitative study examining their perceptions of treatment adherence (1) and reflected the perspective that diabetes care could overtake their lives and overwhelm them. Sadly, this was primarily spoken of by those with poor adherence. This is consistent with a study (16) that found that adolescents and early adults with type 1 diabetes who scored higher on rejection on a measure of illness identity were found to have higher levels of distress related to diabetes and poorer treatment adherence a year later compared to peers with lower rejection scores. The authors described that individuals may reject their medical condition as part of their identity, which can lead to poorer self-care associated with diabetes.

Acceptance schema

Acceptance emerged as a theme from the qualitative study examining adolescents with type 1 diabetes perceptions of treatment adherence (1), which is in line with much of research on diabetes. As the adolescents matured and grew into a greater sense of independence, as did the process of participant's acceptance of diabetes over several years. This process could be viewed as reciprocal, as this increase in acceptance also coincided with reported integration of and adherence to their diabetes treatment regimen. Indeed, the theme of, "Acceptance of lot/life," and perspective that acceptance of diabetes helped with good self-management was seen in a sample of adolescents with well-controlled type 1 diabetes (14). Low levels of acceptance were reportedly associated with poor adherence and low integration of diabetes into day to day life (1). Indeed, avoidant coping in adolescents with type 1 diabetes has been shown to be associated with later diabetes distress, which is then associated with subsequent poorer glycemic control and fewer self-care behaviors (17). Acceptance appeared to be developmental with increased acceptance emerging with maturity and increased age (1). In a sample of adolescents and young adults with type 1 diabetes that were followed over the course of four years, a small increase in acceptance illness identity over time was found (16). Acceptance may develop from the inclusion of health education and addressing emotional issues which may lead to the process of empowerment and compliance with diabetes care recommendations (18).

Cognition schema

Adolescents' cognition schema (thinking) did not emerge from Apple's data until themes were reviewed very late in the analysis process. At this time, cognition was reflected within the sample of adolescents interviewed by Apple (1) as having a significant impact on the adolescents' level of treatment success for their diabetes. Adolescents use cognitive coping strategies to think about their diagnosis and how they understand their treatment process. Cognitive positive coping strategies such as positive refocusing, positive reappraisal, and acceptance can help adolescents with type 1 diabetes have fewer depressive symptoms. Diabetes can help adolescents learn healthy coping skills and identify that taking responsibility for their health results in better treatment outcomes. Cognitive coping strategies have been found to be more effective for successfully adjusting to living with a chronic condition, like type 1 diabetes, compared to behavioral coping strategies because there is no cure for the disease (19).

Maladaptive coping strategies can lead adolescents to

participate in activities such as insulin omission as a way to get out of school or uncomfortable situations (20). Avoidant coping can cause adolescents to increase their diabetes-specific distress which decreases their self-management of treatment success and can impact their glycemic control over time (17). When diagnosed, adolescents experience a range of emotional reactions which often lead to defensive coping mechanisms. Denial can interfere with a patient's ability to monitor their condition, take initiative to seek treatment and manage their illness. Sadness and feelings of loss, such as loss of one's sense of normalcy and freedom are likely to occur. These defense mechanisms may interfere with diabetes self-care and management and likely will impact diabetes treatment, at least at the beginning of diagnosis (21). However, maladaptive coping styles can help adolescents identify an opportunity into intervention before further difficulties ultimately become their treatment outcome (17).

Intentionally schema

The schema of intentionality appeared distinctly different in Apple's results between those with good and poor treatment. Intentionality was defined as adolescents making intentional or purposeful decisions about their treatment (1). Poor treatment may be due to patients feeling overwhelmed by the demands of their self-management such as keeping up with the complicated routine of type 1 diabetes food differentiation and restriction by family or friends (21). Adolescents may be attempting to hold on to a sense of normalcy and by doing so, they reject their illness as a strategy to avoid being emotionally overwhelmed by the demands of their illness. Adolescents in this situation tend to neglect self-care responsibilities by refusing to see their type 1 diabetes as part of their identity. When diabetes interferes with other identity related issues, such as romantic relationships or educational exploration, adolescents may feel like the diagnosis is intruding on all domains of their lives and as a result are usually less satisfied with their lives overall. Ignoring diabetes as part of their identity can lead adolescents to negatively relate to their treatment adherence. Research has shown that rejecting diabetes as part of one's sense of self can reduce adolescents' motivation to adhere to treatment which ultimately leads to worse treatment adherence (22).

Other research has indicated that at first diabetes management is difficult, but as time progresses, adolescents acquire an understanding of how to manage their diabetes. With this better understanding, well-controlled management of type 1 diabetes becomes a habit (14). Interviews from Apple (1) indicated that choosing to make diabetes treatment an integrated part of their lives helped adolescents adhere to their treatment regimen and increased their intention for following through with their treatment. Participants identified that they know if they feel poorly, it is a result of them not following their regimen. A study (14) have identified that adolescents perceived themselves as fortunate to have diabetes because although inescapable, it is manageable. Adolescents understood that managing their diabetes well is beneficial to their futures for avoiding negative health consequences. Patients identified that discipline, maturity, and responsibility are vital in complying with their management protocol. By being intentional in their protocol, adolescents are able to integrate the management of their disease into the nucleus of their daily being. Integrating diabetes into one's identity through acceptance of the disease has been shown to be strongly related to adaptive psychological and diabetes specific functioning (22).

Implications

The implications of the eight psychological treatment schemas for adolescents diagnosed with type 1 diabetes exist for the medical team, the adolescents diagnosed with diabetes, and the adolescents' families. Implications for the medical team offer a comprehensive view of how adolescents perceive diabetes treatment adherence. These eight areas (psychological treatment schemas) for providers to explore with adolescents and work to identify successful treatment strategies. For the adolescents, the eight treatment schemas give providers a structured way in which to discuss the complexities of diabetes treatment. For example, providers can initially focus on all treatment schemas and then focus providing reinforcement for the schemas in which they are doing well and interventions in the schemas in which they are struggling. This could also lead to better understanding for adolescents as well and improved outcomes. Lastly, families can benefit from the eight treatment schemas in a similar way as the adolescents and providers; by gaining an organized way in which to understand their child's experience with the complexities of diabetes treatment which can lead to a shared approach to treatment for all.

Acknowledgments

This article is based on a study first reported in: Apple

RW. Adolescents' experience of the factors influencing their diabetes treatment regimen [dissertation on the internet]. Kalamazoo (MI): Western Michigan University; 2009 Dec. Available from: https://scholarworks.wmich.edu/dissertations/643/?utm_source=scholarworks.wmich.edu%2Fdissertations%2F643&utm_medium=PDF&utm_campaign=PDFCoverPages. A book chapter "Barriers to Care" relating to the barriers and facilitators to care based on the dissertation, which is not as comprehensive as this article and was not discussed specifically as the 8 treatment schemas. The authors would like to acknowledge all of the adolescents diagnosed with type 1 diabetes. These adolescents are the ones who hold the answers to so many questions we still have regarding the psychological aspects of medical treatment.

Funding: None.

Footnote

Provenance and Peer Review: This article was commissioned by the Guest Editors (Berrin Ergun-Longmire, Ethel Clemente and Patricia Vining-Maravolo) for the series "Clinical Pearls in Pediatric Endocrinology and Metabolism" published in *Pediatric Medicine*. The article has undergone external peer review.

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at https://pm.amegroups.com/article/view/10.21037/pm-22-7/coif). The series "Clinical Pearls in Pediatric Endocrinology and Metabolism" was commissioned by the editorial office without any funding or sponsorship. The authors have no other conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

References

1. Apple RW. Adolescents' experience of the factors influencing their diabetes treatment regimen [dissertation on the internet]. Kalamazoo (MI): Western Michigan University; 2009 Dec. Available online: https://scholarworks.wmich.edu/dissertations/643/?utm_source=scholarworks.wmich.edu%2Fdissertations%2F643&utm_medium=PDF&utm_campaign=PDFCoverPages
2. Kamboj MK, Draznin MB. Office management of the adolescent with diabetes mellitus. Prim Care 2006;33:581-602.
3. Alfonsi JE, Choi EEY, Arshad T, et al. Carbohydrate Counting App Using Image Recognition for Youth With Type 1 Diabetes: Pilot Randomized Control Trial. JMIR Mhealth Uhealth 2020;8:e22074.
4. Ayala J, Howe C, Dumser S, et al. Partnerships with providers: reflections from parents of children with type 1 diabetes. West J Nurs Res 2014;36:1238-53.
5. Kenowitz JR, Hoogendoorn CJ, Commissariat PV, et al. Research: Educational and psychological aspects diabetes specific self-esteem, self-care and glycaemic control among adolescents with type 1 diabetes. Diabet Med 2020;37:760-7.
6. Drew LM, Berg C, Wiebe DJ. The mediating role of extreme peer orientation in the relationships between adolescent-parent relationship and diabetes management. J Fam Psychol 2010;24:299-306.
7. Salvy SJ, Ruelas V, Majidi S, et al. Team clinic: Expansion of a multidisciplinary care model for adolescents with type 1 diabetes. Contemp Clin Trials 2020;95:106079.
8. Rechenberg K, Whittemore R, Holland M, et al. General and diabetes-specific stress in adolescents with type 1 diabetes. Diabetes Res Clin Pract 2017;130:1-8.
9. Elkind D. Egocentrism in adolescence. Child Dev 1967;38:1025-34.
10. Lowes L, Eddy D, Channon S, et al. The experience of living with type 1 diabetes and attending clinic from the perception of children, adolescents and carers: analysis of qualitative data from the DEPICTED study. J Pediatr Nurs 2015;30:54-62.
11. King KM, King PJ, Nayar R, et al. Perceptions of Adolescent Patients of the "Lived Experience" of Type 1 Diabetes. Diabetes Spectr. 2017;30:23-35.
12. Chiang JL, Maahs DM, Garvey KC, et al. Type 1 Diabetes in Children and Adolescents: A Position Statement by the American Diabetes Association. Diabetes Care

2018;41:2026-44.
13. Cummings C, Benjamin NE, Prabhu HY, et al. Habit and diabetes self-management in adolescents with type 1 diabetes. Health Psychol 2022;41:13-22.
14. Jonker D, Deacon E, van Rensburg E, et al. Illness perception of adolescents with well-controlled type 1 diabetes mellitus. Health Psychol Open 2018;5:2055102918799968.
15. Ingersgaard MV, Hoeeg D, Willaing I, et al. An exploratory study of how young people experience and perceive living with type 1 diabetes during late adolescence and emerging adulthood. Chronic Illn 2021;17:475-92.
16. Rassart J, Oris L, Prikken S, et al. Illness identity and adjusting to type I diabetes: A four-wave longitudinal study. Health Psychol 2021;40:326-36.
17. Iturralde E, Weissberg-Benchell J, Hood KK. Avoidant coping and diabetes-related distress: Pathways to adolescents' Type 1 diabetes outcomes. Health Psychol 2017;36:236-44.
18. Koller D, Khan N, Barrett S. Pediatric perspectives on diabetes self-care: a process of achieving acceptance. Qual Health Res 2015;25:264-75.
19. Kraaij V, Garnefski N. Cognitive, behavioral and goal adjustment coping and depressive symptoms in young people with diabetes: a search for intervention targets for coping skills training. J Clin Psychol Med Settings 2015;22:45-53.
20. Deeb A, Akle M, Al Ozairi A, et al. Common Issues Seen in Paediatric Diabetes Clinics, Psychological Formulations, and Related Approaches to Management. J Diabetes Res 2018;2018:1684175.
21. Kalra S, Jena BN, Yeravdekar R. Emotional and Psychological Needs of People with Diabetes. Indian J Endocrinol Metab 2018;22:696-704.
22. Oris L, Rassart J, Prikken S, et al. Illness Identity in Adolescents and Emerging Adults With Type 1 Diabetes: Introducing the Illness Identity Questionnaire. Diabetes Care 2016;39:757-63.

doi: 10.21037/pm-22-7
Cite this article as: Apple RW, Rausch RA, Holowicki AN. The eight psychological treatment schemas for adolescents diagnosed with type 1 diabetes. Pediatr Med 2024;7:5.