

Article

Becoming Autonomous and Integrating Insulin Pump Therapy into Life: A Qualitative Analysis of Adolescent Experiences with Type 1 Diabetes Management

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Abstract

Objectives: This study explored perceptions, experiences, and outcomes associated with the choice of insulin therapies among pediatric patients with type 1 diabetes mellitus (T1D). **Methods:** This study included 20 adolescents (8 male and 12 female) with T1D, with a mean age of 15.05 ± 0.91 years, a mean diabetes duration of 5.19 ± 1.2 years, and a mean most recent HbA1c of $7.03 \pm 0.16\%$. Ten of the participants were using an insulin pump ($n = 10$) and another 10 had either refused ($n = 7$) or discontinued ($n = 3$) insulin pump therapy. A qualitative inductive method was employed, using in-depth individual interviews. The interview material was transcribed verbatim and grounded theory was used to analyze the verbal material. **Results:** Four main thematic categories were identified from the narrations that captured both common and divergent perceptions of insulin pump users versus non-users: (1) adjusting to the lifelong diagnosis, (2) exposing diabetes versus hiding it, (3) becoming autonomous and integrating insulin pump therapy into daily life, and (4) worrying over the pump. The third theme, capturing autonomy and integration, surfaced as the core thematic category of this study. **Conclusions:** This grounded theory study revealed that, by using insulin pump therapy, adolescent T1D patients can enhance their autonomy and facilitate the integration of insulin treatment into their life. This study identified processes that inform diabetes education and contribute to ameliorating gaps in the uptake and maintenance of pump therapy in pediatric care.

Keywords: adolescents; experiences; insulin therapy; qualitative method; type 1 diabetes



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1. Introduction

Type 1 diabetes (T1D) is one of most prevalent and most demanding childhood chronic illnesses. T1D management includes dietary control, close glucose monitoring, and administering insulin. Insulin replacement can be administered with multiple daily injections (MDIs) or continuous subcutaneous insulin infusions (CSII) through an insulin pump that is programmed to deliver insulin based on the patient's insulin needs in association with continuous glucose monitoring (CGM)—this is referred to as an automated insulin delivery (AID) system. For children and adolescents with T1D, the AID systems are more effective than multiple insulin injections therapy [1] or standard insulin pump therapy [2]. The treatment choice and its underlying processes differ in each developmental stage: insulin

pump therapy is the treatment of choice for preschool children [3] while, for older children and adolescents, the results are mixed, especially with the rapid changes in newer AID technology. Studies have shown that adolescents have difficulty maintaining insulin pump treatment [4]. Such difficulties may stem from developmental processes, including the desire of adolescents for autonomy and the need for social acceptance [5].

Multiple benefits of insulin pump therapy have been shown, such as improving glycemic outcomes, promoting patient choice, and reducing the burden of T1D [1,2,6]. A recent review found that CSIs lower HbA1c when compared with multiple injections, yet pointed out that the current literature does not provide adequate data and suggested that diabetes technology assessment should include individual and area-level data [6]. The conditions and factors associated with the choice of and satisfaction with insulin pump therapy are poorly studied. There is a need to decipher users' perceptions and to pay attention to the entire lived experience of the young insulin pump user [4,7]. Recent research has focused on the needs and perspectives [6,8] of young insulin pump users and their families, while an older study focused on a young patient's relationship with their physician [9]. Lived experiences can only be captured through individual in-depth interviews, which are complemented by the use of closed-ended questionnaires (e.g., symptoms, regulation, quality of life). Qualitative methods help clinicians answer questions that quantitative research may not be able to answer by "digging deeper" into patients' motivations, perceptions, and expectations regarding T1D [7,10] and technology use in the management of T1D [11,12]. Qualitative studies provide a window into how patients both manage and make meaning of diabetes and are unique in exploring the human perspectives of those affected by diabetes [13]. Further, they can guide clinical recommendations for diabetes management [14].

Our study aimed to evaluate the perceptions and experiences of young patients living with T1D, especially their emotional experiences at the time of diagnosis, with a focus on their choice of therapy for the management of T1D, including CGM and insulin pump therapy. We aimed to shed light on the underlying processes that facilitate treatment choice, adherence and continuity, and the outcome of these choices.

2. Materials and Methods

To explore experiences of living with T1D, we applied a qualitative interpretive grounded theory (GT) methodology [15,16]. We aimed to explore, in depth, the subjective meanings of participants' experiences. The GT methodological approach allowed us to systematically study subjective meanings in an inductive way that involved constructing and analyzing the data throughout the iterative research process. This method enables the researcher to examine each patient's perceptions and experiences, both their cognitive perspective and emotional perspective.

2.1. Participants

Twenty consecutive patients with T1D, aged 11–21 years, were recruited from our diabetes and metabolism outpatient clinic to take part in individual interviews regarding their perceptions on insulin pump utility and experiences of living with an insulin pump for current users or for patients that discontinued use. Originally, 15 participants were recruited and thematic categories were generated. This original analysis suggested a need for additional recruitment to further explore certain themes, until saturation was shown among reoccurring themes, which was achieved after coding 18 participants.

2.2. Inclusion Criteria and Interviewing

The inclusion criteria were age 11–21 years, diagnosis of T1D for at least 6 months, and good use of the Greek language. Exclusion criteria were any developmental disorder or speech disorder. Consecutive patients attending our outpatient clinic on predefined dates of data collection were invited to participate in the interviews. All individuals who were invited to participate agreed to do so, and only one patient deferred the interview to another day due to lack of time. The interviews were conducted in summer 2022, within the premises of the hospital. Each interview was scheduled to last about 15 min, but there were some variations, with several interviews lasting up to 50 min. Mean duration was 13 min. In this study, only the children participated in the interviews, as we focused on the lived experience of living with diabetes and of processes underlying therapy choice. Both the parents and the children consented to participation. Participant demographics and interview data are presented in Table 1. All interviews were conducted by the first author. The interviewer was not involved in the care of the patients. One interview was conducted online, while the other 19 were done in person in a private area adjacent to the clinic.

Table 1. Participants' demographic, therapy choice, and glycemic characteristics.

Participant	Gender	Age	Age at Diagnosis (years)	Diabetes Duration (years)	T1D Therapy Choice	HbA1c (%) Most Recent	HbA1c (%) Yearly Average
P1	Female	11	9	2.00	Pump PLGS + CGM	6.3%	7%
P2	Female	11	7	4.00	Pump PLGS + CGM	7%	6.86%
P3	Male	18	13	3.50	Pump PLGS discontinued	8.3%	8.78%
P4	Female	16	12	4.00	Pump PLGS + CGM	7.1%	7.06%
P5	Male	12	11	0.83	Pump PLGS + CGM	7%	6.85%
P6	Female	21	10	14.00	MDI only (no CGM)	7%	7.3%
P7	Male	14	8	6.00	MDI + CGM	8.07%	8.13%
P8	Female	20	3	18.00	MDI + CGM	6.1%	5.93%
P9	Female	18	16	3.00	MDI + CGM	6.2%	6.47%
P10	Male	17	9	9.00	Pump PLGS + CGM	6.6%	6.8%
P11	Female	18	5	13.00	Pump PLGS + CGM	7.1%	7.33%
P12	Male	12	11	0.75	Pump PLGS + CGM	6.15%	6.2%
P13	Female	13	10	3.00	Pump PLGS + CGM	7.6%	7.76%
P14	Male	16	13	3.00	MDI + CGM	8.5%	7.73%
P15	Female	13	10	3.00	MDI + CGM	6.3%	6.67%
P16	Male	13	11	0.75	Pump PLGS discontinued → MDI	6.5%	6.9%
P17	Female	16	13	4.50	Pump PLGS + CGM	7.7%	7.43%
P18	Male	16	13	2.50	MDI + CGM	7%	7.36%
P19	Female	13	9	4.00	Pump PLGS + CGM	7%	7.47%
P20	Female	13	8	5.00	Pump PLGS discontinued → change to pump with manual combination without automation (patch pump)	7%	7.5%
Mean		15.05	10.05	5.19		7.03%	7.18%

2.3. Research Questions

We focused on the following questions: *How do children with T1D understand their diagnosis? Which processes facilitate the acceptance of the disease, and which make it difficult? Why do some children choose insulin pump therapy and others reject it? What are the lived experiences of adolescents using insulin pump treatment?*

2.4. Ethical Issues and Consent

In the present study, all ethical principles governing research in children were observed and the protocol was approved by the Hospital Ethics Committee (reference number 9146-10/5/2023). The preservation of anonymity and confidentiality, the use of the results only for scientific reasons, the protection of minor children from any possible harm, and the right

to refuse participation or withdraw from the interview were guaranteed. The participants were informed that the data collected from the interviews will not be used for any purpose other than this study. The pseudonymity of the participants and their personal privacy were fully respected throughout the research and after its completion. The researcher provided all the necessary information to the participants and their parents so that they could consent to their participation.

2.5. Data Collection

A semi-structured interview with open-ended questions was developed to collect data to answer our research questions. The questions were based on the literature, and were enriched with the contribution of the partners of our practice (pediatrician, endocrinologist-diabetologist, nurse). Initially, the questions were piloted and adjusted. The final interview included 17 open-ended questions focused on 3 sections: A. Diagnosis and everyday life with T1D; B. Choice of treatment and history of insulin pump use; C. Routine and satisfaction with treatment choice.

2.6. Qualitative Analysis

The interviews were recorded using a portable device. The vocal material was transcribed verbatim with the aim of preserving each phrase and each word unchanged for analysis. The total verbal material collected was 16,000 words. The analysis of the verbal material was based on the grounded theory methodology [15,16], which allows the researcher to search for and theorize regularities through systematic observation, categorization, and comparison. The analysis started with first-level coding, in which each phrase was coded into one or more thematic concepts. Thereafter, through inductive analysis, we identified themes by using a process of, initially, open coding and then cross-checking, refining and adjusting emergent categories. The next step was selective coding, in which we created thematic categories, with the aim of finding common processes that differentiate or unify the emerging thematic categories. Constant comparison was used at all stages of analysis to narrow down similarities and differences. Data were then compared within and between interviews. As data collection and analysis continued, emergent codes were compared with codes of earlier interviews to check for patterns and saturation. Two researchers (first and fourth author) were involved through all coding steps and procedures to ensure confirmability and reflexivity.

2.7. Quantitative Analysis

To test whether demographic data were normally distributed, Shapiro–Wilk test was performed. All variables, except diabetes duration, were normally distributed. Demographic variables and glycemic patients' characteristics were compared between the two groups (group a: pump users, group b: MDI) using one-factor ANOVA. Results are reported in Table 2 as mean $\pm$ standard error (SE). Fischer's exact test was used for comparison of categorical variables. All statistical analyses were performed with the Statistical 8 software (Statsoft, Tulsa, OK, USA). Statistical significance was set at $p < 0.05$.

Table 2. Demographic characteristics of study participants.

Variables	Total (n = 20)	Insulin Pump (n = 13)	Multiple Daily Injections (n = 7)
Age	15.05 $\pm$ 0.91	14.08 $\pm$ 0.71	16.86 $\pm$ 1.12 *
Age at diagnosis	10.05 $\pm$ 0.67	9.85 $\pm$ 0.65	10.43 $\pm$ 1.59
Diabetes duration (yrs)	5.19 $\pm$ 1.2	4.17 $\pm$ 0.95	7.07 $\pm$ 2.13
Most recent HbA1c (%)	7.03 $\pm$ 0.16	7.03 $\pm$ 0.16	7.02 $\pm$ 0.36

Table 2. Cont.

Variables	Total (n = 20)	Insulin Pump (n = 13)	Multiple Daily Injections (n = 7)
Yearly average HbA1c (%)	7.18 ± 0.15	7.23 ± 0.17	7.08 ± 0.29
Socioeconomic status	6.95 ± 0.36	7.15 ± 0.42	6.57 ± 0.69

Note. * $p < 0.05$.

3. Results

Of the 20 children and adolescents who were interviewed, 10 had chosen insulin pump therapy, namely pump therapy with the low glucose suspend feature (PLGS; $n = 10$), while the remaining 10 had either rejected pump therapy ($n = 7$) or had tried pump therapy but discontinued its use ($n = 3$). Table 1 shows, in detail, the demographic and glycemic characteristics of the study population. The patients' mean age was 15.05 ± 0.91 years, the mean diabetes duration was 5.19 ± 1.2 years, the mean yearly HbA1c was $7.18 \pm 0.15\%$, and the mean most recent HbA1c was $7.03 \pm 0.16\%$. When comparing the insulin pump users with the multiple daily injections (MDIs) users in terms of their demographic and glycemic characteristics (Table 2), no difference in terms of diabetes duration, age at diabetes diagnosis, or glycemic control was observed. However, the patients using the pump were significantly younger than those using an MDI regimen.

The thematic concepts that emerged from the first level of coding were compared and consolidated into 22 thematic categories, with the aim of identifying processes that differentiate or unify the children's experiences with living with T1D and with their choice of therapy. Of these thematic categories, four overarching categories emerged as pivotal (Table 3) and are presented here below in detail, along with the verbatim quotes that substantiate them.

Table 3. Central thematic categories and subcategories per treatment group.

Thematic Categories	Subcategories and Relevant Concepts per Treatment Group	
	Insulin Pump Users' Group $n = 10$	Multiple Injections Group $n = 10$ (Refused or Discontinued Pump)
1. Adjusting to the lifelong diagnosis	DIAGNOSIS INITIAL SHOCK AND COPING Initial shock at diagnosis, followed by support and coping P1, P2, P5 Diabetes "not serious" P2, P5, P10, P11 Parental support P10, P11 Parental guidance P1, P2, P11 Nutrition gradual normalization P12	DIAGNOSIS INITIAL SHOCK AND COPING Diagnosis with emergency transport understood as "catastrophe" P16 Shock of very abrupt diagnosis P6, P8, P9, P20 Early illness severity perception P6, P9, P16, P20 Delayed diagnosis distress P6, P9 Parental overt stress reactions P7, P16, P20 Readiness and sibling support P18 Sense of dietary restriction P6, P8, P9
2. Exposing or Hiding diabetes	EXPOSING/SHARING with CGM or PUMP Initial concerns centered around visibility of the device and fear of social stigma P1, P19 No shame at all from start P10 Social exposure "you stop hiding, it is just about exposing oneself" P5, P11 Gradually answering questions P8, P15, P18 Joining groups of diabetics P17, P19 Feeling of normalcy through pump use P2 Acceptance follows opening up P17 Totally accepting P11	HIDING/KEEPING TO ONESELF/RESISTING VISIBILITY Initial shame followed by confidence P9 Avoiding answering questions P3, P6 Feeling different—Social isolation P15, P20 Hiding diabetes P3, P9, P16 Acceptance over time P6, P14, P15 Preference for "discretion" P6, P9 Confidence built over years of experience P6, P8, P9 Opening up with CGM exposure P7, P8, P9, P15

Table 3. Cont.

Thematic Categories	Subcategories and Relevant Concepts per Treatment Group	
	Insulin Pump Users' Group n = 10	Multiple Injections Group n = 10 (Refused or Discontinued Pump)
3. Becoming Autonomous and Integrating insulin treatment into life (core category)	EXPERIENCING EASE, SAFETY, AUTONOMY AND INTEGRATION INTO LIFE Experiencing facilitation/autonomy P1, P2, P4, P5 Experiencing ease of “no piercing in public” P1, Development of confidence through successful management of challenging situations P2 Felt safety and confidence P5, P13 Experiencing integration of device into life “It is as if it is not there” P2, P5 “It is like my belt” P5, P19 “Part of your body” P1, P19 “Just love it” P19 “Feels like a friend” P2 “Like a mobile phone” P2, P4, P19	DESIRING BODILY FREEDOM AND RESISTING RESTRICTION Perceiving pump as burden P3 Perceiving pump as bulky P8 Perceiving permanency of disease P8 Perceiving pump as esthetically displeasing P9 Projecting body contact would not be well tolerated P14 Perceiving pump as reminder of diabetes P16 Experienced bruises and pain from the pump P3, P20 Desiring to feel “free” without a device attached P16 Perceiving pump like a nuisance P8, P16 Perceiving pump as limiting independence P8
4. Worrying over pump therapy	WORRYING OVER DAMAGE OR DETACHMENT of the pump Worrying over pump detachment P1, P13, P17 Worrying over damaging the pump P12, P19 Worrying over beach routine (on/off) P1	WORRYING OVER PROJECTED DAMAGE OR LOSS of the pump Worrying over pump cords getting tangled in sports P14, P20 Fearing loss or damage of pump P3, P7, P14 Worrying over beach routine (taking on/off) P20

3.1. Adjusting to the Lifelong Diagnosis

The narratives about their journey from T1D onset to the present began with the adolescents' initial memories of their diagnosis and hospitalization. The most prevalent theme that emerged was that the diagnosis came unexpected, spurring shock and fear. The permanency of the disease and the negotiation of multiple daily injections was described as being particularly challenging

“At that time [diagnosis], I was in shock and started crying. At first, I was not cool at all, it really got to me.” (P9)

“I knew I had a condition that would never go away. I was worried because this [diabetes] would never go away and I didn't know how to deal with it.” (P20)

The initial understanding of the diagnosis and the initial perception of the disease, differing in severity, were described vividly, and the physicians' communication and explanation of the diagnosis was an important part of this process, being shown in the narrations to play a key role

“I was really shocked when I heard I had diabetes because of my young age and because I knew nothing about diabetes, and because never before had I been in hospital. But thereafter I did well with the help of the nurses and my relatives. Ok this was not what I expected, but it seemed that we could all get used to it.” (P5)

“I had no idea what T1D was and wanted to learn all about it. The doctors explained to us at the hospital what diabetes was all about. I understood that it was nothing much, and would be just fine in my everyday life.” (P2)

As shown in the above two narrations, the adolescents' understanding was rather benign, not focusing on the severity of the disease or permanency of the disease. Most of the participants' narrations contained a more nuanced perception, such as that of P5, an adolescent boy who was diagnosed a year ago and seemed to cope well. On the contrary, a 12-year-old boy (P16) who was rushed to the hospital from a Greek island by emergency air

transport narrated his understanding of the diagnosis as a catastrophe, and remembered thinking “life was going to be ruined”.

“I don’t remember much. I knew I was going to have a problem and I was scared about it. I didn’t know what it was. I thought my life was going to be ruined.” (P16)

During the first days/weeks, in addition to the physicians, family played a key role. In most narrations, family-wide stress was salient during the diagnosis and the physicians’ communication of the diagnosis to the families. Some parents were described as having intense stress reactions. One girl vividly described her parents being “panicked” after they heard about the diagnosis

“I saw my dad and mom crying and that frightened me. That is when my mom took up crochet, to help herself forget. I remember my dad feeding me and my sister kept calling because she was worried sick I was upset seeing them my parents cry, and of course I was in pain from the IV.” (P20)

Physicians’ explanations during the communication of the diagnosis and parental stress responses were both defining processes in the shock experienced by children during their diagnosis, shaping the initial perception of diabetes and the subsequent adjustment process. These processes were unilaterally shown across the narrations, with no defining differences being shown between the two groups (pump users vs refusers) in their adjustment phase.

3.2. Exposing or Hiding Diabetes: “Opening Up” Versus “Hiding It”

A particularly important process after the diagnosis of T1D was the socialization of diabetes: the process of “opening up” to family and friends, communicating the condition, sharing routines, and answering questions. The narrations revealed that some children preferred to hide the diagnosis by avoiding questions or concealing routines. There was clear variability across the groups (pump versus non-pump users) in how open participants were to sharing information, as in the following adolescent pump users

“I’m not ashamed to say that I have diabetes and to explain about the pump that controls insulin. I don’t remember having difficulty with that. In general, the pump has not bothered me at all.” (P10)

“At first, some kids teased me and I was upset. At some point I said to myself this is not going to change so I have to like it.” (P19)

As in the previous narrations, after initially experiencing shock and awkwardness or shame, some participants described gradually exposing themselves, either by self-disclosing their condition or exposing diabetes routines. Interestingly, social exposure was described by participants who used CGM but did not opt for the pump: they originally experienced shame and social anxiety, but thereafter described exposing their CGM device. This exposure was expressed as facilitating “opening up”, reducing social anxiety and shyness, and allowing the participant to become more accepting of T1D.

“The CGM has really helped me psychologically to open up about diabetes. Now I’m much more comfortable when people ask. I used to hide that I had diabetes. Basically, with using the CGM I made the decision to show diabetes. It’s an exposure.” (P8)

“At first, I had this issue where I was ashamed to say that I have diabetes, and especially when people would ask why I needed injections. I got over it, definitely became less insecure when I got the CGM. Doing a scan is less weird. But with the pump I am worried that people will see me. Especially in the summer with the swimsuit the pump will be ugly aesthetically. I am anxious to be seen, there is definitely stress.” (P9)

As explicitly described by the last quotes, CGM exposure minimizes insecurity and social shame. Yet, both P8 and P9 refused the pump. In some narrations, like that of P9, the contrast in perception between CGM and the pump is especially insightful, showing how pump visibility, esthetics, and social acceptance are defining factors in treatment choices, especially for adolescent girls. Similarly concerned but more avoidant, P6, a mature adolescent who has had T1D for a decade and has rejected both the pump and CGM to avoid raising questions, strongly expressed the need to hide diabetes as the main reason preventing her from using any diabetes technology.

“I just did not want it to show. I do not want people to feel sorry for me. People just do not need to know about diabetes. Just my close friends.” (P6)

Hand in hand with the perception that “people just don’t need to know” came hiding and rejection of the technology, which in turn may have perpetuated negative emotionality and concerns such as others feeling sorry for them. Overall, the narrations revealed that non-pump users often expressed resistance to making their condition “visible”, that some viewed the pump as making diabetes more “obvious” and central to their identity, that and some viewed the device as a reminder of illness. On the contrary, pump users, through social exposure, advanced the acceptance process. Interestingly, CGM was a means of partial social exposure for some adolescents, but was differentiated from pump use.

3.3. Becoming Autonomous and Integrating Insulin Pump Therapy into Daily Life

Depending on their age and perceived experience in managing diabetes, the participants described different degrees of autonomy in managing diabetes. Most younger participants’ narratives made frequent reference of the parental role in managing T1D. The participants using an insulin pump unanimously described gaining a sense of *autonomy and agency* in respect to diabetes regimen routines, which was described as empowering them in overcoming daily burdens and restrictions and relying less on their parents.

“Since I got the pump, my mom doesn’t come to school every day to give me insulin injections. I prefer it this way because she used to interrupt me from classes and tests.” (P1)

“From the age of 10 I started doing everything by myself. Completely by myself. Even handling high glucose levels. I feel much better now with the pump. I feel just fine about my diabetes.” (P2)

“When I’m out I don’t have to take out needles and pierce myself. I just press a button and it’s done.” (P4)

As exemplified by P4, most adolescent pump users felt especially autonomous during social activities/outings because they were not forced to interrupt their outings with the hassle of injections. In addition to autonomy, a feeling of “*confidence and safety*” was described, which was linked to agency. Similarly, another adolescent pump user voiced a sense of safety described as “*peace of mind*”, which in both cases was linked to minimizing hypoglycemic episodes

“With the pump my hands are no longer tied. I feel more confident that if I go out and eat something greasy, the pump will cover for me. Before the pump I sometimes forgot the pen. Whereas now I am sure the pump will cover for me. The feeling is confidence and safety.” (P5)

“The positive thing is that I don’t have as many hypoglycemia, it helps me, it alerts me. One time at school I had hypoglycemia but had not realized it. Yet, the pump went off and alerted me. I am lucky I was wearing the pump and the alarm went off, otherwise I would have had hypoglycemia.” (P13)

In line with gaining autonomy, an improved ability to participate in activities, better management during school, and less disruption for insulin administration, the pump was described as becoming essential: an integral part of daily life, “as a part of your life, part of your body”—an in vivo code of two participants

“The pump is all good. I can’t say anything else. It’s in my life now, I can’t imagine what it would be like without it. It becomes a part of your life, a part of your body basically.” (P11)

“The pump is a part of my daily life, my life, and I don’t think I could ever take it off. I cannot part with it because it has helped me a lot, I’m used to having it on me. I like it very much.” (P13)

Interestingly, the previous two quotes capture a very similar experience of seamless integration of insulin pump therapy, yet differ in the age of pump adoption. Insight on early-age adoption and long-term pump use was provided by P11: this narration belongs to a girl who was diagnosed in early childhood and adopted the pump soon thereafter, which makes her narrative a good example how early adoption can lead to technology being viewed as a natural extension of one’s self. Distinctly, the narration of P13 provides valuable insights into successful pump adaptation in early adolescence, with emphasis on the device becoming an essential part of life, despite occasional technical challenges. This case shows how successful integration can lead to strong device attachment and preference, despite adolescents’ increased hesitations regarding their social context.

This theme was the richest theme, providing unique insight into processes underpinning insulin pump treatment choice, maintenance, and outcome, and was differentiated as a central theme of our findings.

3.4. Worrying over Pump Therapy

Five of the participants who used the pump, in addition to the convenience that they experienced, reported *worrying* over pump use: namely, worries over technical difficulties or over damage or loss of the device. Fear of damage or loss of the device was the most common worry, being expressed by four children using the pump. The fear of pump damage appeared to be based on a belief that the pump is fragile and that any damage could lead to dysregulation of blood sugar levels.

“If I fall down, I don’t know what would happen to the pump. A damage would be done, to the machine or to the abdomen. If the pump were damaged then I would have no insulin and it would be all much worse. I will have higher glucose.” (P12)

“I didn’t go out much because I was afraid of experiencing a problem. And at school I was a little aloof because I was afraid that my pump would break.” (P19)

Moreover, five of the children using a pump described experiencing worry and/or fear of potential or real (experienced) *technical* problems. Actual technical difficulties were reported by two children and these were mentioned on the first days of use. Interestingly, such difficulties were reported by children from families that appeared to have limited experience with technology—as one girl described, “we know nothing about technology”.

“Once the shell (CGM) disconnected and we didn’t have a spare part. The pump seemed to be malfunctioning. I was scared at first. We had no more spares and I would have to go so many hours without the pump.” (P1)

The worries reported by children who had discontinued using the pump or who had rejected it were different than those who were currently using it. One girl who discontinued pump use described difficulties during gymnastics practice. For her, the main fear was pump cords being tangled with gymnastics equipment, and she also feared hurting herself

or breaking the device. Similarly, another girl who was an athlete rejected the pump over perceived difficulties during gym practice.

“I used the pump during gymnastics and many times the clip would come off or brake off or the pump cords got tangled. Even my headphones got tangled in the pump. I was also afraid of hurting myself because I had at times hit myself and it gave me a lot of bruises.” (P20)

“I realized that I don’t want to have anything on me. At the moment I don’t want to have anything on me. In sports it will be difficult to have it on me. I want to be free, not afraid of breaking it.” (P14)

“I liked the idea that the pump would give me insulin and I could eat a little more. But when I tried it bothered me and made me feel like I carry a disease on me and it won’t go away. And I had to watch it all the time.” (P16)

The last narration reveals the mixed feelings of a boy who discontinued use. His expectation of facilitation was not met. On the contrary he narrated that his feeling of intrusion was a reminder of this disease. Overall, pump users developed a “partnership” relationship with their device, while non-pump users often viewed the technology as an intrusion rather than aid.

4. Discussion

This qualitative grounded theory study investigated adolescents’ experiences of diabetes management among outpatients with type 1 diabetes, with focus on choice of diabetes technology. Twenty participants with diabetes shared, in an open-ended way, their journey with diabetes, including the first shock of diagnosis; the resulting stress in the context of personal and familial reactions; various modes of “opening up” and socialization of diabetes or “hiding” it; choosing or refusing technology; reaching various levels of autonomy and integration of insulin treatment into life; and worrying over their condition and chosen therapy. Very few studies have captured T1D trajectories in an open-ended way that allows for beliefs and emotions to surface. Our analysis captured four pivotal themes that were salient in the narrations and that emerged as differentiating the experiences and perceptions of adolescents that were using pump therapy and those that had rejected it or discontinued pump therapy. The richest theme and central theme of gaining autonomy and integration of treatment into life captures the emotional journey of pump adoption, particularly the transition from fear to autonomy and, finally, to the integration of treatment into life.

The first theme that emerged captures the *shock and stress of diagnosis*, which was evidenced for all participants, but the shock was particularly intense for children with a delayed diagnosis or urgent transport, children who perceived the disease as severe based on how they understood the words of physicians, and children whose parents had overt stress reactions. The greater that impact that a young person perceives diabetes to have on his or her life, the more distress he/she subsequently experiences. In adolescence, personal model beliefs/illness beliefs have been shown to predict both anxiety and dietary-self-care, thereby determining diabetes outcomes [17]. The physicians who are the first to diagnose diabetes should be mindful in how the new diagnosis is communicated to parents and patients. The communication of the diagnosis is remembered positively when the diagnosis was explained gradually, and physicians emphasized that the patient could have a “normal life” and that the treatment was “easy”. Also described as helpful was when patients’ feelings were addressed upon hearing the news [9]. Other qualitative studies have suggested that the unexpected nature of the diagnosis is a significant burden for both children and their families, with parents negotiating fears of diabetes impacting their children’s development [18,19]. Moreover, other factors, such as genetic and environmental

factors, may also predispose children to intense stress responses and/or may reduce their resilience to stressors. It has been shown that children with T1D experience stressful conditions with significantly increased frequency compared to controls, especially during the 2 years prior to their diagnosis of T1D, which may contribute to the development of T1D [20]. The shock of diabetes diagnosis may lead to the development of depression, which could result in difficulty in coping with treatment demands and choices [21]. Usually, the pump is offered 1–2 months after T1D diagnosis, in order to facilitate diabetes management and relieve patients and families from the burden of diabetes. However, families suffering from post-diagnosis stress may not be able to accept these treatment changes.

Socially *exposing* T1D versus hiding surfaced as a pivotal concern in the narrations of adolescents with T1D. The social exposure of a CGM device and/or the insulin pump seems to promote acceptance and reduces feelings of shame. The narrations revealed that, at diagnosis, most children experienced shame and social anxiety stemming from T1D routines, yet the participants using technology explicitly described that the pump and CGM devices socially exposed them, which in turn led to habituation, less social anxiety, and more personal acceptance. It seems that socialization of diabetes starts in the first days after diagnosis and is initiated by the family, for example in how they communicate the diagnosis with family members and friends. As seen in clinical practice, some families are more private and talk less about the diagnosis, or even at first hide the diagnosis from family and friends, fearing stigma. Accordingly, we need to consider the possibility that families that are more technology-oriented may also be more open socially. Concealing diabetes can even be dangerous, for example in cases of hypoglycemic episodes, the treatment of which depends on the help of those around the T1D patient. To address concealment, a recent study suggested allowing self-care activities in the child's classroom, a strategy which normalizes diabetes and its care, enhances the child's and teacher's confidence, and facilitates acceptance of diabetes by peers, along with promoting greater community awareness [22]. Concealment, and the resulting vigilance associated with social avoidance, may be associated with chronic stress [9], since avoidance maintains shame and inhibits normalization and personal acceptance. This is important to address early in diagnosis since the socialization process is an important part of the adjustment process, and any chronic illness requires an ongoing adjustment and a modified self-image [23]. Facilitating the sharing of one's diagnosis can be a critical part of the initial psychoeducation training, including teaching parents to enhance exposure and facilitate normalization and acceptance.

The sense of *autonomy, safety, and agency* surfaced as an important psychosocial experience primarily for adolescents who were pump users. The theme of building independence and integrating the pump into daily life provides valuable insight into the emotional journey of pump adoption, particularly the transition from fear to autonomy and agency. The strive for autonomy is both a global human desire and an adolescent developmental task. Specifically, for adolescents with T1D, gaining a sense of autonomy is extremely important psychosocially and developmentally [5]. In addition to the immediate benefit of better regimen adherence, it has been well documented that, when patients gain a sense of autonomy, they feel more competent and better able to follow their daily regimen and attain health goals [24,25]. A study with adolescents with T1D suggested that metabolic control in adolescence is best targeted by focusing on diabetes self-management and on how parents transfer diabetes management tasks [26]. Similarly, a qualitative descriptive study found that all components of autonomy development (cognitive, behavioral, and emotional) were similar in healthy adolescents and adolescents with diabetes, but that the group with diabetes was more developed in terms of recreational activities and self-care [27]. Autonomy support has been associated with increased perceived competence, and care providers' communication styles, enhancing perceived competence through au-

tonomy support, may contribute positively [28]. Along the lines of autonomy building is the notion of *a sense of control* over diabetes, which is a central theme among youth with T1D [12] and positively associated with metabolic control. A high internal locus of control has been associated with better glycemic control in adults with T1D who use insulin pump technology, which suggests that psychological factors such as self-efficacy may be linked with better well-being and improved glycemic control among pump users [29]. Along these lines, our finding that pump users were significantly younger than MDI users may indicate that some patients who reject the pump treatment may be older adolescents who have had T1D for many years and, over the years, have gained experience and established adequate glycemic control and ensuing self-efficacy in the management of T1D without the use of technology. It is important to note that, in Greece, pump use is fully funded by the national health system for all T1D patients. On the other hand, children who were diagnosed in early childhood (circa 2000–2010) did not initially have the government funding to opt for pump therapy. This is reflected in the fact that participants using the pump were significantly younger than those using the MDI regimen. Importantly, this central theme of gaining autonomy and agency culminated in the notion of pump integration into life, with some participants describing seamless integration of insulin pump treatment into their daily life. Accordingly, the metaphorical descriptions of the device as “part of the body, part of life” show how insulin pump treatment can become integrated into personal identity. These experiences demonstrate how initial technical and social challenges can be overcome through a combination of education, peer communication, and developmental maturity.

Worrying over the pump surfaced as a prevailing emotional response described by both users and non-users. Interestingly, users worried less than non-users. Namely, users described contained technical worries during the first days of use, while worries of detachment or misuse were primarily voiced by younger users and athletes. This suggests that pump users feel confident and well adapted in use of technology. On the contrary, non-users described broader worries and preconceptions that were centered around social acceptance and bodily disturbance of the pump. It is important here to remember that worry is part of living with diabetes and that some of the worry projected onto the pump may be a broader worry over disease management. This worrying has been previously described under the notion of *diabetes distress*, which refers to the emotional burden, stress, and worry associated with the demands of managing T1D [30]. Therefore, worrying expressed by our participants may be more broadly relevant to T1D management but, under the context of the interview, was elaborated in conjunction with pump use. All participants described worrying over multiple daily injections in the period prior to commencing pump use, yet worrying mentioned under this theme was voiced alongside the benefits and conveniences of pump use; thus, it was more contained and framed within the broader challenge of managing diabetes. Themes of worries and control have similarly surfaced as central to young pump users’ everyday life with diabetes, which is often characterized by uncertainty and coping [12]. Similarly, previous research has shown that pump users reported greater flexibility and feeling more in control, experiencing less worry and reduced hypoglycemia avoidance behaviors [31].

Strengths and Limitations

In this study, we used in-depth interviews, which are most appropriate to obtain open perceptions and personal experiences. An additional strength of the interview method is its flexibility in using prompts and follow-up questions. Our selection of participants showed variety in their age, diabetes duration, and social background. Moreover, there might have been selection bias in regards to technology affinity. Limitations: Glycaemia is very well controlled in this group and may not be typical of T1D adolescents. The findings are not to

be generalized because the grounded theory is a substantive theory; thus, it is specific to an outpatient unit of particular characteristics, and not universally applicable.

5. Conclusions

This grounded theory study sheds light on the intricacies underlying insulin treatment choices for adolescents with T1D. The rich narrations of 20 adolescents with T1D revealed that pump users were more willing to expose T1D socially and thereby gained a sense of *autonomy* in T1D management, which enabled better integration of insulin treatment into their life. Importantly, pump users experienced more agency over disease management and less worry, especially over hypoglycemic episodes. Differentially, pump refusers were less willing to expose themselves socially, hiding their diagnosis while worrying over pre-perceived disturbances of the pump.

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Abbreviations

The following abbreviations are used in this manuscript:

T1D	Type 1 diabetes
MDI	Multiple daily injections
CGM	Continuous glucose monitoring
CSII	Continuous subcutaneous insulin infusion
AID	Automated insulin delivery
PLGS	Pump therapy with low glucose suspend feature

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