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REVIEW

# Prevalence of and Reasons for Discontinuation of Continuous Subcutaneous Insulin Infusion in People with Type 1 Diabetes: A Systematic Review

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## Abstract

The introduction of continuous subcutaneous insulin infusion in clinical care has led to more optimal glycemic and quality-of-life outcomes, compared with multiple daily injections (MDI). Despite this, some insulin pump users revert back to MDI. The aim of this review was to include the most recent rates of insulin pump discontinuation among people with type 1 diabetes and to identify reasons for and factors associated with discontinuation. A systematic literature search was conducted using the Embase.com, MEDLINE (via OVID), PsycINFO, and CINAHL databases. Titles and abstracts of eligible publications were screened, and baseline characteristics of the included studies were extracted, as were variables in the context of insulin pump use. Data were synthesized into themes: indications for insulin pump initiation, persons with type 1 diabetes (PWD)-reported reasons for, and factors associated with insulin pump discontinuation. A total of 826 eligible publications were identified and 67 were included. Discontinuation percentages ranged from 0% to 30% (median 7%). The most frequently mentioned reasons for discontinuation were wear-related issues (e.g., device attached to the body, interference with daily activities, discomfort, affected body image). Related factors included hemoglobin A1c (HbA1c) (17%), issues with following treatment recommendations (14%), age (11%), gender (9%), side effects (7%), and comorbidity- and complication-related factors (6%). Despite many developments in insulin pump technology, discontinuation rates and PWD-reported reasons for and factors associated with insulin pump discontinuation in more recent studies were comparable to earlier reviews/meta-analyses. Continuation of insulin pump treatment depends on a knowledgeable and willing health care provider (HCP) team and a close match with PWDs' wishes and needs.

**Keywords:** Type 1 diabetes, Insulin pumps, CSII, Discontinuation, Review.

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## Introduction

INSULIN PUMPS ARE used for continuous subcutaneous insulin infusion (CSII),<sup>1</sup> replacing self-injection with multiple daily injections (MDI).<sup>2</sup> When used appropriately CSII better resembles the physiological insulin delivery compared with MDI. The introduction of CSII in clinical care has led to more optimal glycemic outcomes, compared with MDI.<sup>3,4</sup> Improved glycemic and quality-of-life outcomes due to insulin pump use have yielded reduced complications and decreased mortality.<sup>4-6</sup> However, various studies have shown that only a minority of persons with type 1 diabetes (PWDs<sup>7,8</sup>) achieve the recommended glycemic target levels.<sup>9</sup> This means that many PWDs are still at risk of developing complications, and insulin pump treatment has not reached its full potential in terms of glycemic outcomes.<sup>10-12</sup>

In addition, many PWDs do not yet use an insulin pump. The international SWEET study showed that in pediatric centers of reference <50% of people with T1D are using an insulin pump, ranging from 5% in South America to 80% in North America (Europe: 45%).<sup>13,14</sup> Use in the adult population is significantly lower. Furthermore, despite the more optimal outcomes achieved by insulin pump treatment, some insulin pump users revert back to MDI. Reported discontinuation rates vary widely. Estimates from older meta-analyses and reviews range from 0% to 36%.<sup>15-17</sup> With more widespread use of insulin pumps and improved technology, reported rates still range from 0% to 18%.<sup>18</sup> Understanding the reasons of discontinuation of insulin pump use is therefore becoming increasingly important for successful initiation and continuation of insulin pump treatment.

Many studies on PWDs using insulin pumps have focused on outcomes, that is, glycemic outcomes, hypoglycemia, and quality of life. Only few have looked at the characteristics of PWDs who discontinue pump therapy and the reasons why they do so.<sup>19-22</sup> The role of health care providers (HCPs) should also not be underestimated as it is known that increased shared decision making improves glycemic outcomes and stimulates PWDs to take a more active role in their diabetes management.<sup>23,24</sup>

In this study, we will review the literature to include the most recent rates of insulin pump discontinuation (including sensor-augmented pump treatment and [hybrid] closed-loop systems) and the associated reasons for and factors of discontinuation among people with type 1 diabetes (T1D).

## Materials and Methods

### Search strategy and screening

We conducted a systematic literature search. Searches were performed using the following databases: Embase.com, MEDLINE (via OVID), PsycINFO, and CINAHL. The search terms comprised variations of:

- “type 1 diabetes” (e.g., “diabetes mellitus, type 1,” “type 1 diabetes mellitus,” “T1D,” “T1DM,” “diabetes type 1,” “DT1,” “diabetes mellitus type 1,” “type one diabetes mellitus,” “type one diabetes,” “diabetes type one,” “diabetes mellitus type one,” “juvenile diabetes,” “insulin-dependent diabetes,” “IDD,” “insulin-dependent diabetes mellitus,” “IDDM,” “brittle diabetes”)
- “discontinuation” (e.g., “stop,” “discont\*,” “cease,” “cessation,” “finish\*,” “terminat\*,” “halt\*,” “opt out”)
- “continuous subcutaneous insulin infusion” (e.g., “automated insulin delivery,” “automated insulin dosing,” “AID,” “sensor-augmented pump,” “SAP,” “hybrid closed-loop,” “hybrid closed loop,” “HCL,” “advanced hybrid closed-loop,” “advanced hybrid closed loop”)

See Supplementary Table S1 for more details on the search. Titles and abstracts of eligible publications were independently screened by Pim Dekker and Giesje Nefs based on inclusion and exclusion criteria; disagreements were solved through discussion. Inclusion and exclusion criteria are listed in Table 1. Only observational studies were included, because we were only interested in insulin pump discontinuation in the context of real-world routine care.

TABLE 1. INCLUSION AND EXCLUSION CRITERIA

<i>Inclusion criteria</i>	<i>Exclusion criteria</i>
Journal articles or scientific abstracts	Discontinuation of a specific feature of an insulin pump
English language	Pilot/acceptability studies
Written between 2000 and 2020	Case studies
Switching from insulin pump to MDI	Randomized clinical trials
Studies about people with type 1 diabetes <sup>a</sup>	Discontinuation after temporary use <sup>c</sup>
Mentioned numbers or ratios of people discontinuing insulin pump use <sup>b</sup> and/or mentioned reasons/factors for discontinuing	Temporary discontinuation due to traveling
Only observational studies (quantitative or qualitative)	Discontinuation in the context of an intervention
	Incomplete or unclear information with respect to discontinuation
	Discontinuation in the context of implantable insulin pump or transplantation
	Abstract not available

<sup>a</sup>In case of T1D/T2D combinations, only the numbers about people with T1D were taken into account. In case separate numbers for T1D were not reported, number of the combined sample was only used if people with T2D constituted <5% of the cohort.

<sup>b</sup>Or if these numbers could be calculated.

<sup>c</sup>For example, during pregnancy, during hospital stay.

MDI, multiple daily injections; T1D, type 1 diabetes; T2D, type 2 diabetes.

*Data extraction, synthesis, and analysis*

“PWDs” stands for persons with T1D and/or their parents/guardians. Multiple publications based on the same data set (e.g., in case of registries) were identified as such and all were included. In case of mixed T1D/T2D studies, only the results of people with T1D were taken into account. In case separate results for T1D were not reported, results of the mixed sample was only used if people with T2D constituted <5% of the cohort. Baseline characteristics of the included studies comprised the following variables: author, study design, follow-up time, population description, number of people included in the study, sex/gender, age, diabetes duration, hemoglobin A1c (HbA1c) and hypoglycemia.

The following variables related to insulin pump discontinuation were extracted: indication for insulin pump initiation, duration of insulin pump use, insulin pump details, glucose monitoring method, number and percentage of people discontinuing pump use, age of insulin pump discontinuers, PWD-reported reasons for discontinuation of insulin pump use, and factors associated with discontinuation of insulin pump use. Studies including only insulin pump discontinuers (i.e., no discontinuation rates available) were also included, because they provided valuable information on reasons for discontinuation.

After extraction, data were summarized and where applicable and possible, multiple groups of *n*, mean, and standard deviation were combined into single groups using the StatToDo website.<sup>25</sup> Data were then synthesized into themes for the following variables: indications for insulin pump initiation, PWD-reported reasons for and factors associated with (e.g., data from electronic health records [EHR] data or questionnaires) insulin pump discontinuation. The pooled discontinuation percentage was calculated using a weighted

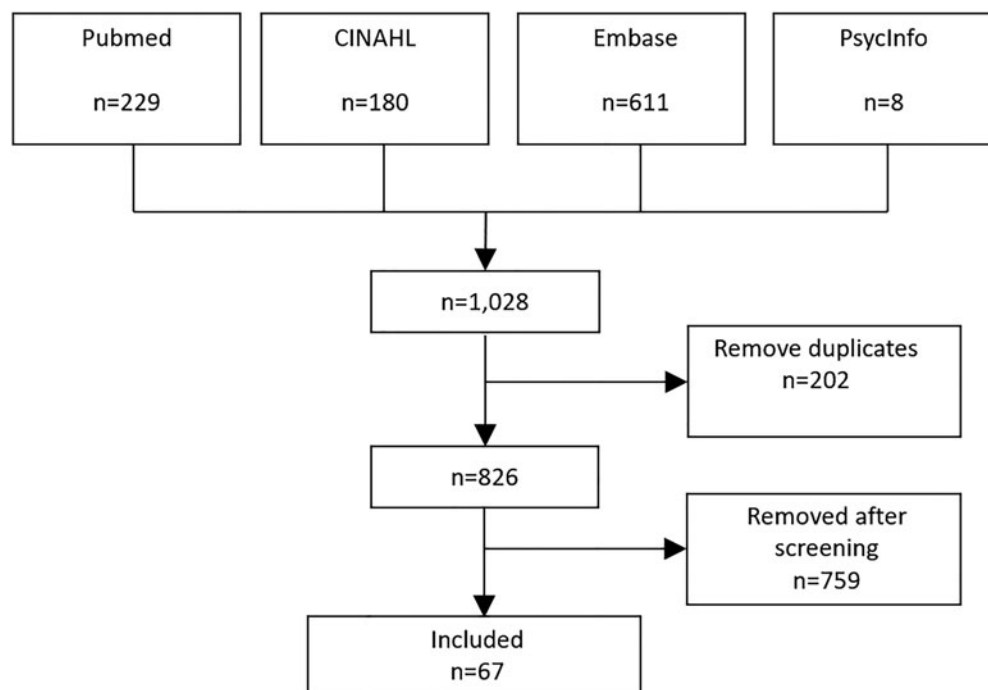
average fixed effects model as well as a REML random effects model, performed in STATA v17 (meta command).

**Results***Included studies*

After excluding duplicates, a total of 826 potentially eligible publications were identified based on title and abstract. A total of 67 publications were included after applying the inclusion and exclusion criteria (Fig. 1, Supplementary Table S2): 42 articles and 25 congress abstracts.<sup>18–22,26–87</sup> Most studies were published between 2010 and 2017. More than half of the included studies were from Europe (Table 2). Most studies were single-center, longitudinal prospective EHR studies, and equally distributed geographically (Table 2). These were followed by multicenter, longitudinal, prospective registry studies, which were most abundant in Europe. Not all the information on the required parameters was mentioned in all publications (Table 3, Supplementary Table S3).

*Data on insulin pump use and discontinuation*

Information on indications for insulin pump treatment initiation was reported in only 20 publications (Table 4). Of 82 reported indications, the top 3 reasons comprised hyperglycemia, hypoglycemia, and lifestyle flexibility. Other indications included (but were not limited to) glycemic variability, complications, pregnancy (wish), needle fear, quality of life, and side effects. The mean/median duration of insulin pump use for pump discontinuers was provided in 17 publications and ranged between 0.3 and 4.8 years (median [interquartile range (IQR)]: 2.1 [1.6–2.6] years) (Table 3).



**FIG. 1.** Flowchart of literature search.

TABLE 2. STUDY DESIGNS AND GEOGRAPHICAL DISTRIBUTION OF STUDIES

Study design	Part of the world			Total n (%)
	USA/Canada <sup>a</sup> N	Europe <sup>b</sup> n	Other <sup>c</sup> n	
Single-center, longitudinal, prospective EHR	10	11	7	28 (41.8)
Multicenter, longitudinal, prospective registry	4	9	0	13 (19.4)
Multicenter, longitudinal, prospective EHR	1	5	3	9 (13.4)
Single-center, cross-sectional EHR	0	7	1	8 (11.9)
Multicenter, cross-sectional registry/survey	3	1	0	4 (6.0)
Multicenter, cross-sectional analysis (total sample) and longitudinal prospective (subsample) registry	0	1	0	1 (1.5)
Multicenter, cross-sectional EHR/survey	0	1	0	1 (1.5)
Qualitative, single-center, cross-sectional interviews	0	1	0	1 (1.5)
Single-center, cross-sectional survey	1	0	0	1 (1.5)
Single-center, longitudinal, retrospective EHR	0	1	0	1 (1.5)
<b>Total, n (%)</b>	<b>19 (28)</b>	<b>37 (55)</b>	<b>11 (17)</b>	<b>67 (100)</b>

<sup>a</sup>Canada (n=4), USA (n=15).

<sup>b</sup>Austria (n=2), Czech Republic (n=1), Finland (n=2), France (n=2), Germany (n=3), Germany/Austria (n=6), Greece (n=3), Ireland (n=2), Italy (n=3), The Netherlands (n=2), Poland (n=2), Scotland (n=1), Spain (n=6), United Kingdom (n=2).

<sup>c</sup>Australia (n=4), Israel (n=2), Japan (n=1), Kuwait (n=3), Russia (n=1).

EHR, electronic health records.

TABLE 3. AVAILABLE INFORMATION ON REVIEW PARAMETERS IN PUBLICATIONS

	Number of publications	%	Median (IQR) unless mentioned otherwise	Range
<b>Baseline characteristics</b>				
Duration follow-up, years	49	73	3.8 (1.0–8.0) <sup>a</sup>	0.5–25
Number of PWDs, n (total)	66	99	141 (58–608)	5–48,716
Sex/gender, % female	46	69	55 (48–60)	10–71
Age, years	50	81	14 (12–28)	0.4–85
Age at onset of diabetes, years	12	18	Mean (SD): 7.4 (2.8)	3.5–14
Diabetes duration, years	42	63	7.0 (5.1–15.0)	0–67
HbA1c	52	78	Mean (SD) <sup>b</sup>	
%			8.3 (0.8)%	7.0–10.8
mmol/mL			67 (9)	53–95
Hypoglycemia	28	42	— <sup>c</sup>	— <sup>c</sup>
<b>Information on insulin pump use and discontinuation</b>				
Indication for pump initiation	20	30	NA	NA
Duration of pump use, years	19	28	2.1 (1.6–2.6) <sup>d</sup>	0.3–4.8
Pump details (type, brand)	19	28	NA	NA
Glucose monitoring method (SMBG, FGM, RT-CGM)	17	25	NA	NA
SAP or HCL	7	10	NA	NA
No. of insulin pump discontinuers, %	64 <sup>f</sup>	96	6.9 (3.0–13.0)	0–30
0–≤12.5 years <sup>g</sup>	16		5.6 (1.2–14.5)	0–25
>12.5–≤20 years <sup>g</sup>	15		7.2 (4.0–11.3)	0–30
>20 years <sup>g</sup>	17		5.0 (3.0–12.9)	0–26
Age of pump discontinuers	18	27	14.9 (13.2–17.2) <sup>e</sup>	11.2–44.5
PWD-reported reasons for discontinuing pump use	34	51	NA	NA
Factors associated with discontinuing pump use	36	54	NA	NA

<sup>a</sup>n=35: information was mentioned in 49 of the included studies, but mean or median was reported in only 35 publications.

<sup>b</sup>n=46: information was mentioned in 52 of the included studies, but mean or median was reported in only 46 publications.

<sup>c</sup>Due to the heterogeneity in descriptions it was not possible to summarize this information quantitatively.

<sup>d</sup>n=17: information was mentioned in 19 of the included studies, but mean or median was reported in only 17 publications, of which one reported the duration for the entire cohort.

<sup>e</sup>n=15: information was mentioned in 18 of the included studies, but mean or median was reported in only 15 publications.

<sup>f</sup>n=3 publications reported on studies including only insulin pump discontinuers. These publications did provide information on reasons for discontinuation.

<sup>g</sup>For n=16 publications age was not specified.

FGM, flash glucose monitoring; HbA1c, hemoglobin A1c; HCL, hybrid closed loop; IQR, interquartile range; NA, not applicable; PWD, people with type 1 diabetes; RT-CGM, real-time continuous glucose monitoring; SAP, sensor-augmented pump; SD, standard deviation; SMBG, self-monitored blood glucose.

TABLE 4. CATEGORIES OF INDICATIONS FOR INSULIN PUMP INITIATION, PWD-REPORTED REASONS FOR, AND FACTORS ASSOCIATED WITH DISCONTINUING INSULIN PUMP USE

<i>Indication for insulin pump initiation</i>			<i>PWD-reported reason for insulin pump discontinuation</i>			<i>Factors associated with insulin pump discontinuation</i>		
	<i>n<sup>a</sup></i>	<i>%</i>		<i>n<sup>a</sup></i>	<i>%</i>		<i>n<sup>a</sup></i>	<i>%</i>
Hyperglycemia	19	23.2	Wear-related issues	40	28.6	HbA1c <sup>b</sup>	17	16.5
Hypoglycemia	18	22.0	Glycemic outcomes	19	13.6	Following of treatment recommendations <sup>c</sup>	14	13.6
Lifestyle flexibility	9	11.0	Discouragement	13	9.3	Age <sup>d</sup>	11	10.7
Glycemic variability	7	8.5	Life intrusions	12	8.6	Sex/gender <sup>e</sup>	9	8.7
Complications	5	6.1	Technical problems	10	7.1	Side effects <sup>f</sup>	7	6.8
Pregnancy (wish)	5	6.3	Work load	9	6.4	Comorbidity <sup>g</sup>	6	5.8
Needle fear	3	3.7	Side effects	8	5.7	Complications <sup>g</sup>	6	5.8
Quality of life	3	3.7	Costs	6	4.3	Socioeconomic factors <sup>h</sup>	5	4.9
Side effects	2	2.4	Reliance	6	4.3	Hyperglycemia	3	2.9
Various	11	13.4	Pregnancy	1	0.7	Diabetes duration <sup>i</sup>	2	1.9
			Various	16	11.4	Duration pump use <sup>j</sup>	2	1.9
						Hypoglycemia	2	1.9
						Cost	1	1
						Various	18	17.5
Total	82	100	Total	140	100	Total	103	100

<sup>a</sup>As described in the Methods section, indications, reason for and factors associated with insulin pump discontinuation were scored. For each of these three main categories, the indications, reasons and factors were then subcategorized, so these *n*-numbers do not represent numbers of publications, but numbers of indications, reasons and factors, respectively, across publications.

<sup>b</sup>Higher HbA1c generally associated with higher discontinuation rates.

<sup>c</sup>Problems following treatment recommendations were generally associated with higher discontinuation rates.

<sup>d</sup>Here, higher age as a factor for higher discontinuation rates mainly means later teens/young adults. Information on middle and higher age groups is largely lacking.

<sup>e</sup>Females generally seem to have higher discontinuation rates.

<sup>f</sup>Skin infections and allergies associated with higher discontinuation rates.

<sup>g</sup>Mainly DKA, but also nephropathy and retinopathy were reported to be positively associated with higher discontinuation rates.

<sup>h</sup>Factors such as lower socioeconomic status, household earnings, and level of education were reported to be associated with higher discontinuation rates.

<sup>i</sup>Two publications provided conflicting results, finding negative and positive associations with discontinuation.

<sup>j</sup>Duration of insulin pump treatment was negatively associated with discontinuation rates.

DKA, diabetic ketoacidosis.

Information on the brand and/or type of insulin pump used was provided in 19 publications. Brands reported were Medtronic (with various Minimed pump models: 506, 507, 508, 512, 620G, 640G, 722, and the VEO), Roche, Omnipod, Animas, Deltec, Insulet, and Disetronic.

Only 17 publications provided information whether or not continuous glucose monitoring (CGM) was used as glucose monitoring method, of which 10 publications reported use of CGM.<sup>32,34,43,51,52,54,64,66,80,87</sup> Of these 10 publications, one reported use of flash glucose monitoring (FGM),<sup>51</sup> six reported the use of SAP treatment,<sup>32–34,43,54,87</sup> and one reported the use of a HCL automated insulin delivery (AID) system (Medtronic 670G).<sup>52</sup> Of the studies reporting discontinuation percentages (or for which these could be calculated) (*n* = 64), the median discontinuation percentage over the studies was 6.9% (IQR: 3.0%–13.0%, range: 0%–30%). The pooled discontinuation percentages of the weighted average fixed effects and REML random effects models were 5.8% (95% confidence interval [CI]: 5.7%–5.9%) and 9.5% (95% CI: 6.1%–12.9%), respectively.

#### *PWD-reported reasons for insulin pump discontinuation*

PWD-reported reasons for discontinuing insulin pump use were provided 140 times in 34 publications (Table 4). By far, the most mentioned reasons (29%) were wear-related issues.

These varied considerably across studies, but main themes of reasons included constantly having a device attached to the body, interference with daily activities (mainly during sports activities and also in summertime: wearing less practical clothes at the beach or while traveling), discomfort, and affected body image. The next most frequently mentioned reasons were related to a lack of improvement in glycemic outcomes (e.g., high glucose values, high HbA1c), or even deterioration (14%). Discouragement issues (e.g., generally disliking the pump, suboptimal following of treatment recommendations, too much freedom) and life intrusions (e.g., visibility of the pump, increased confrontation with diabetes, alarms) each made up 9% of the reasons mentioned for discontinuing pump use.

Seven percent of reasons for discontinuing insulin pump use were due to technical problems with the insulin pump, for example, problems with catheters (e.g., kinks, blockages, and leakage), connection problems, cannula insertion problems, adhesion problems, and faulty or broken equipment. Less frequent reasons for discontinuation included workload (6%), side effects (6%), costs (4%), reliance (4%), and pregnancy (1%).

#### *Factors associated with insulin pump discontinuation*

Factors related to discontinuing insulin pump (i.e., not reported by PWDs, but objectively determined from EHR data) use were provided 103 times in 36 publications

(Table 4). HbA1c was related most frequently (17%) to insulin pump discontinuation. Compared with insulin pump continuers, insulin pump discontinuers often had higher HbA1c before insulin pump start and experienced a lack of improvement, or even deterioration, after insulin pump initiation. Issues with following treatment recommendations (e.g., low motivation, low self-monitoring of blood glucose [SMBG] frequency) made up 14% of the factors related to insulin pump discontinuation. Age was related to discontinuation in 11% of factors. Generally, adolescents and young adults were more likely to discontinue insulin pump use, compared with younger children.

Gender was mentioned in 9% of factors as being associated with insulin pump treatment discontinuation. Females were more likely to discontinue insulin pump use. Side effects (e.g., lipohypertrophy, skin problems, infusion set intolerance) comprised 7% of the factors related to insulin pump discontinuation. Comorbidity- and complication-related factors each comprised 6% of the factors, including mainly mental disorders (e.g., depression, attention deficit hyperactivity disorder [ADHD], eating disorders), and diabetes-related complications (diabetic ketoacidosis [DKA], nephropathy, retinopathy) and thyroid-disease. People with these comorbidities and/or complications were more likely to discontinue insulin pump use. Less frequent reasons for discontinuation included socioeconomic factors (5%: e.g., household earning, level of education of PWD or parent, socioeconomic status), diabetes duration (2%), duration of insulin pump use (2%), hypoglycemia (2%), and cost (1%).

## Discussion

Despite the fact that insulin pumps have led to better glycemic and quality-of-life outcomes, there is still a sizeable proportion of PWDs who discontinue insulin pump use. With the emergence of the most recent AID systems, which yield unprecedented results, it is becoming increasingly important to prevent PWDs from discontinuing use of these systems. Our aim was to gain better understanding of the reasons for and factors associated with insulin pump discontinuation. Despite available literature, discontinuation is often not the main subject of studies, likely due to the relatively small size of this group of PWDs.

In this literature review, we found that rates of discontinuation ranged from 0% to 30%, which is consistent with earlier reviews on this topic.<sup>15,18</sup> Contrary to expectations,<sup>18,33</sup> we did not observe a decrease in discontinuation rates over the years. It remains to be determined if this is due to insufficient data or to persistent issues in the use of insulin pumps. Most studies reported on PWDs in their early teens to early adulthood. This is consistent with findings from Wong et al. who could not analyze discontinuation rates in PWDs >26 years due to insufficient numbers.<sup>22</sup> The extent of glucose excursions and variability are still the most frequently reported indications for insulin pump treatment initiation, similar to a decade ago.<sup>88</sup>

Wear-related issues as reasons for insulin pump discontinuation were mentioned most frequently in the literature, as previously reported in a study by Seereiner et al.<sup>74</sup> Many people who discontinue insulin pump therapy have problems with the device being visible, confronting them with their condition, and the pump not staying attached to the body

properly due to adhesion problems. They also experience decreased lifestyle flexibility due to limitations in, for example, doing sports or traveling (i.e., they are experiencing less rather than more freedom and comfort). Lack of improvement or even deterioration in glycemic outcomes are also frequently mentioned PWD-reported reasons for discontinuation. This is consistent with a previous meta-analysis.<sup>15</sup>

Discouragement-related reasons, for example a general dislike of the insulin pump and less following of treatment recommendations, were also mentioned by PWDs relatively frequently as were reasons related to life intrusions (mainly being confronted with the disease and also with intimacy issues). Next, technical problems were mentioned, which is not consistent with Binek et al. who reported that operating the insulin pumps and technical problems did not pose any problems in their study. This may be explained by the support of caregivers in this pediatric group.<sup>37</sup> Furthermore, technology is rapidly developing: many disadvantages from a few years ago will likely have been solved by now.<sup>89–91</sup> Technological developments and particularly more optimal glycemic outcomes will no doubt help decrease insulin pump discontinuation rates.

HbA1c was found to be the factor which was most frequently associated with insulin pump discontinuation, consistent with the PWD-reported lack of improvement in glycemic outcomes as a reason for discontinuation. Among people who discontinued, HbA1c levels were higher at insulin pump initiation and more discontinuers showed a lack of improvement of HbA1c after initiation. A possible explanation for this is that for a long time in many countries insulin pumps were only reimbursed for PWDs with suboptimal HbA1c, using them as a “last resort.”<sup>92,93</sup> Age was also associated with insulin pump discontinuation as PWDs in their late teens/early adolescence seemed more likely to discontinue insulin pump use.

Although the data were not sufficient to warrant a formal analysis, we did observe that glycemic outcomes as reasons for discontinuation were mentioned more frequently for the 0–12.5 years group than for the 12.5–20 years and >20 years groups. Also, wear-related issues as reasons for discontinuation were mentioned more frequently for the >20 years group, compared with the 0–12.5 years and 12.5–20 years groups. Parental support is very important for children and adolescents with T1D. Young children supported by their parents show more optimal following of treatment recommendation and glycemic outcomes,<sup>18,55</sup> but for older youth, this support gets increasingly hampered due to increasing autonomy during puberty.<sup>30</sup> Glucose management is also becoming increasingly difficult as a result of hormonal changes.<sup>86</sup>

With respect to sex/gender, females appeared to be more likely to discontinue insulin pump use. Adolescent girls tend to be more concerned about their body image than boys.<sup>18</sup> Binek et al. found that after insulin pump discontinuation, girls show improvements in glycemic outcomes, whereas boys show a deterioration, which may relate to differences in diabetes care engagement.<sup>37</sup> Also, Tanenbaum et al. reported that women showed higher insulin pump uptake, despite facing more barriers.<sup>80</sup> A low frequency of SMBG was also related to higher insulin pump discontinuation rates. Possible explanations for this link are that SMBG behavior, bolus behavior, and underdosing of insulin may affect HbA1c and that SMBG behavior is related to psychosocial variables.<sup>94</sup>

Often PWDs decide to discontinue insulin pump treatment due to lifestyle-related reasons, despite improved/improving glycemic outcomes.<sup>18</sup> Indeed, indications like motivation and lifestyle flexibility have been found to be suboptimal predictors for glycemic outcomes.<sup>19,51</sup> A mismatch between expectations of benefits and burdens that both PWDs and HCPs have about insulin pump treatment is likely to play a role.<sup>2,95,96</sup> HCP teams play a very important role in managing these expectations. Assessing expectations together will identify possible barriers to (continued) insulin pump use, which may be addressed for example by training in problem-solving skills,<sup>80</sup> including the family and other support networks.<sup>74</sup> Of course HCPs should be sufficiently knowledgeable about and open to diabetes-related technology, which is not always the case and also becomes increasingly challenging with the current pace of developments.<sup>97</sup>

It is important to see if the PWDs (and their family/supporting network) and their HCPs need additional support in starting with the insulin pump,<sup>30,86</sup> taking into account that HCPs' assumptions about "suitable candidates" for insulin pump treatment (e.g., educated, technology savvy people) may in fact not always be correct.<sup>98,99</sup> At our own treatment center, we notice that the decision to discontinue insulin pump use is often based on advice by the HCP team. In the included studies in our review, it is often unclear if the PWD or the HCP (team) initiated insulin pump discontinuation, but likely a large part of PWDs discontinuing insulin pump treatment due to lack of improvements in glycemic outcomes will do so at the HCP's advice.

Consequently, the often used term "suitability" for insulin pump treatment is a relative one: the same PWD may be more or less "suitable" depending on the availability, skills, and motivation of the HCP team.<sup>100</sup> In other words, the availability of tailored support for PWDs who want to engage in insulin pump treatment is likely to be much more important than their individual, family, and psychological characteristics. There seems to be consensus in the literature that ongoing education, including HCP and device manufacturer support, is one of the most important pillars of "successful" insulin pump treatment, especially for people who are most at risk for discontinuing (mainly adolescents, young adults, and females).<sup>22,37,46,80,94</sup> There are, however, global differences in education.

### *Strengths and limitations*

This systematic review provides an update on prevalence estimates for insulin pump discontinuation. A key strength of this study is that in addition to PWD-mentioned reasons for insulin pump discontinuation, associations between demographic/clinical/psychological factors and insulin pump discontinuation were also assessed. Another strength is the time span of 20 years that this review covers, allowing assessment of changes in insulin pump discontinuation over the years. There also are several limitations to note. First, many of the included studies are pediatric studies, complicating generalization to the whole group of PWDs who discontinue. In this context, it is important that future studies also focus on insulin pump use/discontinuation in the >65 years group since increasing problems with eyesight and manual dexterity may negatively affect insulin pump use.

TABLE 5. RECOMMENDATIONS FOR MINIMIZING THE RISK OF INSULIN PUMP DISCONTINUATION AMONG PEOPLE WITH TYPE 1 DIABETES

1	Explicitly monitor and discuss the working relationship between the PWD and the HCP team. <sup>74</sup>
2	Manage expectations, that is, make PWDs aware of potential issues which they were not aware of, for example, the amount of work required to use the insulin pump, <sup>51</sup> or the impact of having a device attached to the body, especially for many women, <sup>18,67</sup> in other words: the added burden.
3	Peer-to-peer contact may contribute to establishing realistic expectations, <sup>80</sup> provide validation for common burdens, and aid finding practical solutions for some issues.
4	Realize that in this day and age, expectations are also heavily influenced by social media and agents of manufacturers. <sup>64</sup>
5	Realize that certain aspects of insulin pump/sensor treatment, for example alarms, may be regarded positively by some and negatively by others <sup>89,103,104</sup> depending on personal preferences. <sup>94,106</sup>
6	Give PWDs the opportunity to experience a (sensor-augmented) insulin pump system during a short-term trial to facilitate the decision to switch to such a system, <sup>107</sup> as hands on experience may improve trust in technology. <sup>42,108</sup> This may not (yet) be available in every country.
7	Based on HCPs' knowledge of the various devices and taking into account PWDs' preferences and challenges, a treatment plan can be set up which meets both PWDs' and HCPs' (team) goals <sup>58</sup> and which balances the benefits of insulin pump use with its daily burden. <sup>80</sup> This plan should be updated periodically.
8	Because PWDs may need not only medical but also practical and mental support, the HCP team approach should be multidisciplinary (including the availability of a psychologist/social worker, nurse educator, dietician). <sup>21,42,86</sup> For example, wear-related issues have both a practical and a psychological side, each requiring a different approach.
9	Once insulin pump (system) treatment has started, monitor PWDs closely and provide ongoing support and education in insulin pump therapy, especially during the initial months of therapy.
10	Keep PWD and HCP skills and knowledge up-to-date and continuously weigh burdens and benefits of insulin pump use.
11	Support in school is essential for the younger age groups. <sup>46</sup>
12	If there is no improvement in glycemic outcomes 6–12 months after initiating pump treatment, education may be reconsidered to prevent discontinuation. <sup>21</sup>
13	Should PWDs discontinue insulin pump treatment after all, re-education on MDI and frequent follow-up in terms of glycemic outcomes and quality of life are important. Unfortunately the time between discontinuation and the first visit thereafter is all too often quite long. <sup>18</sup>



Second, our study did not include the latest generation hybrid closed-loop AID systems, which may lead PWDs to make different considerations due to good results and experiences with these systems. Having said this, a proportion of PWDs for whom the burdens of having devices attached to the body outweigh the advantages of the new AID systems will remain. Also, these systems are very new, and data on real-world discontinuation rates among users of these advanced systems are largely lacking. Unfortunately, only 7 publications<sup>33,34,43,52,54,87,101</sup> provided information if use of insulin pumps was in combination with glucose sensors, but these publications did not seem to stand out in terms of reasons for discontinuing. Summarizing, it is too early to say what the real-world discontinuation rates among users of these new systems will be.

Third, in this review, more single-center than multicenter studies were included. Shulman et al. have shown large variation in pump use across centers<sup>102</sup> and results of single-center studies very much depend on study population, center- and HCP-level factors, country, and reimbursement arrangements.<sup>17</sup> In particular, cost-related reasons for discontinuing insulin pump/sensor treatment vary between countries due to differences in insurance coverage.<sup>17,80</sup> This complicates identification of universal predictors of insulin pump discontinuation. Fourth, PWDs who were on insulin pump/CGM treatment at the time of the studies, or previously, may have been a selected group of motivated PWDs with knowledge and willingness to perform the necessary work of insulin pump treatment.<sup>59</sup> Fifth, studies used different criteria for participant selection, hampering comparisons across studies.<sup>100</sup>

Sixth, diversity factors such as race and ethnicity were mostly not taken into account, as noted by Tanenbaum et al.<sup>80</sup> This is an important limitation since race and ethnicity have been associated with technology use and treatment outcomes.<sup>105</sup> Finally, many studies included low participant numbers, preventing sufficient statistical power.

## Conclusions and Recommendations

Insulin pump discontinuation rates and PWD-reported reasons for and factors associated with insulin pump discontinuation in more recent studies were comparable with earlier reviews/meta-analyses,<sup>15,16</sup> despite many developments in technology. Possibly certain aspects of technology have not improved sufficiently and/or PWD- and HCP-related factors causing insulin pump discontinuation are technology-independent or go beyond technology (i.e., are not device-specific). Insulin pump therapy is complex, depending not only on the device but also on accessibility in terms of reimbursement, continuous and ongoing education, personal preferences, and ideas of when benefits outweigh burdens (and vice versa), and service and support by a HCP team, family/other social networks and pump manufacturers.<sup>17</sup> Furthermore, factors may be different between countries and even within countries. The decision to start insulin pump treatment should include expectations and attitudes toward devices and technology, the need for better outcomes and wishes from the PWD.

There are no one-size-fits-all criteria. Table 5 provides recommendations toward (setting up) such a dialogue. Of course “successful” insulin pump treatment depends on the

definition of success, which can comprise different combinations of glycemic outcomes and quality of life, but will inherently include a knowledgeable and willing HCP team and a close match with PWDs’ wishes and needs.<sup>100</sup> Finally, it should be noted that, according to these results, the vast majority of PWDs (~95%) continue with insulin pump treatment. This is nothing short of remarkable, seeing that nowadays a much more heterogenous group of PWDs is treated by a much more heterogenous group of HCPs, dealing with more heterogenous clinical problems, compared with highly selected groups of PWDs in specialized centers during the early days of insulin pump treatment.

## Authors’ Contributions

P.D.: conceptualization; writing—original draft (lead); data curation (lead); formal analysis (lead); and writing—review and editing (equal). H.-J.A.: conceptualization and writing—review and editing (equal). T.S.: conceptualization; writing—review and editing (equal). M.d.V.: writing—review and editing (equal). E.B.: writing—review and editing (equal). D.M.: conceptualization and writing—review and editing (equal). G.N.: conceptualization (lead); writing—original draft; data curation; formal analysis; and writing—review and editing (equal).

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## Supplementary Material

Supplementary Table S1  
Supplementary Table S2  
Supplementary Table S3

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