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Survey of Insulin Site Rotation in Youth with Type 1 Diabetes Mellitus

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Abstract

Objective—Injection site rotation is an important component of insulin administration and helpful in preventing lipodystrophy in type 1 diabetes (T1DM). We examined the number of injection/infusion sites (sites) used by youth with T1DM and their perceived barriers to using new sites for insulin.

Methods—Two hundred-one youth with T1DM completed a 24-item survey about site rotation practices and barriers to site rotation during a routine diabetes appointment.

Results—Fifteen percent of youth reported using at least four distinct sites in their rotation plan, while 22% reported using only one site. A negative correlation was found between number of sites used and the number of perceived barriers endorsed by youth on multiple daily injections. Fear of pain was the most common barrier endorsed by youth.

Conclusion—Many youth with T1DM may not adhere to an adequate site rotation plan. Regular assessment of insulin sites and counseling regarding adequate site rotation is needed when managing diabetes in youth. Relaxation and distraction may help to reduce youths' fear of pain when rotating to new insulin sites.

Keywords

Type 1 diabetes; youth; insulin; adherence

INTRODUCTION

Poor adherence to insulin administration is a problem for youth with type 1 diabetes mellitus (Greening, Stoppelbein, Konishi, Jordan, & Moll, 2007; Patino, Sanchez, Eidson, & Delamater, 2005; Stewart, et al., 2003). Survey studies suggest that as many as 50% of youth with type 1 diabetes do not administer insulin according to the recommendations of their treatment team for frequency, dosing, and timing (Greening, et al., 2007; Patino, et al., 2005; Stewart, et al., 2003). Insulin administration is a cornerstone of modern treatment in type 1 diabetes (Silverstein, et al., 2005; Sperling, 1996). Serious health complications or death can result for patients who do not administer insulin or who administer insulin incorrectly (Silverstein, et al., 2005).

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In modern diabetes therapy, there are three main insulin regimens for youth: conventional therapy, multiple daily injections (MDI) and continuous subcutaneous insulin infusion (CSII) (Silverstein, et al., 2005; Sperling, 1996). Youth on conventional therapy use fast-acting and intermediate acting insulins which are injected typically two-three times daily. For youth on a multiple daily injection regimen (MDI), recommendations for insulin management call for mealtime injections of fast-acting insulin to manage blood sugars during the meal and in the post-prandial period and an injection of a long-acting insulin to manage blood glucose levels between meals. Youth on this regimen may administer at least four injections daily. Youth on a continuous subcutaneous insulin infusion regimen (CSII) use an insulin pump to administer insulin through a temporary flexible catheter which is inserted into subcutaneous tissue and worn in rotating sites for 2–3 days (Silverstein, et al., 2005; Sperling, 1996). For all of these regimens, multiple behaviors are involved in effective dosing of insulin. Indeed, a recent review article highlights 40 specific steps involved in effective insulin administration (Coffen & Dahlquist, 2009) as well as specific knowledge, including when and how much insulin to administer and whether to titrate insulin based on activity, blood glucose levels, and/or food effects (Coffen & Dahlquist, 2009). Each step can play an important role in glycemic control and effective insulin management (Coffen & Dahlquist, 2009; Silverstein, et al., 2005). Past literature examining youths' adherence to insulin has generally overlooked their adherence to the process of administering insulin. However, a more detailed examination of how youth regularly administer insulin may yield data useful for patient education and intervention development. For example, one behavior that has received limited attention in the literature is youths' use of multiple site rotation for delivering insulin (Becker, 1998). For patients with type 1 diabetes, eight areas have been identified for insulin administration. These areas include the right and left sides of patient's abdomen, arms, buttocks, and thighs (Chase, 2006; Sperling, 1996). It is known that injection sites that are overused can become dystrophic which may prevent optimal insulin absorption and lead to increased insulin requirements and/or poor metabolic control (Hofman, et al., 2007; Johansson, et al., 2005; Silverstein, et al., 2005; Sperling, 1996). Thus, it is important for patients to adhere to a rotation plan for insulin administration to prevent lipodystrophy and promote better absorption.

This study examined the number and location of injection/infusion sites (sites) reported by youth with type 1 diabetes and their perceived barriers to site rotation. We applied the Health Belief Model (HBM) as our theoretical framework for examining parents' and youths' adherence to an adequate rotation plan for insulin administration. The HBM assumes that a patients' adherence to a specific health behavior is determined by five factors: 1) perceived susceptibility to illness, 2) perceived severity of consequences, 3) perceived benefits of the health behavior, 4) perceived barriers to adherence to the behavior, and 5) perceived cues to action (Glanz, Rimer, & Marcus Lewis, 2002; Rosenstock, 1974). In our application of the HBM, we expected that youth would be more adherent to an adequate site rotation plan, if they knew the recommendations for site rotation and the perceived benefits of regular rotation (e.g., better glycemic control, absence of lypodystrophy) outweighed the perceived costs of rotation (e.g., pain, awkwardness of using new sites). In our clinic, youth are counseled on site rotation at least annually. Therefore, it was hypothesized that at least 50% of youth in this sample would report an adequate personal rotation plan, characterized by at least four distinct sites. It was also hypothesized that there would be negative correlations between the number of sites reported by youth and the number of perceived barriers reported by youth and their average blood glucose control. Finally, to understand better the youth who report an adequate site rotation plan, the number of sites reported by youth was examined based on parent and child demographic variables. In the absence of a literature base examining insulin administration behaviors in youth with type 1 diabetes, these analyses were exploratory and proposed as a method of understanding who might benefit from a targeted intervention for site rotation.

RESEARCH DESIGN AND METHODS

Population and sample

Participants were parents or youth with type 1 diabetes who attended a pediatric diabetes clinic within a large academic medical center in the Midwestern, United States. The hospital's pediatric diabetes clinic serves approximately 600 youth with type 1 diabetes. Inclusion criteria were: a) a confirmed diagnosis of type 1 diabetes, b) child age between 2 and 17 years, c) time since diagnosis of at least 12 months (to allow for adjustment to diabetes), and d) the presence of at least one primary caregiver (e.g. parent/guardian) at the recruitment appointment. Families were excluded from the study if they were non-English speaking, the child was developmentally delayed, or the parent or child had a diagnosis of severe psychopathology resulting in a psychiatric hospital admission within the last 12 months.

Two hundred and five families were approached for this study. Of these, 201 agreed to participate, for a response rate of 98%. The average age of youth was 11.8 ± 3.4 years and their mean time since diagnosis was 5.9 ± 3.4 years (range= 1.0 to 15.9 years). Youth were nearly evenly divided based on gender (45% male) and insulin regimen (52% MDI; 48% CSII). The majority of youth described themselves as Caucasian (86%). Youth had a mean Hemoglobin A1c (HbA1c) of $8.7 \pm 1.8\%$ (range: 5.5 – >14.0). There was a significant difference in HbA1c reported by youth using MDI versus CSII ($p < 0.01$), with youth on MDI reporting a higher mean HbA1c ($9.0 \pm 2.1\%$) than CSII ($8.3 \pm 1.2\%$). Table 1 provides a summary of demographic characteristics for this sample.

Procedure

This study was approved by the institutional review board with a waiver of documentation of written informed consent. Families who met inclusion criteria were recruited during a routine diabetes appointment to complete a survey. Demographic, but no identifying, information was requested. As part of their clinical care, all patients had their HbA1c level checked during the study appointment. Participants were asked to provide a report of the youth's HbA1c level for the study appointment directly on the survey. Families who completed the survey were compensated with a \$5 gift card to a popular retail store.

Survey data

A survey was designed for this study to assess participants' use of multiple sites for insulin administration. The survey contained 24 items asking participants' about their diabetes history, current diabetes regimen for insulin administration, and common barriers to and perceptions regarding the use of multiple sites for insulin administration. Barrier items were developed based on the clinical experience of the investigators and research specific the management of T1DM in children (Wysocki, Greco, & Buckloh, 2003). The items were judged to be face valid, based on the review of three certified diabetes educators (one not affiliated with the research project) and a parent of an adolescent with T1DM. The final survey included 9 barrier items specific to insulin administration and site rotation. Youth responded true or false to the barrier items based on how true the item was for them. Barrier items were scored to yield a total barrier score (total possible score= 9), with positively phrased items reversed scored so that higher scores reflected more barriers to site rotation. In addition, the survey included a body drawing on which youth marked all of the sites they currently use for insulin. The survey was designed to take approximately 10 minutes to complete. Parents of children ages 2–11 were asked to complete the survey for their child, while participants ages 12–17 were given the option to complete the survey on their own or to have a caregiver assist them. The decision to have parents complete the survey for children 2–11 years was based on the current recommendations for diabetes self-

management in children and adolescents which suggests parents and children share daily diabetes self-care management until children are at least 12 years old (Silverstein, et al., 2005).

Statistical Analyses

All data were analyzed using SPSS statistical software (version 16; 2008). To examine sample characteristics, means, standard deviations, and frequencies were calculated for variables. To examine Hypothesis 1, the frequency of youth reporting at least four insulin sites was calculated and compared to the benchmark of 50% proposed in the hypothesis. Data were also examined according to the mean number of sites reported by youth on MDI and youth on CSII. These means were compared using an independent sample t-test. To examine Hypothesis 2, a series of Pearson product-moment correlations were used to examine the association between number of sites reported by youth and the number of perceived barriers to site rotation and youth's HbA1c. Additional analyses compared the percentage of youth on MDI and youth on CSII who endorsed each barrier using chi-square analyses. Finally, exploratory analyses were conducted to examine the number of sites reported by youth based on specific demographic variables. These analyses were conducted separately for youth on MDI and youth on CSII. To examine the association between number of sites and child age or time since diagnosis, Pearson product-moment correlations were used. For this study, parents' marital status (married or not married) and education (less than college or college and greater) were coded as dichotomous variables. Therefore, differences were examined using a series of independent sample t-tests. For all study analyses, an a priori alpha level was set at 0.05.

RESULTS

Depending on child age, surveys were completed by either a parent/caregiver and/or the child. Forty-one percent of surveys were completed by youth independently, while 59% were completed by youth with assistance from a parent. There was no difference found in number of sites when surveys were completed by with a parent versus the youth alone [$t(194) = -1.13, p = 0.26$]; therefore, data were collapsed for analysis.

With respect to insulin administration, the average number of sites used by youth was 2.34 ± 1.0 . Thirty-six percent of youth reported two sites, followed by three sites (25%), one site (22%), and four sites (15%). Thus, our hypothesis which predicted at least 50% of youth would report having four or more sites, was not supported. A significant difference was found in the mean number of sites reported by youth on CSII versus MDI [$t(197) = 8.19, p = 0.001$]. Specifically, youth on MDI reported more sites in their rotation plan (2.81 ± 0.90) than youth on CSII (1.81 ± 0.82). Over 94% of youth on MDI reported two or more different sites in their rotation plan. In contrast, 81% of youth on CSII reported using only one or two sites. Consistent with existing research, there was a positive correlation between child age and HbA1c, suggesting a tendency for older youth in this study to report higher HbA1c levels ($r = 0.39, p = 0.001$). However, contrary to our hypothesis, there was no correlation between HbA1c and number of sites reported by youth ($r = 0.13, p = 0.08$).

Demographic Characteristics of Number of Sites

Exploratory analyses were conducted next to examine number of sites reported by youth based on specific demographic variables. Because there was a significant difference in the number of sites reported by youth on MDI versus CSII, analyses were conducted separately for youth based on insulin regimen. No correlations were found between number of sites and child age (MDI: $r = 0.04, p = 0.70$; CSII: $r = -0.01, p = 0.99$) or time since diagnosis (MDI: $r = -0.09, p = 0.37$; CSII: $r = 0.07, p = 0.49$) for youth on MDI or on CSII. Similarly, when

controlling for regimen type, no differences were found between number of sites and parental marital (MDI: $p=0.26$; CSII: $p=0.89$) status or highest grade level completed by fathers (MDI: $p=0.75$; CSII: $p=0.06$) or mothers (MDI: $p=0.88$; CSII: $p=0.79$).

Self-reported Barriers to Multiple Sites

Table 2 lists the percent of youth who endorsed barriers to trying new sites along with χ^2 analyses which examined differences in the percentage of youth endorsing each barrier. Forty-nine percent of youth on MDI reported fear that new insulin sites would be painful compared to 64% of youth on CSII. Interestingly, 76% of youth on MDI and 61% of youth on CSII reported believing that rotating sites would improve overall diabetes control. However, 54% of youth on MDI and 67% of youth on CSII also endorsed comfort with their existing routine as a barrier to adopting new sites. There was no difference in the number of barriers endorsed by youth on MDI and youth on CSII, (2.0 ± 1.3 and 1.7 ± 1.4 , respectively). There was a negative correlation between number of perceived barriers to site rotation and the number of sites reported ($r = -0.28$, $p = 0.01$) for youth on MDI. Interestingly, there was also a negative correlation between the number of perceived barriers to site rotation and HbA1c ($r = -0.21$, $p = 0.05$) for youth on MDI. It is possible that youth on MDI with lower HbA1c have fewer sites in their rotation and thus may perceive more barriers to site rotation because they have less experience trying new sites. No correlations were found between the number of perceived barriers to site rotation and number of sites ($r = -0.21$, $p = 0.06$) or HbA1c reported by youth on CSII ($r = 0.07$, $p = 0.56$).

DISCUSSION

Regular rotation of insulin sites is a standard recommendation for diabetes self-care (Silverstein, et al., 2005; Sperling, 1996). We designed this study to collect survey data from youth with type 1 diabetes and their parents to assess youth's current plan for site rotation and their perceptions of barriers to using multiple insulin sites. The theoretical framework used to guide this study was the Health Belief Model, which predicts that a patient will adhere to a specific self-care behavior based on how the patient perceives its importance and likelihood to benefit to his/her overall health as well as weighs the cost of adherence (Glanz, et al., 2002; Rosenstock, 1974). In this study, over 80% of youth reported receiving instructions for using multiple sites as part of their diabetes management. However, our findings also suggest that youth with type 1 diabetes and their families may not be following an adequate plan for site rotation. Our clinic teaches families regardless of their insulin regimen to consider all eight approved areas for insulin administration in their rotation plan (Walsh & Roberts, 2000). Thus, when considering the possibility of eight distinct insulin sites, our data suggest that youth on MDI are using only about one-third of available sites as part of their rotation plan and youth on CSII are using approximately one-quarter of available sites. If the upper thighs are removed from a rotation plan, a recommendation which is sometimes made to patients on CSII because of concerns related to the rate of insulin uptake in the tissue, our data suggest youth on CSII are similarly using only one-third of available sites as part of their rotation plan, a number which still may not offer youth adequate opportunity to rotate to novel sites and avoid the development of lipodystrophy.

Lipodystrophy is the most common adverse consequence associated with inadequate insulin site rotation (de Villiers, 2005; Johansson, et al., 2005; Vardar & Kizilci, 2007). Lipodystrophy is a degenerative disorder of subcutaneous tissue which can cause thickening of the tissue and sometimes lumps or dents in affected areas (Kordonouri, Lauterborn, & Deiss, 2002). Lipodystrophy is not dangerous in itself. However, research suggests that it can reduce the absorption of insulin at the site by as much as 25%, which in turn, can lead to poorer blood glucose control (Johansson, et al., 2005). Also, due to increase insulin resistance at the site, some patients with lipodystrophy may require higher total doses of

insulin to achieve optimal glycemic control. In cases of mild lipodystrophy, early detection and time off from insulin at the site may provide an opportunity for the affected tissue to heal and reverse many of the effects of dystrophy. However, in some patients and/or more severe cases, the dystrophic tissue may never heal completely, making these sites suboptimal for insulin administration (de Villiers, 2005; Johansson, et al., 2005). In all cases, detection is key to preventing further skin damage and/or adjusting insulin recommendations for patients (de Villiers, 2005). To detect lipodystrophy, a physical exam with finger palpation of insulin sites should be conducted as lipodystrophy can often be hard to detect with a visual inspection alone (de Villiers, 2005). To palpate the site, providers should use their fingers to firmly rub injection sites back and forth in a sweeping motion seeking areas where the tissue feels changed from normal (de Villiers, 2005). As stated previously, dystrophy can feel like areas of hardened tissue (e.g., tissue may feel muscular in nature and lumpy) or in some cases, may feel very soft to the touch and visual inspection may show a protuberance in the affected area. In addition, areas of lipodystrophy may evidence red marks suggesting repeated insulin injections. Nurses and primary care providers can play an important role in helping to detect dystrophy and making recommendations for site rotation. Similarly, as an additional prevention tool, it may be helpful to educate parents and youth about the signs of dystrophy and encourage parents and youth to monitor insulin sites and schedule an appointment with their health care provider if they are concerned that a site may be becoming dystrophic.

In addition to providing patient education specific to the causes and effects of lipodystrophy, our findings highlight a need for nurses and diabetes educators to work directly with youth and parents to help to address perceived barriers to adequate site rotation. Consistent with the HBM, if patients perceive barriers to site rotation to be significant, these barriers may prevent them from adopting new sites, even in cases where youth and parents understand the benefits of having multiple sites available for insulin (Glanz, et al., 2002). In this study, common barriers to using new insulin sites were fear that sites would hurt, problems reaching sites or concern that sites would be awkward, and comfort with the existing routine. For youth and parents who are concerned about reaching unfamiliar sites, scheduling an education appointment to practice these new sites with guidance from a nurse or diabetes educator may be a necessary strategy to overcome this barrier and build confidence. Related, it may help families if the nurse or diabetes educator could help families identify someone else to administer injections to new sites. For example, for youth attending schools with a nurse or aide, it may be possible to work out a plan with the youth's school nurse or aide to use only new sites for injections at school and save existing sites for home management. For youth and parents concerned that unfamiliar sites will be painful, teaching coping strategies may be helpful. For example, for young children, it may effective to teach parents how to use distraction to help their child to cope with their fear while they become more familiar with new sites. Common distraction techniques which parents could try with their young children include singing, interactive toys or puzzles, make believe blowing out candles, or books. For older children and adolescents, brief cognitive behavioral techniques including relaxation training, cognitive distraction, cognitive reappraisal, comforting self-talk, and reducing any behavior or thoughts that may cue children to be fearful of new sites (e.g., saying to the child at the time of the injection, "I promise this won't hurt.") may be needed. Alternatively, behavioral strategies, including use of an incentive plan for adequate site rotation, could help youth to try new sites and to maintain adequate site rotation over time. In tracking goals related to site rotation, older youth or parents may find it helpful to use a modified log book where they can record injection sites across the day. In our clinic, when counseling families, we typically do not recommend youth and parents introduce a new site using a topical analgesic or applying an ice cube to the site before injection. While we find these strategies can be very effective in managing pain for behaviors performed infrequently (e.g., annual venous blood draws, placing a

continuous glucose sensor to complete a glucose profile), we do not find these strategies to be practical for daily insulin injections due to the extra planning and time they require. Similarly, we caution families in using these strategies when placing infusion sites, because they increase the length of time needed to place the infusion site and may actually contribute to greater anticipatory anxiety as youth wait to place the infusion site. Finally, for youth and parents who seem ambivalent to changing their personal rotation plan or report comfort with their current routine, it may be helpful to use components of motivational interviewing to help them to recognize the connection between proper site rotation and the realization of their own diabetes care goals, such as greater independence in diabetes self-care, improved glycemic control, and/or improved physical well-being in order to create the behavior change (Channon, et al., 2007; Rollnick, 2007).

There are some limitations to the current study. First, this study used survey data obtained directly from youth and families. While all participants were instructed that their data would be kept confidential, self-report data are vulnerable to a social desirability bias. Thus, it is possible that these data may over-report the actual number of insulin sites used by youth with type 1 diabetes. Second, this study used a convenience sample of youth with type 1 diabetes recruited at one of their regularly scheduled diabetes appointment. This study did not make attempts to recruit youth with type 1 diabetes who were not coming to their diabetes appointments as recommended or youth who came only annually to the pediatric diabetes clinic. Thus, it is possible that the results may not generalize to all youth with type 1 diabetes, especially youth who only intermittently seek care from a tertiary pediatric diabetes clinic. Finally, this study did not collect data from practitioners to compare to youths' self-report. Therefore, no data can be reported specifically quantifying patients' adherence to their rotation plan as defined by their diabetes practitioner. Future research may want to include physician/nurse responses in order to quantify youths' adherence to site rotations as a component of their insulin management.

The results of this study have implications for clinical practice. First, these findings suggest that many youth with type 1 diabetes may not be adhering to an adequate site rotation plan. Thus, regular assessment of insulin administration sites and follow up on recommendations to rotate sites is important for detecting lipodystrophy in youth with type 1 diabetes. As mentioned earlier, areas that are dystrophic may appear as a lump, a dent, or as red and swollen tissue which is hard to the touch. In most cases, it is easier to detect lipodystrophy using finger palpation versus visual inspection and early detection and time off from the site may help to preserve the site for future insulin use (de Villiers, 2005; Johansson, et al., 2005; Kordonouri, et al., 2002). Nurses and primary care providers can play an important role in recognizing the signs of dystrophy and counseling youth and families on adequate site rotation in between youths' quarterly diabetes clinic appointments.

Second, this study suggests that information on site rotation alone is not sufficient to help most families of youth with type 1 diabetes to try new sites in their rotation plan. Therefore, to help families overcome perceived barriers to multiple insulin sites, medical providers may need to become creative and use a combination of education and behavioral techniques to help families implement adequate site rotation.

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Table 1

Sample characteristics

Variable	M	SD
Age (years)	11.8	3.4
Time since diagnosis with type 1 diabetes (years)	5.9	3.4
	Frequency	%
Gender Boy	91	45%
Girl	110	55%
Race White	173	86%
Non-white	28	14%
Insulin regimen	105	52%
Multiple Daily Injection	96	48%
Continuous subcutaneous insulin pump		
Father's education	111	55%
Less than college	90	45%
College or greater		
Mother's education	103	51%
Less than college	98	49%
College or greater		
Marital Status	127	63%
Married	74	37%
Not married		

Table 2

Perceived barriers to insulin sites reported by youth on MDI or CSII

Perceived barrier	MDI (% “true”)*	CSII (% “true”)	X ²	p
Afraid new insulin sites will be more	49	66	5.78	0.02
Tried a new insulin site and it hurt more current sites	43	37	0.73	0.46
New sites are more awkward and	44	55	1.92	0.19
Received instruction for new sites from diabetes team	86	82	0.87	0.43
Comfortable with the current routine and not want to try new sites	54	67	3.30	0.08
Have had problems with new sites (e.g., leaking insulin, infusion site problems)	16	19	0.34	0.57
It is hard to get to new sites to do an injection/place infusion site	24	33	1.72	0.19
Have been told by the diabetes team use current insulin sites	9	3	2.70	0.14
Using new sites for insulin can improve diabetes control	76	61	4.91	0.04

*
% “true” is the percentage of youth reporting that the particular barrier was true for them