HHS Public Access

Author manuscript

J Pediatr Endocrinol Metab. Author manuscript; available in PMC 2020 April 08.

Published in final edited form as:

J Pediatr Endocrinol Metab. 2018 January 26; 31(2): 213–219. doi:10.1515/jpem-2017-0435.

Improved medical-alert ID ownership and utilization in youth with congenital adrenal hyperplasia following a parent educational intervention

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Abstract

Background—Classical congenital adrenal hyperplasia (CAH) is a potentially life-threatening condition, and adrenal crisis is a major cause of morbidity and mortality in affected children. Medical-alert identification (ID) could prevent complications of adrenal crisis by identifying the need for time-sensitive, critical treatment. Our objectives were to evaluate usage of medical-alert IDs by CAH youth, ownership and awareness of IDs amongst their parents, and the effect of an in-clinic educational intervention on ID utilization.

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Author contributions: All the authors have accepted responsibility for the entire content of this submitted manuscript and approved submission.

Employment and leadership: M.S.K. is Co-Director of the CHLA CAH Comprehensive Care Center and is an Advisor on the CARES Foundation Medical & Scientific Advisory Board.

Honorarium: None declared.

Supplemental Material: The online version of this article offers supplementary material (https://doi.org/10.1515/jpem-2017-0435).

Methods—Fifty families of youth with classical CAH secondary to 21-hydroxylase deficiency (11.2 ± 5.0 years old, 58% female) were prospectively studied. An in-clinic needs assessment survey was administered at baseline to parents, paired with an educational intervention, and a follow-up needs assessment phone survey 1 month post-intervention. A quality improvement (QI) framework was utilized with plan-do-study-act (PDSA) process-improvement cycles.

Results—At baseline, 20/50 (40%) CAH families owned a medical-alert ID, of which only 10/20 (50%) of ID owners reported usage >3 days per week. Only 26/50 (52%) parents were aware of ID options. Post-intervention, ID ownership doubled to 39/50 (78%; $p < 0.05$), usage amongst ID owners reached 100% (39/39), and awareness increased to 42/50 (84%; $p < 0.05$). A surprising barrier reported by five Spanish-speaking families was the inability to order medical-alert IDs online.

Conclusions—Only a small percentage of CAH youth frequently wear a medical-alert ID, but utilization can be effectively improved with an in-clinic educational intervention. Further study is merited to assess a potential reduction in morbidity and mortality of adrenal crisis with increased medical-alert ID utilization.

Keywords

adrenal insufficiency; congenital adrenal hyperplasia; patient identification system; pediatrics; quality improvement

Introduction

Adrenal insufficiency is a potentially life-threatening condition that can affect children from birth, and adrenal crisis is a major cause of morbidity and mortality in these high-risk youth [1–3]. Classical congenital adrenal hyperplasia (CAH) due to 21-hydroxylase deficiency is the most common cause of primary adrenal insufficiency in children, affecting 1:10,000–25,000 newborns [1]. Adults with CAH have a frequency of 5.8 adrenal crises per 100 patientyears [4], although there is a paucity of data in regards to incidence of adrenal crisis in children. CAH youth can have both adrenocortical and adrenomedullary dysfunction which can result in severe hyponatremia, hyperkalemia and hypoglycemia due to impaired production of cortisol, aldosterone and epinephrine [5, 6]. Associated complications of adrenal crisis could include hypotension and hypovolemic shock requiring emergent resuscitation [5–7].

Treatment for adrenal crisis is dependent upon prompt initiation of glucocorticoid replacement and volume resuscitation. To address the management and acuity of adrenal crises, the Endocrine Society Clinical Practice Guideline for primary adrenal insufficiency, as well as the European Expert Consensus Statement, recommends that all patients with adrenal insufficiency receive education regarding timely stress-dose glucocorticoid administration (i.e. within 1 h of onset of symptoms) including a review of the emergency injection of hydrocortisone [4, 8, 9]. As well, patients should be encouraged to wear or carry medical-alert identification (ID) to notify providers of the need for steroid replacement. A large percentage of adrenal crises occur outside the home, with low awareness levels of families and healthcare providers regarding the principles of emergency glucocorticoid

administration [4]. Therefore, effective utilization of medical-alert IDs could identify adrenal crises early and trigger immediate intervention [9]. A European working group has developed a common emergency card for patients with adrenal insufficiency that has been designed to provide quick and easy information to the healthcare worker in an emergency situation [10]. There is also an ID card being created to use commonly in Europe, and in countries such as Brazil, for patients with adrenal insufficiency. Patient and/or parent education on the treatment of adrenal crisis with emergency glucocorticoids, along with a medical-alert ID explaining the need for treatment to healthcare personnel, could prevent complications of adrenal crisis with a more timely intervention. However, there remains a need to evaluate both patient and parent education regarding ownership and frequent usage of medical-alert IDs, in families of youth with adrenal insufficiency.

The objective of this study was to evaluate parents of youth with primary adrenal insufficiency due to CAH in regards to ownership, awareness, and frequency of use of medical-alert IDs, and to determine the effect of an in-clinic educational intervention on ID utilization.

Subjects and methods

Study participants

We studied 50 families of children with CAH in the Children's Hospital Los Angeles (CHLA) CAH Comprehensive Care Center as part of a prospective, longitudinal cohort study design. The research related to human use has complied with all the relevant national regulations, institutional policies and in accordance with the tenets of the Helsinki Declaration, and has been approved by the CHLA Committee on Clinical Investigations (Institutional Review Board). Informed consent was obtained from 46 families, with the remaining four participating on a quality improvement (QI) basis.

All patients had classical CAH secondary to 21-hydroxylase deficiency (72% salt-wasting, 28% simple virilizing). The average age of patients with CAH was 11.2 ± 5.0 years (range 4–24 years; only two were older than 18 years) and 58% were female. Inclusion criteria included a previous diagnosis of classical CAH due to 21-hydroxylase deficiency based on biochemical and/or genetic testing, and age ≥2 years. All participants were on glucocorticoid requirements for daily physiological replacement dosing, as well as stress dosing in the setting of illness or injury. Exclusion criteria included children <2 years (due to decreased medical-alert ID usage in infants and young toddlers) and patients who did not have a parent present at the time of the clinic visit.

Study methods

We implemented a QI initiative regarding medical-alert IDs in patients presenting for routine CAH clinic visits. We performed: (1) an in-clinic needs assessment in the form of a baseline survey of parents to evaluate outcome measures of ownership, awareness of medical-alert ID and alternative medical alert options, as well as frequency of use of medical-alert IDs in their children; (2) an in-clinic educational intervention; and (3) a follow-up phone call and survey 1 month post-intervention. Outcome measures included: the percentage of families

who owned a medical-alert ID, the percentage of families aware of medical-alert ID and alternative medical alert options, and the percentage of families with “frequent usage” (defined as usage >3 days per week) of a medical-alert ID.

Baseline in-clinic needs assessment—The initial needs assessment was an in-clinic survey that included questions designed to elicit parent ownership (“Do you have a medical-alert ID?”), awareness (“Are you aware of the alternative medical-alert ID products such as wallet cards, iPhone® emergency ID?”), and “frequent usage” in regards to medical-alert IDs. The survey included additional questions to determine barriers to ownership and “frequent usage” (e.g. “You have not heard of a medical-alert ID”, “You don’t like the way it looks”, “You were unable to obtain a medical-alert ID at this time”, and “You have misplaced yours”). Spanish translation for Spanish-speaking parents was provided by the medical assistant administering the survey.

In-clinic educational intervention—Following the completion of the in-clinic survey, a hand-out detailing six medical-alert ID and alternative medical alert options was provided to the parent as an educational intervention (Supplemental Material). The hand-out described how to obtain medical-alert ID products, set up an emergency medical alert on an iPhone®, was designed to be visually appealing, and was written at a third-grade reading level.

One-month follow-up needs assessment (post-intervention survey)—A longitudinal, follow-up needs assessment was completed 1 month after the in-clinic intervention. Each parent who completed the baseline in-clinic survey received a telephone call from the research team 1 month following the clinic visit, and the needs assessment survey was re-administered at that time. Barriers to obtaining a medical-alert ID were recorded, with additional resources provided to the family when such barriers were identified.

QI methodology: PDSA cycles

Rapid plan-do-study-act (PDSA) process-improvement cycles [11] were utilized as a systematic series of steps to optimize the process of enrollment and participation in this clinic-based study. The research team met at monthly intervals to assess a PDSA cycle and to implement the next set of adjustments for the subsequent PDSA cycle. Therefore, with each cycle, the research team was able to implement adjustments to process measures (e.g. survey distribution in the clinic). The in-clinic needs assessment (survey) and in-clinic educational intervention (hand-out) components remained unchanged throughout the study.

Data were aggregated in a run chart, by clinic visit and month of collection, to examine trends or patterns over a specific period of time [11]. Balance measures, such as clinic flow procedures and effects on time spent by the patient in clinic, were assessed on a monthly basis via interviews with clinic staff over the 6-month duration of the study.

Statistical analysis

A chi-squared (χ^2) test was used for comparisons between the initial and 1-month follow-up needs assessment surveys. The run chart was analyzed for runs (series of points in a row on

one side of the baseline median), shifts (six or more consecutive points above or below the baseline median), and trends (five or more consecutive points above or below the baseline median) [11]. Three probability-based rules were used for evaluation of the run chart to analyze for nonrandom data patterns based on an error of $p < 0.05$. A baseline median was constructed from the initial needs assessment data obtained prior to implementing the educational intervention.

Results

Over a 6-month period, 75 children and adolescents with CAH were pre-screened for eligibility (Figure 1). Fifteen patients did not meet the eligibility criteria as they were infants. Sixty parents were approached during a clinic visit, completed the in-clinic needs assessment survey, and received the educational hand-out. However, 10 surveys were not successfully collected in PDSA Cycle 1 by the physician, leaving 50 parents who were contacted for the 1-month follow-up survey. Observations occurred over four successive PDSA cycles, which included 16 families in Cycle 1, 16 families in Cycle 2, eight families in Cycle 3 and 10 families in Cycle 4.

Baseline in-clinic needs assessment

There were 20/50 (40%) families who reported that they owned a medical-alert ID, and 26/50 (52%) parents who reported that they were aware of medical-alert ID options (Table 1). Of the families who owned a medical-alert ID, only 10/20 reported “frequent usage” of IDs.

One-month follow-up needs assessment (post-intervention survey)

The needs assessment survey performed at 1-month post-intervention showed that ownership of medical-alert IDs increased significantly by the end of the study, doubling from 20/50 to 39/50 (78%, $p < 0.05$; Table 1). Parent awareness of ID options increased from 26/50 to 42/50 (84%, $p < 0.05$). In those families who owned a medical-alert ID, “frequent usage” doubled from 50% to 100% of families (39/39, $p < 0.05$).

The post-intervention survey also revealed several barriers to obtaining a medical-alert ID. Five families with Spanish-speaking parents reported lack of access to electronic payment methods with which to purchase a medical-alert ID online (i.e. could not obtain a credit card, or did not have access to a computer or the Internet). As well, other barriers to ID utilization included youth disliking ID styles ($n = 5$), and a lack of parental knowledge regarding the importance of consistent medical-alert ID usage ($n = 7$).

QI: PDSA analysis

The PDSA Cycle 1 identified the suboptimal collection of in-clinic surveys, due to physician difficulty collecting the completed survey during the clinic visit (Figure 2). Ten surveys completed by parents were not collected by the physician during Cycle 1. Thus, Cycle 2 implemented a modification of having the clinic medical assistant collect the survey at the end of the clinic visit. This resulted in a considerable improvement in the collection of completed surveys, with no missed surveys in Cycle 2. Cycle 3 implemented pre-screening

of patients 2 days prior to the clinic visit, instead of 1 week prior as was done in Cycles 1 and 2. By the completion of the cycle, the number of patients recruited per clinic had doubled. Cycle 4 further modified Cycle 3 by having the medical assistant screen all patients who were in clinic for glucocorticoid use during their medication intake and reconciliation; however, there was no increase in the number of patients recruited per clinic in Cycle 4. Clinic staff showed no significant concerns in terms of disruption of clinic flow, delay in wait times, or increase in time spent by patients in clinic.

Between each PDSA cycle there was a significant increase in both percent ownership and "frequent usage" of medical-alert IDs following the educational intervention, with run chart methodology showing a shift of eight points above baseline median for both outcomes ($p < 0.05$, Figure 3). Parent awareness of medical-alert IDs also increased following the educational intervention, between Cycles 1 and 4 ($p < 0.05$).

Discussion

The main finding of our study was that an in-clinic educational intervention can rapidly improve parental ownership, awareness and frequency of use of medical-alert IDs in youth with primary adrenal insufficiency due to CAH. We were able to observe these improvements after only 1 month from the time of the intervention. Parent awareness of medical-alert ID options increased by 62%, and the ownership of IDs amongst families doubled following the educational intervention. We had identified a relatively low adherence to frequent utilization of IDs in our cohort of CAH youth prior to the educational intervention. However, by 1-month post-intervention, 100% of families who owned a medical-alert ID reported frequent use of IDs (>3 days per week).

Our overall goal was to systematically educate families of CAH youth on medical-alert IDs in a busy clinic setting, in order to effectively improve awareness, ownership and rates of adherence to life-saving IDs in affected youth. However, our longitudinal needs assessment uncovered socioeconomic barriers for certain families that were independent of simply a knowledge deficit. The striking finding was that 10% of families surveyed had a Spanish-speaking parent who did not have a personal credit card with which to purchase an online medical-alert ID, and/or lacked access to a computer or the Internet at home. These important barriers to equal access to medical-alert IDs could be addressed in the pediatric endocrinology clinic visit by utilizing in-clinic computer resources, in-person assistance with online ID purchases, and having those families without credit cards purchase a cash gift card for the online payment.

In addition, by utilizing a QI framework that was well suited for this type of in-clinic study, we were able to address gaps in process implementation, and thereby maximize the participation of families with a priority condition in a busy endocrinology clinic. We found that shifting the screening of patients closer to the day of clinic was an effective way of increasing the number of participants in the study, likely due to improved accuracy in identifying patients scheduled for clinic. As well, the importance of a multi-disciplinary team approach was highlighted by the pivotal role played by clinic medical assistants in the distribution and collection of the in-clinic survey. The educational intervention for parents,

as a comprehensive, one-page hand-out on medical-alert IDs, was feasible to implement by staff during clinic, and was non-disruptive to clinic work flow. The impact of this intervention was seen with significantly improved outcomes related to the utilization of medical-alert IDs across PDSA cycles, and improved process of care for these patients. This model could be reproduced in other pediatric endocrinology centers.

Several study limitations deserve comment. Our study was restricted to youth with CAH, given that CAH is the most common form of primary adrenal insufficiency in children. However, the findings in the CAH cohort could be generalizable to youth affected by other forms of adrenal insufficiency, such as panhypopituitarism. Secondly, as part of the QI design, changes were made to our in-clinic process during the study period with each PDSA cycle. The impact of each PDSA cycle cannot be independently assessed, however, making it difficult to assess the impact of improved communication between the healthcare team and families with each subsequent PDSA cycle, as an example. Lastly, although we were able to observe significant changes in outcomes after only a 1-month period, longer-term evaluations could be implemented to ascertain if changes are sustainable over a longer period of time post-intervention.

In summary, a simple, in-clinic educational approach is under-reported in the literature in regards to medical-alert ID utilization, but proved highly effective at improving the ownership, awareness, and “frequent usage” of IDs in youth with CAH. Utilization improved dramatically from 50 to 100 percent in families owning an ID, with improvements in ID ownership and awareness after only 1 month following a feasible educational intervention. Barriers to ID ownership do exist for certain families, which could then be addressed in the clinic to equalize access to IDs. Improved medical-alert ID utilization in these and other youth with adrenal insufficiency could lead to the prompt ID and treatment of these at-risk individuals, and potentially, through timely emergency treatment, improve outcomes of morbidity and mortality associated with adrenal crises. Further studies are needed to assess the clinical impact of increased medical-alert ID utilization in youth with adrenal insufficiency.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

We gratefully thank our patients and their families from the CHLA CAH Comprehensive Care Clinic for their participation, and the Center for Endocrinology, Diabetes and Metabolism clinic staff for their assistance and support. We thank Susan Wu, MD and Jennifer Maniscalco, MD for providing QI mentorship. We thank CARES Foundation for support of our designated CAH Comprehensive Care Center, and Mitchell Geffner, MD for reviewing the manuscript and providing feedback.

Research funding: *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (Funder Id: 10.13039/100009633), Grants supporting the writing of the paper: 1K23HD084735-01A1 (NIH/NICHD) and CARES Foundation Congenital Adrenal Hyperplasia (Funder Id: 10.13039/100002759) Comprehensive Care Center award to M.S.K. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH.

Competing interests: The funding organizations played no role in the study design; in the collection, analysis, and interpretation of data; in the writing of the report; or in the decision to submit the report for publication.

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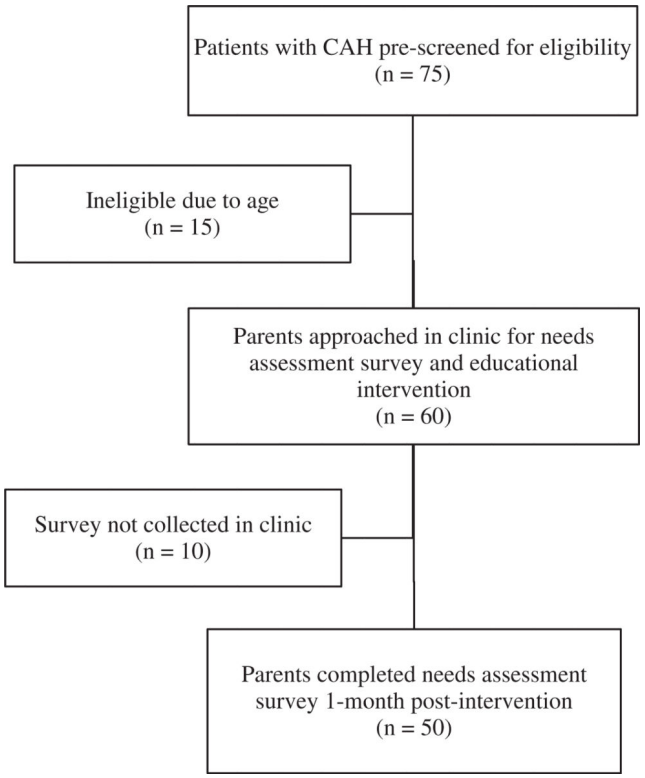

Figure 1:

Study flow chart.

Seventy-five children and adolescents with adrenal insufficiency due to congenital adrenal hyperplasia (CAH) were pre-screened for eligibility. Fifteen patients did not meet eligibility criteria based on age as they were infants. Sixty parents were approached during a clinic visit to complete an in-clinic needs assessment survey on ownership, awareness, and the frequency of use of medical-alert identification by their children. They also received an educational intervention in the form of a hand-out on medical-alert identification. Ten surveys were not collected by the physician during the clinic visit. Fifty parents completed a follow-up needs assessment survey by phone, 1-month post-intervention.

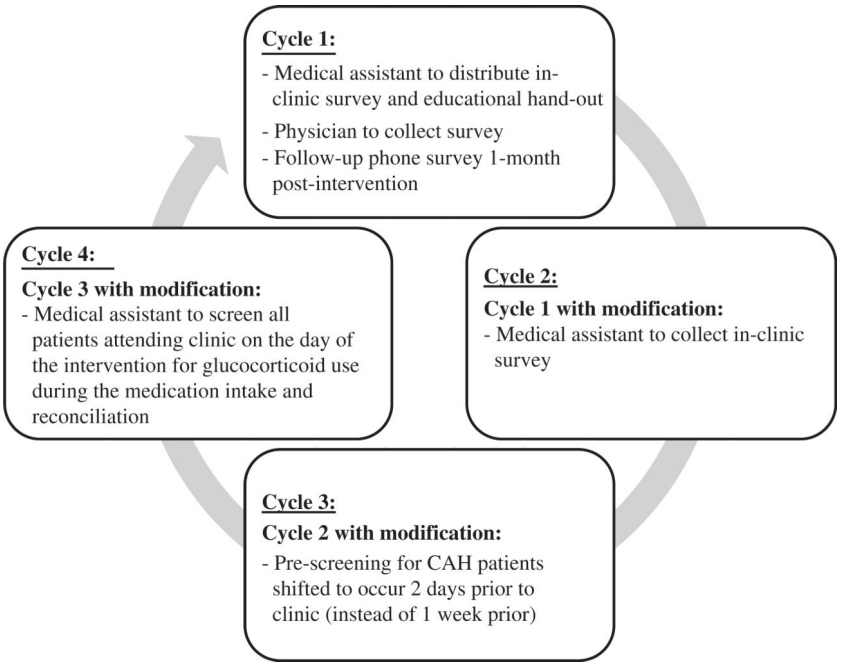

Figure 2:

Plan-do-study-act (PDSA) cycles.

Rapid PDSA process-improvements cycles were utilized to optimize participation in the study. In Cycle 1, the medical assistant distributed both the in-clinic needs assessment survey and the educational intervention for parents (hand-out on medical-alert IDs). However, the physician was unable to reliably collect the survey from the parent during the clinic visit. Cycle 2 implemented having the medical assistant collect the surveys, with no missed surveys as a result. Cycle 3 implemented a shift in timing for the pre-screening of patients with congenital adrenal hyperplasia (CAH) to 2 days prior to the clinic visit, instead of 1 week prior, which doubled the number of patients recruited per clinic as a result. Cycle 4 further modified Cycle 3, with the medical assistant screening all patients in clinic for glucocorticoid use during their medication intake and reconciliation.

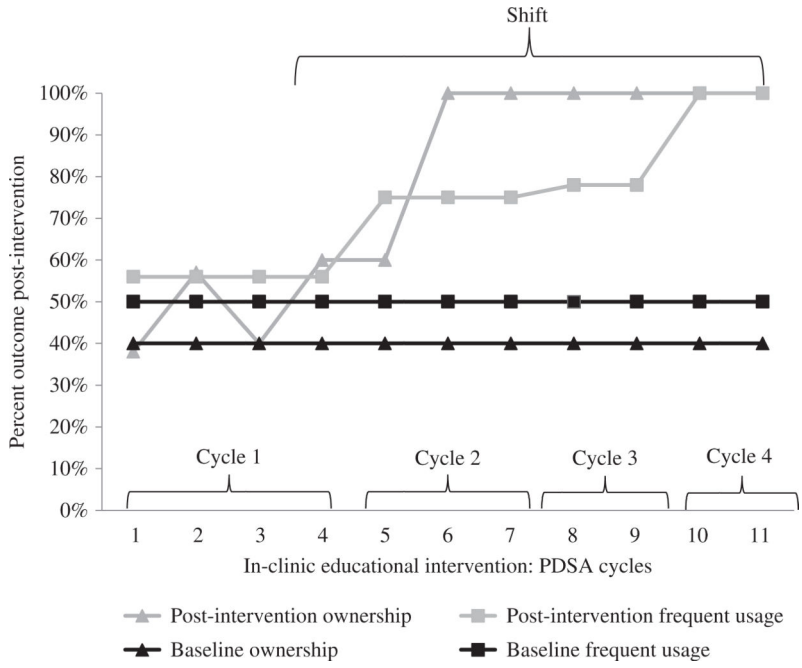

Figure 3:

Run chart detailing observations over six consecutive months, across four successive plan-do-study-act (PDSA) process-improvement cycles.

A total of 50 families completed a baseline in-clinic needs assessment survey and educational intervention, along with the same survey 1-month post-intervention. The following number of families participated per PDSA cycle: Cycle 1 (n = 16), Cycle 2 (n = 16), Cycle 3 (n = 8), and Cycle 4 (n = 10). Baseline percent medical-alert ID ownership and "frequent usage" (>3 days per week) in those families who owned a medical-alert ID were 40% and 50%, respectively, with significant increases post-intervention in both outcomes between each PDSA cycle, and a shift of eight points above baseline median ($p < 0.05$ for both).

Table 1:

Medical-alert ID ownership, awareness and frequency of use in families of CAH youth at baseline and 1 month following an in-clinic educational intervention.

Parents surveyed (n = 50)	In-clinic baseline	1-month Post-intervention	p-Value
Ownership of a medical-alert ID	40% (20/50)	78% (39/50)	<0.05
Awareness of medical-alert ID options	52% (26/50)	84% (42/50)	<0.05
Owners of a medical-alert ID with “frequent usage” (>3 days/week)	50% (10/20)	100% (39/39)	<0.05

J Pediatr Endocrinol Metab. Author manuscript; available in PMC 2020 April 08.