

Variation in Use of Internet-Based Patient Portals by Parents of Children With Chronic Disease

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Objectives: To assess the use of Internet-based portals among families of children with chronic diseases and to describe characteristics of portal registrants and users.

Design: Retrospective observational study.

Setting: Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, using data from September 1, 2003, through February 29, 2008.

Patients/Participants: Parents of children with diabetes mellitus, juvenile idiopathic arthritis, or cystic fibrosis.

Interventions: Parents of children with a chronic disease were given the opportunity to access health-related information for their children via an Internet-based portal.

Outcome Measures: Percentage of families who obtained a portal account (registered), used the portal for the first time within 3 months and again 3 to 6 months

after registration, number of times logged in, and session length.

Results: Of 1900 families, 27.9% obtained a portal account. Of those, 47.8% used the portal within 3 months of registration and 15.9% continued to use the portal 3 to 6 months after registration. Families of African American patients and of patients insured by Medicaid were less likely to obtain a portal account. More outpatient visits and having private health insurance coverage were associated with increased portal registration and use.

Conclusions: Understanding the feasibility of portal use by parents is an important first step to using portals for improving self-management, patient-provider interactions, and outcomes for children with chronic diseases. Subsequent studies should address parent perceptions of the value portals add to the management of the chronic disease of their child and ways to increase that value. Barriers to using portals among racial minorities and publicly insured families should also be studied to address disparities.

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IN 1998, JAMA PUBLISHED A CONSENSUS statement concerning the use of electronic technology by patients to obtain health-related information.¹ Shortly thereafter, the US Department of Health and Human Services published the findings of a science panel that proposed strategies to achieve the following vision: "Interactive health communication will play an essential role in enhancing health, minimizing total burden of illness, and optimizing relationships between individuals and health professionals."^{2(p3)} Evidence that parents of children with a chronic disease will use such tools is limited.

Adult studies have explored the use of electronic tools for patients to inform themselves and to enhance their ability to manage their health care. Internet-based communication with health care provid-

ers among adults has been associated with perceptions of enhanced communication^{3,4} and being more informed regarding health care.^{5,6} Other studies have shown Internet-based coaching can benefit adults with chronic diseases. A randomized controlled trial⁷ showed Internet-based coaching improved satisfaction with care. Another randomized controlled trial of Internet use to promote self-management showed significant improvement in some health indicators.⁸ Ross and Lin⁹ published a review article that concluded that although patients would likely not be harmed by having access to their electronic health record (EHR), evidence has been inconsistent regarding the potential benefits of EHRs in relation to adherence, patient education, and patient empowerment. Finally, a number of large organizations such as Geisinger Health

System, Group Health, and Beth Israel Deaconess Medical Center have demonstrated that Internet-based portals are used and liked by adult patients.^{7,10,11}

Data from studies in pediatric settings are limited. Two studies in the pediatric literature tested the usability of an electronic pain diary for children with chronic diseases.^{12,13} Others tested the effectiveness of Internet-based self-management tools for adolescents with hemophilia¹⁴ and asthma.¹⁵ To our knowledge, the use of Internet-based patient portals that allow parents of children with chronic diseases to access the medical record of their child has not been studied.

In 2009, the American Academy of Pediatrics published a policy statement concerning the use of personal health records (PHRs) to improve the quality of health care for children. The policy statement recognized that although great potential exists for electronic PHRs to positively affect health care for children, many unknowns exist, along with a need for standards and incentives to use PHRs.¹⁶ The PHR has been defined by the Markle Foundation's Connecting for Health Collaborative as "an electronic application through which individuals can access, manage and share their information, and that of others for whom they are authorized in a private, secure and confidential environment."^{17(p14)} Although the PHR is typically perceived as consisting of information managed by the patient or individual, the information in the EHR is managed by health care professionals. The College of Medical Informatics of the American Medical Informatics Association concluded that the integration of PHRs and EHRs would be more relevant and beneficial to patients and thus should be the preferred model.¹⁸ This model is made available to patients through electronic gateways,¹⁷ which are also referred to as patient portals.

The objective of this study was to evaluate portal use among families of children with chronic diseases by describing registration in an Internet-based portal and characteristics of registrants and nonregistrants, retention of portal users, characteristics of portal users and nonusers, and frequency of portal use. Based on our early experience, we hypothesized that most families would obtain a portal account by the end of the study period and that significant disparities would be found with respect to race and health insurance status. This study is a first step toward determining both the role that patient portals potentially can have in improving interactions among parents of children with chronic diseases and the health care professionals who care for them, and, ultimately, the effect of those portals on health-related outcomes.

METHODS

Ours was a retrospective observational study of portal registration and use incorporating data from September 1, 2003, through February 29, 2008. It was conducted at Cincinnati Children's Hospital Medical Center and was approved by the hospital's institutional review board. The focus of this study was parents of children with 1 or more of 3 chronic diseases: cystic fibrosis (CF), diabetes mellitus (DM), and juvenile idiopathic arthritis (JIA). These diseases were chosen because they are common, and the clinical teams treating individuals with those conditions were interested in collaborating in the

portal development. The portals were developed in-house by the Department of Information Services of Cincinnati Children's Hospital Medical Center in response to the expressed desires of families and health care professionals for ready access to key portions of the EHRs of patients. The portals are secure Internet-based applications that provide access to laboratory results in tabular and graphical formats, secure messaging capabilities to health care providers, visit history, ability to upload documents to share with health care providers (eg, school-related forms), medication information, and reminders for laboratory tests and clinic visits.

Although the portals shared a common infrastructure and user interface, the content was customized for each disease so parents could easily locate the most critical information regarding the disease of their child. The portals were designed using family input and refined with formal usability methods.¹⁹ Parental awareness of the portals was developed, and portal registration was promoted with guidance from the marketing department of the Cincinnati Children's Hospital Medical Center. Each clinic worked with the marketing department to develop flyers and mailings. In addition, efforts to introduce the portals and register families during clinic visits were common to all 3 clinics. A timeline of the major marketing efforts by clinic appears in the eTable (<http://www.archpediatrics.com>). Although teenagers could obtain a portal account with full access, parents were the focus of these efforts.

STUDY POPULATION

Patients were included in the study if they were recorded in at least 1 of the hospital's disease-based clinical registries for the 3 target diseases (CF, DM, and JIA), were younger than 18 years, and had a portal account opened by a parent by February 29, 2008. Patients are entered into the chronic disease-based registries by clinic personnel when diagnosed. Since reports for subsequent clinic visits are generated using the registries, any missed patients would be discovered and included at their next visit. Patients were excluded if they did not have at least 1 outpatient visit at 1 of the 3 disease-specific hospital-based clinics during the calendar year of 2007 or did not speak English, as identified by clinic personnel. Since portal usage data were associated with families and not patients, the unit of analysis was the family.

OUTCOME MEASURES

Measures of portal registration and use were developed from portal administrative records dated from September 1, 2003, through February 29, 2008. Registration was measured by the percentage of families who had obtained a portal account by February 29, 2008. Families were designated as initial users if they had used the portal at least once within 3 months after registration. They were designated as ongoing users if they had used the portal at least once within 3 months after registration and within 3 to 6 months after registration. Families were included in the analysis of portal use only if they had obtained accounts before September 1, 2007, in order to give them 6 entire months before the study end date to use the portal. Portal use was measured by the total number of times families had logged into the portal. *Portal session time* was defined as the amount of time that had elapsed between the time the parent logged in and the time of the last action of the session.

Measures of demographic characteristics and health care use were selected based on the literature pertaining to adults and were obtained from chronic disease registries and hospital ad-

Table 1. Characteristics of the Study Population by Disease^a

Characteristic	CF (n = 175)	DM (n = 1336)	JIA (n = 389)	Total (N = 1900)
No. of hospitalizations, mean (median) ^b	0.44 (0)	0.10 (0)	0.01 (0)	0.11 (0)
No. of outpatient clinic visits, mean (median) ^b	5.9 (5)	1.6 (2)	1.3 (1)	2.0 (2)
Mean age of child, y	9.7	12.6	10.8	12.0
Race, %				
White	87.4	81.0	87.4	82.9
African American	1.1	10.8	5.9	8.9
Other	11.4	8.2	6.7	8.2
Medicaid insurance, %	30.1	24.3	15.8	23.1
Female sex, %	51.4	51.3	73.3	55.8
Family residence area, %				
Large metropolitan	78.9	84.2	67.0	80.2
Small metropolitan	11.4	7.9	22.9	11.3
Rural	9.7	7.9	10.1	8.5

Abbreviations: CF, cystic fibrosis; DM, diabetes mellitus; JIA, juvenile idiopathic arthritis.

^aPercentages may not total 100 because of rounding.

^bDuring the calendar year of 2007.

ministrative databases. The demographic characteristics were defined by using the data values at the time of the study end date and included insurance type; age, race, and sex of the patient; and area of family residence (large metropolitan area, small metropolitan area, or rural). Area of family residence was determined using zip codes and the 2003 Urban Influence Codes developed by the US Department of Agriculture.²⁰ Health care use data included the number of hospitalizations and outpatient visits during the calendar year of 2007. For families with more than 1 child, patient-level demographic data were used from the child who had been diagnosed first. The number of outpatient visits and hospitalizations were summed across children.

STATISTICAL ANALYSIS

Descriptive statistics and cross-tabulations were developed to describe demographic characteristics, health care use, portal registration, portal use within 3 months after registration, and portal use within 3 to 6 months after registration. Predictors of registration were identified using bivariate analysis and logistic regression. The dependent variable was whether the family had obtained (registered for) a portal account. The independent variables were the demographic and health care use variables described in the Outcome Measures subsection of the text. Since a large number of families had no hospitalizations, this variable was dichotomized. A bivariate analysis consisting of χ^2 analyses for categorical variables and the non-parametric Kruskal-Wallis test for continuous variables was conducted to identify candidate variables with *P* values less than .10 for inclusion in the logistic regression model. The final model included only significant variables. Similarly, portal use data were analyzed to identify patient and family characteristics associated with initial and ongoing portal use. Using the method described herein, 2 models were developed for which the dependent variables were whether families had used the portal within the first 3 months after registration (initial users) and whether initial users continued to use the portal within the 3-month to 6-month time frame after registration (ongoing users). Finally, descriptive statistics were developed for the number of times families used the portal and the length of their portal sessions (in minutes). To account for the varying number of sessions across families, weighted averages were used to describe session length.

RESULTS

Inclusion and exclusion criteria resulted in 1960 eligible patients, which translated to 1900 families because 58 families had 2 or more eligible children. For families with 2 or more eligible children, patient-level demographic data from the oldest child was used for analysis purposes. Also, 21 patients had 2 diseases each, of which 1 was DM. These children all received the DM diagnosis after being diagnosed with CF or JIA. For the purposes of analysis, they were included in the disease category pertaining to their first diagnosis. This resulted in 19 patients with CF and DM being included in the CF category and 2 patients with JIA and DM being included in the JIA category. Of the 1900 families, 175 were included in the CF, 1336 in the DM, and 389 in the JIA categories.

Table 1 summarizes the demographic characteristics of the study population by disease, demonstrating that patients with CF had higher rates of health care use. Other notable differences were that a higher percentage of patients with CF were insured by Medicaid, a higher percentage of patients with DM and CF lived in large metropolitan areas, and a higher percentage of patients with JIA were girls.

Figure 1 illustrates the disposition of the families by registration and portal use. Of the 1900 families, 530 (27.9%) had opened a portal account (registered). Thirty-two families were excluded from further portal use analysis because their registration date did not allow them to use the portal for a full 6 months before the study ended. Of the 498 included families, 238 (47.8%) were initial users and only 79 (15.9%) were ongoing users. **Figure 2** illustrates the cumulative percentage of families who registered over time, by disease.

Table 2 describes the demographic characteristics of the study population, portal registrants, and users. Some noteworthy observations were that 23.1% of the total population was insured by Medicaid compared with only 9.2% of initial users and 3.8% of ongoing users.

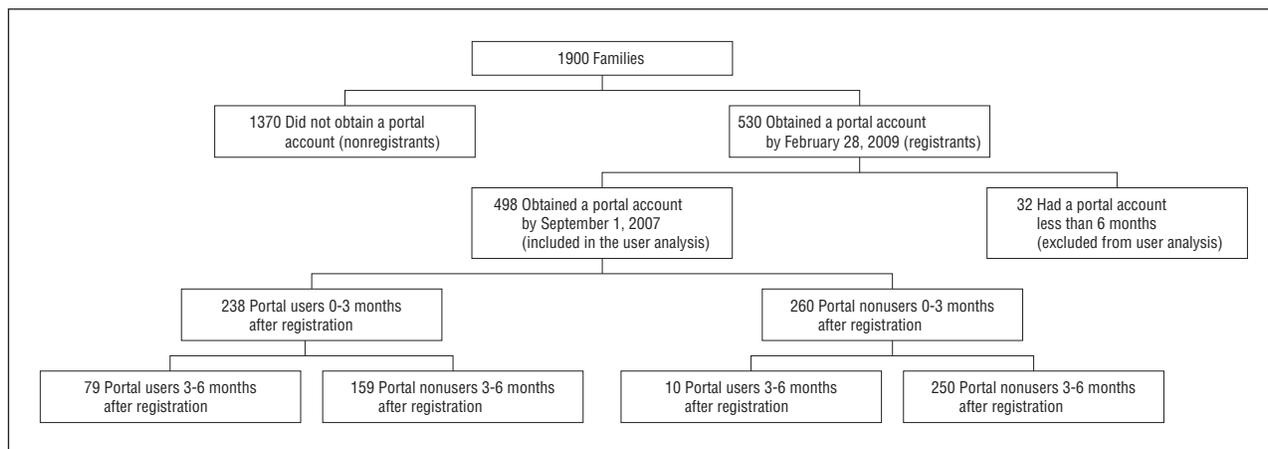


Figure 1. The study population by portal registration and use.

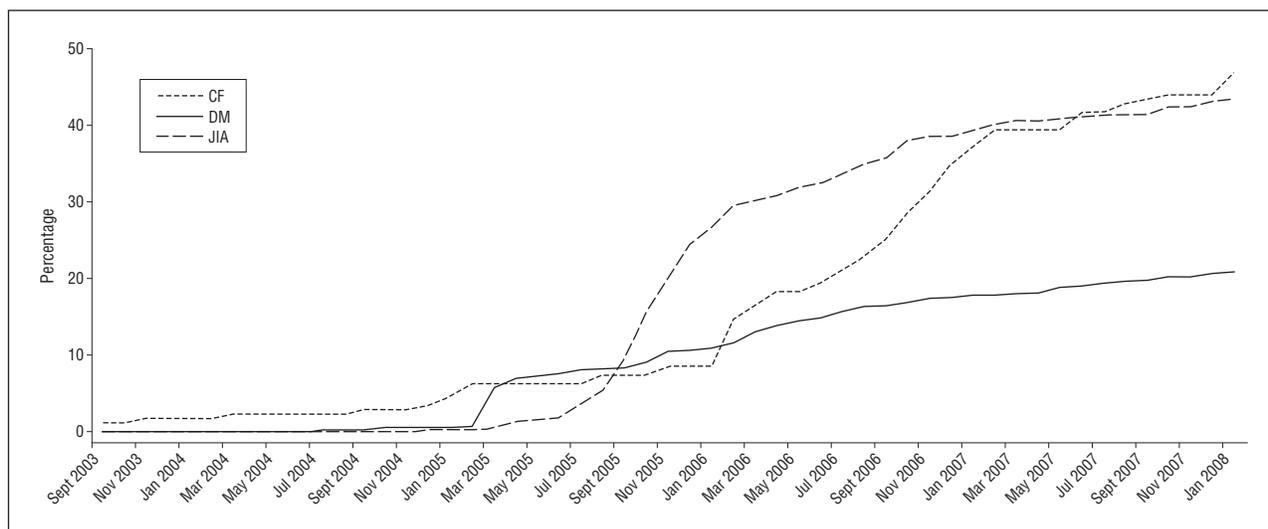


Figure 2. Cumulative percentage of families obtaining a portal account, by disease. CF indicates cystic fibrosis; DM, diabetes mellitus; and JIA, juvenile idiopathic arthritis.

ers. A similar pattern was seen among African Americans. Also, the mean number of outpatient visits for the total study population was 2.0 compared with 4.4 for ongoing portal users.

Tables 3, 4, and 5 summarize the predictors of portal registration and use. The odds ratios in Table 3 show that registration is associated with more outpatient visits. African Americans and those insured by Medicaid were less likely to register. Table 4 shows that among portal registrants, parents of patients insured by Medicaid were less likely to use the portal. Also, compared with parents of patients with CF, parents of patients with DM and JIA were less likely to be portal users. The number of outpatient visits trended toward significance (odds ratio [95% confidence interval], 1.12 [0.98-1.39]). Given that patients with CF had the highest average number of outpatient visits, it is difficult to discern whether the disease, health care use, or both function as predictors of initial portal use. Table 5 shows that among initial portal users, parents of patients insured by Medicaid were less likely to be ongoing users and that more outpatient visits were associated with ongoing portal use.

Table 6 summarizes descriptive statistics for the number of times portal users had accessed the portal and the length of their sessions. The mean number of times families used the portal was 4.5 within 3 months of registration and 7.2 times if they continued portal use 3 to 6 months after registration. These data are positively skewed, with the median number of times families accessed the portal equaling 2.0 for both time periods. The weighted mean session length was 5.0 and 6.1 minutes within 3 months and 3 to 6 months after registration, respectively.

COMMENT

In this population, 27.9% of families obtained a portal account. Although not completely comparable, Kaiser Permanente reported that member household ability to access electronic health services grew to 14% during a 3-year period.²¹ The population in that study consisted of adults, not all of whom had a chronic disease, and did not include access to an EHR. Group Health reported that

Table 2. Characteristics of the Study Population, Portal Registrants, and Portal Users^a

Characteristic	Study Population (N = 1900)	Registrants (n = 530)	Initial Users (n = 238)	Ongoing Users (n = 79)
No. of hospitalizations, mean (median) ^b	0.11 (0)	0.10 (0)	0.16 (0)	0.25 (0)
No. of outpatient clinic visits, mean (median) ^b	2.0 (2)	2.5 (2)	3.2 (2)	4.4 (2)
Mean age of child, y	12.0	11.6	11.3	11.8
Race, %				
White	82.9	89.1	88.2	89.9
African American	8.9	2.5	1.7	1.3
Other	8.2	8.5	10.1	8.9
Medicaid insurance, %	23.1	11.2	9.2	3.8
Female sex, %	55.8	57.4	54.6	45.6
Family residence area, %				
Large metropolitan	80.2	79.8	78.6	79.8
Small metropolitan	11.3	13.4	13.9	11.4
Rural	8.5	6.8	7.6	8.9

^aPercentages may not total 100 because of rounding.

^bDuring the calendar year of 2007.

Table 3. Predictors of Portal Registration Among 1900 Families

Predictor	OR (95% CI)
No. of outpatient clinic visits	1.20 (1.11-1.30)
Disease	
Cystic fibrosis	1 [Reference]
Juvenile idiopathic arthritis	1.77 (1.07-2.93)
Diabetes mellitus	0.61 (0.38-0.96)
Race	
White	1 [Reference]
African American	0.31 (0.17-0.56)
Other	1.14 (0.76-1.64)
Insurance type	
Private	1 [Reference]
Medicaid	0.35 (0.26-0.48)

Abbreviations: CI, confidence interval; OR, odds ratio.

25% of its members had registered to access their shared medical record during a 3-year period.¹¹ At Beth Israel Deaconess Medical Center, 11% of patients had registered for and used a portal at least once during a 4-year time period.²² Thus, although portal registration in our population was fewer than hypothesized, it exceeded that reported by other large organizations.

In our study, less than half of portal registrants used the portal within the first 3 months of registration and even fewer (15.9%) continued to use it (Figure 1). This magnitude of decline was seen in another study of primary care practices, which showed that during a 3-month time period, the percentage of portal registrants who logged in at least once declined from 76% to slightly more than one-third.²² One possible explanation for the decline in portal use in our study is that most test results are given to the parent at the time of the clinic visit.

Similar to other studies of adults, our study showed disparities in accessing electronic health data by race and insurance status. Hsu et al²¹ found that individuals of a race other than white and those living in neighborhoods of lower socioeconomic status were less likely to take advantage of Internet-based health services. An-

Table 4. Predictors of Initial Portal Use Among 498 Portal Registrants

Predictor	OR (95% CI)
No. of outpatient clinic visits	1.12 (0.98-1.39)
Disease	
Cystic fibrosis	1 [Reference]
Juvenile idiopathic arthritis	0.06 (0.02-0.20)
Diabetes mellitus	0.07 (0.02-0.24)
Insurance type	
Private	1 [Reference]
Medicaid	0.44 (0.22-0.90)

Abbreviations: CI, confidence interval; OR, odds ratio.

Table 5. Predictors of Ongoing Portal Use Among 238 Initial Portal Users

Predictor	OR (95% CI)
No. of outpatient clinic visits	1.33 (1.21-1.46)
Insurance	
Private	1 [Reference]
Medicaid	0.30 (0.11-0.84)

Abbreviations: CI, confidence interval; OR, odds ratio.

other study²³ showed that secure electronic messaging between patients and health care professionals was less frequent among patients with Medicaid and older adults, and a study of community practices²² concluded that non-registrants in a patient portal were more likely to be of a race other than white and to be insured by Medicaid. Finally, a study of the use of an electronic PHR in a large health network²⁴ showed that users were more likely to be white.

Study results concerning the association of health care use with portal use have not been as consistent. In our study, health care use measured by the number of outpatient visits was positively associated with registration and portal use. Similarly, Miller et al²⁴ concluded that sicker patients, as measured by the number of health prob-

Table 6. Descriptive Statistics for Portal Use

Variable	No. of Times Logged In		Session Length, min ^a	
	Initial Users	Ongoing Users	Initial Users	Ongoing Users
Mean (SD)	4.5 (7.8)	7.2 (14.9)	5.0 (4.4)	6.1 (7.9)
Median	2.0	2.0	3.8	4.0
Range	1.00-69.0	1.00-72.0	0.02-29.6	0.10-59.0

^aOwing to the large variation in the number of times families logged in, weighted session length statistics were calculated.

lems and clinic visits, were more likely to be users of an electronic PHR. However, Weingart et al²² found that portal registration with access to the EHR of the patient was associated with fewer office visits.

The results from our study and others support the notion that incongruity exists among patients between reported interest in using EHRs and actual behavior. A survey by the Markle Foundation showed that 65% of US residents are interested in accessing their electronic PHR and that a relatively high level of interest exists regardless of age and race.²⁵ Another large survey of adult patients resulted in 36% of respondents stating they were interested in reading their medical record. Health status, health care use, educational level, and income level were not related to interest level.²⁶

Among our population of parents of children with a chronic disease, 27.9% had registered for portal use after marketing efforts were enacted by the clinics to build awareness and promote registration. Significant disparities by race and insurance status were found, indicating that barriers to adopting these tools may exist, especially among racial minorities and publicly insured families. Tang et al¹⁸ suggest a need exists to better understand how a PHR fits into the daily activities of an individual, which is especially important for parents of children with chronic diseases who require more time and family resources to manage the child's disease.

Our study population involves 3 diseases from 1 geographic area, which may limit generalizability to other settings and chronic diseases. Another limitation is that we do not have data concerning the various marketing efforts used and the ways health care providers engaged families in discussions regarding the portal. Thus, we cannot gauge the effect marketing efforts and provider communication had on portal registration and/or use, which could account for some of the variation in portal registration and use across outpatient clinics. Also, we collected data only from the parents of children with chronic diseases, not the patients themselves. Although 26 of the 530 families had multiple user names, we could not discern whether they belonged to parents and/or patients. It is also conceivable that families had multiple users for single user names, but we could not tell which family members had accessed the portal.

The first step toward understanding how portals can be used to improve self-management and patient-provider interactions, which could ultimately improve outcomes for children with chronic diseases, is to better understand the feasibility of portal use among the parents of patients. Subsequent studies should address the value, if any, that families perceive portals add to the man-

agement of the chronic disease of their child and should suggest ways to increase that value. It will be important to study ways that families might incorporate portals into the daily management of the disease of their child and potential incentives for families to access patient portals. An important next step will be to determine barriers to using portals among racial minority and publicly insured families so that disparities regarding access to such resources can be addressed and ultimately lessened or eliminated.

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Author Contributions: Drs Byczkowski and Britto had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. *Study concept and design:* Byczkowski and Britto. *Acquisition of data:* Munafo and Britto. *Analysis and interpretation of data:* Byczkowski, Munafo, and Britto. *Drafting of the manuscript:* Byczkowski. *Critical revision of the manuscript for important intellectual content:* Byczkowski, Munafo, and Britto. *Statistical analysis:* Byczkowski. *Obtained funding:* Britto. *Administrative, technical, and material support:* Byczkowski, Munafo, and Britto. *Study supervision:* Britto.

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Americans will spend nearly \$1.8 billion on Halloween candy this year. As rates of childhood obesity continue to climb, we owe it to our children to reprioritize. Nearly 1 in 3 children are overweight or obese in the United States, causing them to face a lifetime full of chronic disease stemming from obesity, and—for the first time—an even shorter lifespan than their parents.

—Penny Lee, "Halloween Need Not Haunt Childhood Obesity Epidemic," *The Huffington Post*, October 29, 2010