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An Inventory of Healthy Weight Practices in Federally-Funded Hemophilia Treatment Centers in the United States

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Abstract

In the hemophilia population, obesity has an adverse effect on health care cost, chronic complications, and joint disease. Although staffs of federally-funded Hemophilia Treatment Centers in the United States (HTCs) anecdotally recognize these outcomes, practices to promote healthy weights have not been reported. This evaluation identifies routine practices among HTCs in body mass index (BMI) assessment, perceptions about need to address obesity, and roles in offering evidence-based strategies to promote healthy weights. A telephone survey was developed to assess HTCs practices including patient BMI assessment and counseling, perceptions about the importance healthy patient weights, and HTCs roles in weight management. Ninety of the 130 federally-funded HTCs contacted elected to participate and completed the telephone survey. Of these, 67% routinely calculated BMI and 48% provided results to patients. Approximately one third classified obesity correctly for children (30%) and adults (32%), using the Centers for Disease Control and Prevention (CDC)'s BMI cutoffs. Most HTCs (87%) reported obesity as an issue of “big” or “moderate” concern and 98% indicated HTC responsibility to address this issue. Most centers (64%) address patient weight during comprehensive visits. One third (33%) of centers include a nutritionist; of those without, 61% offer nutrition referrals when needed. Most (89%) HTCs do not have a protocol in place to address healthy weights; 53% indicated guidelines

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are needed. HTC offer services to help improve weight outcomes. Training programs for calculating and interpreting BMI as well as identification of appropriate guidelines to apply to the HTC patient population are needed.

Introduction

Overweight and obesity are associated with adverse health outcomes such as heart disease, diabetes, some cancers, hypertension, stroke, liver disease, gallbladder disease, sleep apnea, respiratory problems, and osteoarthritis [1]. Mental health outcomes may include stigmatization, discrimination, and lowered self-esteem. Overweight is identified by a body mass index (BMI) between 25 and $<30 \text{ kg/m}^2$ for adults, and 85th to $<95^{\text{th}}$ age- and sex-specific percentiles for children (aged 2–19 years); obesity is identified by a BMI of ≥ 30 for adults and 95th percentile for children [1, 2]. In 2009–2010, 35.7% of U.S. adults were obese; 16.9% of U.S. children and adolescents were obese [3]. Recent estimates of the annual medical costs of obesity are as high as \$147 billion [4]. On average, persons who are obese have annual medical costs that are \$1,429 more than for those with a normal weight [4].

In contrast to current understanding about obesity-related health risks for the general population, the study of overweight and obesity-related health risks faced by individuals with bleeding disorders is in its infancy. Persons with hemophilia are living longer and therefore are at risk for developing chronic conditions that may be further complicated by overweight/obesity [5, 6, 7, 8]. Emerging evidence makes the importance of obesity prevention clear. Obesity has become a key public health problem for the hemophilia population [7].

Analysis of data from CDC's Universal Data Collection System (UDC) collected between May 1998 and May 2002 revealed that the prevalence of overweight and obesity among children and youth with hemophilia in the US was similar to that among the general population [9]. Interestingly, in a 2011 Canadian study of boys under 18 years of age with hemophilia, the prevalence of obesity was increased for those with severe hemophilia compared to those with mild or moderate hemophilia [8]. Furthermore, when compared to Canadian population data, hemophilic boys who were 2–5 years old tended to have a higher prevalence of overweight and obesity compared to the age-matched Canadian population. In contrast, the prevalence of overweight/obesity was similar among older hemophilic boys and the age-matched general population.

Soucie, et al. [9], studied the relationship between joint range of motion and age for a national sample of U.S. children and adolescents with hemophilia, aged 2–19 years old using multivariate analysis of UDC data. Higher body mass index (BMI) was associated with decreased joint range-of motion (ROM) regardless of the severity of hemophilia [9]. Additionally, joint ROM became more limited as age and BMI increased. In a subsequent study, Monahan, et al. [7], carried out multivariate analysis of UDC data to identify predictors of physical functioning in boys with hemophilia, aged ≥ 18 years. Obesity was associated with increased risk for inactivity and limited mobility as indicated by use of mobility aids including crutches/walkers and wheel chairs.

Financial costs related to factor replacement can be great. Factor products have been shown to account for the majority of annual costs for hemophilia care. Johnson et al. summarized studies from 1998–2007 and showed that clotting factor costs account for 45%–93% of the total health care cost for hemophilia depending on severity and treatment regimen [10]. Guh et al. showed that the annual mean expenditures for health care during 2008 for Medicaid-enrolled children with hemophilia were \$113,867 and \$142,987 for adults with hemophilia [11]. Further complicating the cost is the fact that, product dosage is currently based on body weight as opposed to ideal body weight. As a result, factor usage and cost are increased by overweight and obesity. For instance, analysis of a large U.S. health care medical claims database from 2001 to 2007 revealed that the median hemophilia-related cost per kg over 4 years for non-inhibitor patients, ranged from \$837 to \$1043 [12].

Although overweight and obesity are health problems faced by many people with hemophilia, little has been documented about the knowledge of providers or current practices of hemophilia treatment programs related to weight management and obesity prevention. To address this gap, the CDC Healthy Weight Working Group conducted a survey of federally funded Hemophilia Treatment Centers (HTC) to identify routine clinical practices of BMI assessment, perceptions about the issues of overweight and obesity, and the role of HTCs in assisting patients with bleeding disorders to attain and maintain a healthy weight.

Materials and Methods

Subject protection

No HTC patient data were collected as part of this evaluation and participation by HTC staff implied consent to take part in the evaluation.

Sample

A representative from each of the 130 federally funded HTCs was contacted by telephone between May and August 2009 and invited to participate in this survey of routine clinical practices. Ninety HTCs from all 10 regions of the Maternal and Child Health Bureau (MCHB), U.S. Department of Health and Human Services, elected to participate.

Data Collection and Analysis

Data to address the objectives of this assessment were obtained using a telephone survey administered to participating HTCs. The survey instrument was developed with input from members of CDC's Division of Blood Disorders and the HTC-affiliated Healthy Weight Working Group. Survey items were developed to address centers serving both adults and children; some of the questions used were adapted from the unpublished survey tools used in the 2009 MMWR Assessment Body Mass Index Screening of Elementary School Children [13]. Items were selected with the underlying goal of identifying how HTCs assess weight and describing approaches used to help patients reach or maintain a healthy weight.

Questionnaire development

The questionnaire consisted of three sections, and is shown in Appendix A. The first section addressed the ways in which BMI was defined, measured and collected. Standard definitions for overweight and obesity for children and adults were used in the survey [1,2]. The second section covered questions related to each HTC's perception of weight issues and included questions about the percentage of its patient population estimated to be overweight or obese and how much of a concern obesity was for the center. The third section addressed questions about the HTC's role and programs accessed to address weight issues, time spent during a patient visit addressing these issues, professionals responsible for helping patients maintain a healthy weight, and the geographic location of the respondent's HTC.

Telephone Interview schedule

A structured interview schedule was developed to collect details from the appropriate participating contact in each HTC. All HTCs were identified using the directory of HTCs available on the CDC's Division of Blood Disorders website for hemophilia [14]. From this resource, a list of potential contacts was made for each center that included nurse coordinators, physical therapists, social workers and/or nutritionists. Data were collected during a 30-minute telephone interview with the identified contact at each participating HTC. Interviewers called each facility and asked to speak with the identified contact to discuss activities dealing with weight issues for each facility. A maximum of three attempts were made to reach a representative from each facility within the set time frame. The interviewer adhered to a standardized, structured interview protocol.

Data management and Analysis

Data were entered into a database using Microsoft Excel. IBM SPSS v 19.0 software was used for data management and statistical analysis [15]. Descriptive statistics, including frequencies and cross tabulations, were applied to summarize characteristics of the participating centers and to quantify screening, education and intervention practices routinely carried out.

Results

Ninety of the 130 HTCs contacted responded to this survey and provided feedback about staff involvement, weight monitoring practices and level of concern and intervention for patient overweight and obesity. For most centers, survey responses were provided by a nurse coordinator, nurse practitioner or research nurse (n=75). At other centers, responses were provided by a clinical, program, or research coordinator (n=9), dietitian (n=4), or by a social worker (n=1) or health educator (n=1). Eighty seven (n=78) percent of centers reported that patients served by their HTC included children, and 83% (n=75) reported that patients served included adults. Ninety-nine percent of HTCs indicated that they routinely documented measured weights and heights in patient charts. Sixty seven percent of centers reported that they calculated BMI for patients at clinic visits. BMI was most often calculated automatically by an electronic medical record (37%) or using a web-based computer program (33%). Almost half of the centers (48%) indicated that they reported BMI results to the patient. Among centers that provided care to adults, 36% used the standard cutoff values

for obesity and for overweight; 44% reported using other or subjective definitions, and 19% did not know the definitions used by their center. For children, 32% used the standard cutoff values for defining both obesity and overweight, while 41% reported using subjective definitions to classify obesity for children, and 26% did not know the definitions used by their center.

Most centers identified obesity as a “big concern” (38%) or “moderate concern” (49%); few centers viewed obesity as a “small concern” (11%) or as “not a concern” (1%). Almost all respondents indicated that helping patients maintain a healthy weight was a shared responsibility that included the patient (99%), family (99%), HTC (98%), primary care provider (97%) and schools (85%). Within the HTCs, all team members (hematologist, nurse coordinator, physical therapist, nutritionist and social worker) were responsible for talking with patients about healthy weight. Fifty-five percent of centers reported spending 0–5 minutes talking with patients of normal weight about the importance of maintaining a healthy weight; two thirds reported spending 5–15 minutes talking with patients who were overweight or obese about the importance of achieving and maintaining healthy weight.

While the majority of centers (64%) regularly provided consultation to patients about healthy weight maintenance at each comprehensive visit, 16% did so sporadically and 18% did not address weight at each comprehensive visit. When educational messages were provided to overweight patients, topics included health risks of being overweight or obese (33%), advice on how to increase physical activity (34%) and follow a healthier diet (21%), make lifestyle changes (15%), use portion control (10%), and decrease TV and computer screen time (3%). Seven percent of centers reported that no educational message was given. For patients who were overweight or obese, 51% of centers reported making referrals to nutritionists external to the HTC for services. In other centers patients were counseled by HTC staff, without other referral (36%). About one quarter of centers (26%) referred patients to a weight management program, 11% referred to a physical therapist, and 11% to the primary care provider for weight management. Only 2% of centers reported using all of these referral strategies, and 10% reported taking none of these actions. Only six centers (7%) had a written protocol or guidelines to address excess weight in their clinic population. Of centers without a written protocol, 53% indicated that a protocol was needed at their center while 13% indicated a protocol was not needed.

Open-ended questions were asked about barriers or benefits encountered in helping patients maintain a healthy weight. The most common topics reported as barriers to helping patients maintain a healthy weight included patient defensiveness, cultural differences, family misconceptions about obesity, distance to the HTCs, and financial barriers. The most common topics reported as benefits of maintaining a healthy weight included fewer joint bleeds, less pain, enjoyment from participating in sports, and increased confidence and self-esteem.

Discussion

This is the first evaluation to assess how HTCs address weight in the hemophilia population. We found that obesity is reported to be a moderate to a major concern for many centers,

consistent with concerns raised nationally. Unexpectedly, we found that while most HTC routinely calculated patient BMI, they did not routinely use the available guideline [1] recommended to identify people that were overweight and obese. This suggests that clinicians may not only need updated information about current weight guidelines, but they also need training in order to better identify these problems. Furthermore, when BMI was calculated, results were not routinely reported to patients. Interestingly, evidence from a national sample of adults indicates that among overweight or obese patients, being told by a physician that they were overweight was associated with more realistic perceptions of their weight, desire to lose weight, and report of recent attempts to lose weight [16]. HTC providers have an important opportunity to educate hemophilia patients about their weight at HTC visits and apply evidence-based approaches to promote behavior changes needed to achieve healthy weight goals.

Few centers reported having a clinic protocol or guidelines to address overweight although most centers reported that they would like to have one. The need to maintain a healthy weight was viewed as a responsibility that should be shared among families, healthcare providers, including HTCs, and schools. Although not investigated by this survey, linkage of HTCs with additional community partners and resources may offer expanded education opportunities for HTC patients and staff to learn about healthy weight maintenance and evidence-based strategies for behavioral change. HTCs can also engage in promotion of policy and environmental changes that will help make dietary improvements and increasing activity feasible and rewarding [17]. The development of guidelines for HTCs to address overweight offers an opportunity to help clinicians systematically and appropriately evaluate patients' BMIs and to take action to support patients' achievement of a healthy weight.

Many HTCs reported patient/family defensiveness about discussion of healthy weight issues as an obstacle in addressing this topic. Guidelines and provider education materials that include practical communication tools would facilitate effective collaboration with patients towards lifestyle behavior changes and improved weight outcomes.

There were a few limitations to our investigation. Most notably, we were not able to interview staff from all the HTCs. We were able to contact only 90 (70%) of the 130 HTCs so findings may not be representative of the full range of treatment center practices in the U.S. However, our sample is geographically diverse, as it includes HTCs from each MCHB region across the nation which constitutes a reasonable representation. Next, since not all people with hemophilia seek care at HTCs there is some concern as to whether these findings could be generalized to the hemophilia population outside of the HTCs. Lastly, since the survey was administered by personnel from the CDC, there is a chance that some of the participants may have given answers deemed more favorable.

Next Steps

We provided a novel assessment of HTC weight practices, and identified opportunities to strengthen clinical and public health practices that address the critical problem of obesity in the hemophilia population. Information gained from this evaluation can be applied to build on the experiences of HTCs. The needs of HTCs identified by this evaluation can be

addressed by developing educational materials and evaluating the effectiveness of interventions to improve weight outcomes of the HTC population.

Conclusion

HTCs recognize that obesity is a risky and costly clinical and public health problem in hemophilia. Patients receiving care at HTCs are more likely to benefit if current NIH guidelines for assessment of BMI are applied consistently and if tools for healthy weight intervention strategies are available to HTC staff. The knowledge gained from this evaluation will be useful in provider training modules; these modules would help improve weight management practices and thus reduce the prevalence of overweight and obesity in people with hemophilia.

Appendix A: Healthy Weight Practices Survey

HTC Name/Region _____

Person Interviewed and (Title): _____

DOCUMENTING AND DISCUSSING BMI

How are height/weight documented in you patient charts?

- Inches/Pounds
- Centimeters/Kilograms
- Both

Are they:

- Self-reported
- Measured
- Both
- Other: _____

How is height measured?

- Measuring tape
- Stadiometer attached to weight scale
- Stadiometer detached from weight scale
- Height measurement scale built into or affixed to the wall (not a mounted stadiometer)
- Unsure
- Other: _____

How is weight measured?

- Triple beam/clinical balance
- Professional rotary pointer mechanical clinical balance
- Professional digital balance with an **attached** display screen (not bathroom style)
- Professional digital balance with a detached **display** screen (not bathroom style)
- Digital bathroom scale
- Manual bathroom scale
- Unsure
- Other: _____

Does your center calculate the Body Mass Index for each patient?

- No
- Yes, if yes, how
 - Computer Program (if yes, list website utilized)
 - Paper and Pencil
 - Electronic Medical Records
 - Unsure
 - Other:

Do you tell your patients their BMIs?

- No
- Yes

If yes, what growth charts do you use to interpret the BMI results for them?

- 2000 CDC growth chart
- Previously developed growth charts
- We don't use a growth chart
- Unsure
- Other: _____

What is your center's definition of **overweight** for children? Adults?

- | | | | |
|------------|---|----------|---|
| (Children) | <input type="checkbox"/> BMI greater than _____ | (Adults) | <input type="checkbox"/> BMI greater than _____ |
| | <input type="checkbox"/> Other _____ | | <input type="checkbox"/> Other _____ |
| | <input type="checkbox"/> Don't Know | | <input type="checkbox"/> Don't Know |
| | <input type="checkbox"/> We don't see adults | | <input type="checkbox"/> We don't see children |

What is your center's definition of **obese** for children? Adults?

- | | | | |
|------------|---|----------|---|
| (Children) | <input type="checkbox"/> BMI greater than _____ | (Adults) | <input type="checkbox"/> BMI greater than _____ |
|------------|---|----------|---|

- | | |
|--|--|
| <input type="checkbox"/> Other | <input type="checkbox"/> Other |
| <input type="checkbox"/> Don't Know | <input type="checkbox"/> Don't Know |
| <input type="checkbox"/> We don't see adults | <input type="checkbox"/> We don't see children |

PERCEPTIONS AND ROLES

How much of a concern is obesity for your center?

- A big concern
- Moderate concern
- Small concern
- Not a concern
- Unsure
- Other

What percentage of your patient population do you feel are overweight _____%

Or obese? _____%

HTC ACTIONS AND PROGRAMS

In your opinion, who is responsible for helping patients maintain a healthy weight? Rank the following from 1 being most responsible to 5 being the least responsible

- HTC
- Patient
- Family
- School
- Primary car provider
- Unsure
- Other: _____

Which HTC team member is responsible for talking to your patients about healthy weight? (Please choose all that apply)

- Hematologist
- Nurse Coordinator
- Physical Therapist
- Nutritionist
- Social Worker
- None
- Other _____

Is there a nutritionist on your team

No

If no, do you offer referrals? Yes No

Yes

If yes, do they come to comp care clinic? Yes No

Other _____

About how much time is spent talking to normal weight patients about the importance of maintaining a healthy weight?

Less than 5 minutes

5-15minutes

More than 15 minutes but less than 30

30 minutes or more

About how much time is spent talking to patients at risk, overweight or obese about the importance of maintaining healthy weight?

Less than 5 minutes

5-15minutes

More than 15 minutes but less than 30

30 minutes or more

With what frequency is consultation for healthy weight maintenance given to patients?

It is done routinely with each comp clinic visit

It is done sporadically with each comp clinic visit

It is done only for patients that are at risk, overweight, or obese

It is not done with each comp clinic visit

Other: _____

For patients who are overweight or obese, what educational messages are given? (No Probes)

Lifestyle Changes

Health Risks of being overweight and obese

Benefits of physical activity and healthy eating

Decrease screen time

Decrease portion size

Modify/Healthy diet

Increase physical activity

- No message is given
- Other (please specify): _____

If a patient is overweight or obese what actions does your center take? (No probes)

- Counsel the patient/family directly
- Refer to a nutritionist
- Refer to a Physical therapist
- Refer to primary care provider
- Refer to weight management program
- All of the above
- None of the above
- Other (please specify): _____

Does your center have a written protocol or guideline to address increasing weight in the patient population?

- No
- Yes
- Unsure
- Other (please specify): _____

If no, do you think a written protocol or guideline to address increasing weight is needed at your center?

- No
- Yes
- Unsure
- Other (please specify): _____

If yes, would you be willing to provide a copy of the protocol or guideline to the CDC?

- No
- Yes

Do you have nutrition, physical activity and/or other intervention programs available to your patients?

- No
- Yes

If yes, please describe.

What percentage of your patients takes advantage of the previously mentioned services?

_____ %

How is the effectiveness of these services assessed?

How well do you feel these services meet the needs of your patient population?

___ Very Well

___ Moderately Well

___ Slightly Well

___ Not Well

___ Unsure

___ Other: _____

What **barriers or obstacles** have you encountered in helping patients maintain a healthy weight? (i.e. is the family food source secure?)

What **benefits or rewards** have you encountered in helping patients maintain a healthy weight?

Do you have anything you would like to share?

Appendix B: Collaborators

EO and SO designed and administered the questionnaire. JD, MR, EA, SM, and MD, with the Healthy Weight Working Group, provided input on survey development. EA, JD and MR designed the evaluation study. EA analyzed data. JD, EA, MR, and EO wrote the paper, with input from SM, MU and MD.

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