Quantifying Nutrition and Weight Management Challenges with Possible Solutions for Individuals with Down Syndrome

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BACKGROUND

• A majority of the 250,000 individuals with Down Syndrome (DS) in the United States are overweight or obese, more so than neurological patients and patients with other intellectual disabilities.

• Such overweight/obesity adds life-limiting comorbidities such as dyslipidemia, hypertension, diabetes, sleep apnea, depression, osteoarthritis and osteoporosis to their already complicated list of medical diagnoses.

• Overweight/obesity can also impact quality of life for individuals with DS. Research has demonstrated that obesity has an impact on community participation, independent living, and self-esteem. Weight becomes yet another stigma for patients with DS who are already “different” from their peers.

• The CDC, National DS Society, and NIH all have identified nutrition, activity, and weight management as research gaps for this population.

Studies Comparing Pediatric Overweight/Obesity Prevalence

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>Group 1</th>
<th>Group 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Curtin et al. (2010)</td>
<td>Children (ages 3-17)</td>
<td>30.4% obese</td>
<td>23.6% obese</td>
</tr>
<tr>
<td>De et al. (2008)</td>
<td>Children (ages 2-18)</td>
<td>24% overt</td>
<td>17% overt</td>
</tr>
<tr>
<td>Slevin et al. (2014)</td>
<td>School children</td>
<td>33% overt</td>
<td>24% overt</td>
</tr>
</tbody>
</table>

PROJECT 1: NUTRITION CHALLENGES

Objective: Understand nutrition challenges identified by individuals with DS.

Methodology: We distributed an IRB approved survey instrument to 33 individuals with Down syndrome, ages 13 and older, who were seen by the Massachusetts General DS Program over a 12-mo timeframe.

Average number of challenges identified by individuals with DS surveyed: 3.9

Main Nutrition Challenges Identified by Individuals with DS

PROJECT 2: OVERWEIGHT/OBESEITY

Objective: Determine the prevalence of overweight and obesity among children and adults seen in our program.

Methodology: We analyzed the Body Mass Index (BMI) of all patients with DS seen in our program from July 1, 2012 to November 1, 2013 via retrospective chart review. Anthropometric measurements were available for 70% of our patients.

In children, 2-19, overweight is clinically defined as a BMI at or above the 85th percentile and lower than the 95th percentile for children of the same age and sex; obesity is defined as a BMI at or above the 95th percentile for children of the same age and sex. In adults, ages 20 and older, overweight is clinically defined as a BMI of 25 kg/m², but less than 30 kg/m²; obesity is defined at a BMI of 30 kg/m² or greater.

Prevalence of Overweight/Obesity in the MGH DS Program

<table>
<thead>
<tr>
<th>Ages</th>
<th>Gender</th>
<th>N</th>
<th>% Overweight</th>
<th>% Obese</th>
<th>% Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>2-19</td>
<td>Female</td>
<td>33</td>
<td>36%</td>
<td>18%</td>
<td>54%</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>40</td>
<td>35%</td>
<td>30%</td>
<td>65%</td>
</tr>
<tr>
<td>20-60</td>
<td>Female</td>
<td>88</td>
<td>23%</td>
<td>58%</td>
<td>81%</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>120</td>
<td>38%</td>
<td>42%</td>
<td>80%</td>
</tr>
<tr>
<td>All Ages</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-19</td>
<td>Female</td>
<td>121</td>
<td>26%</td>
<td>47%</td>
<td>73%</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>160</td>
<td>35%</td>
<td>39%</td>
<td>77%</td>
</tr>
<tr>
<td>20-60</td>
<td>Female</td>
<td>281</td>
<td>33%</td>
<td>42%</td>
<td>75%</td>
</tr>
</tbody>
</table>

PROJECT 3: TECHNOLOGY USAGE

Objective: Assess the use of mobile technology in individuals with DS to better understand the promise that nutrition apps may hold for this technologically adept community.

Methodology: Same as Project 1

64% Percentage of individuals surveyed using a smart phone or tablet

Down Syndrome and Smart Phone/Tablet Usage (n=21)

- Mean # of devices owned: 1.7
- Mean # of daily minutes independent when using device: 105 minutes
- Percentage of individuals using apps: 90%

PROJECT 4: BMI TREND

Objective: Better estimate the natural BMI trend for individuals with DS.

Methodology: Longitudinal height and weight data for 35 randomly selected individuals with DS were abstracted from their medical records, including 2 to 4 visits spanning 6 to 12 months. A crude estimate of 6-month change in BMI was calculated as percent change from baseline to the follow-up assessment closest to 6 months (and not outside 4 to 8 months). A more detailed estimate of change in BMI was obtained from variance components estimated from a random-dmons linear mixed model that used all data.

Results: The crude estimate of 6-month percent change in BMI was an increase of 0.35 kg/m² or 3.1% with a standard deviation (SD) of 1.43 kg/m² or 4.5% among the 35 patients with applicable follow-up schedules. The model estimated variation in 6-month change in BMI was a SD of 1.45 kg/m² or 4.7% given a mean baseline BMI of 31.5 kg/m², quite close to the crude estimate.

PROJECT 3: TECHNOLOGY USAGE

- Mobile devices used by individuals with DS
  - iPhone/iPad/iPad mini
  - Kindle
  - Android tablets

CONCLUSIONS

- Nutrition interventions are necessary because the natural trend is for BMI to increase, rather than stay the same, over time.
- Variation in BMI change is substantial, so large sample sizes are needed for future nutrition projects in order to provide adequate power to detect modeled differences in BMI change.
- Improvement in BMI is easier for younger children and young adults with DS to help [them] live a healthier life.

REFERENCES


CONTACT

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Project 1: Nutrition Challenges
- When asked, individuals with Down syndrome identify an average of 3.5 nutrition challenges. The most common nutrition challenges were: exercising more, losing weight, choosing healthier snacks, and eating smaller portions.

Project 2: Overweight/Obesity
- Overweight/obesity has a disproportionate burden on individuals with DS when compared to the total population.

Project 3: Technology Usage
- Mobile devices may hold promise for this community because of a high percentage of individuals with DS using smart phones or tablets, as well as a high percentage interested in an app created specifically for people with DS to help [them] live a healthier life.

Project 4: BMI Trend
- Nutrition interventions are necessary because the natural trend is for BMI to increase, rather than stay the same, over time.

Variation in BMI change is substantial, so large sample sizes are needed for future nutrition projects in order to provide adequate power to detect modeled differences in BMI change.