

Background

Physicians and patients may vary significantly in their prioritization of health concerns. Failure to address patients' health priorities can lead to poor chronic condition management and disengagement with the healthcare team. The Baylor College of Medicine Transition Medicine Clinic is a patient-centered medical home in an academic setting for adults with intellectual/ developmental disabilities. The second most common diagnosis among our patients is Down syndrome (19%). In efforts to improve patient health and adherence to chronic condition office visits, we surveyed our patients with Down syndrome and their caregivers asking about their health priorities and educational preferences for addressing their health concerns.

Objective

To understand the health education priorities and educational preferences reported by adults with Down syndrome and their caregivers.

Design/Methods

We created a web-based survey asking respondents to rate up to three topics on which they wanted further education. Topics were generated based on issues commonly addressed during visits (see Figure 1). Respondents also rated their preferred way of receiving health-related education (see Figure 2). Demographic questions included: role of person completing the survey and patient's age and sex. The survey was in both English and Spanish.

The survey was disseminated to patients with an active MyChart secure messaging account in the electronic health record (EHR). Additionally, patients and their caregiver seen in clinic between June – December 2019 were offered the opportunity to complete the survey in clinic via iPad if they had not already completed the survey. Patients (if able) and their caregiver were asked to complete separate surveys. Survey data were analyzed using analysis of variance and the Mann-Whitney U-test.

Results

Table 1 describes 135 survey respondents. Figures 1 and 2 report overall survey results. There were no statistically significant differences between patients and parent caregivers regarding health topics of interest.

Regarding preferred ways to discuss health topics, noting that lower mean ratings were more positive:

- The only significant differences were between patients and parent caregivers as shown in Table 2.
- There tended to be more interest in nutrition for older patients rather than for younger patients ($r=.426$, $p=.002$).
- However, there were no significant differences based on patient age, sex, or survey language.

Table 1. Participation and Demographics

Respondents		
Patient	21	(15.6%)
Parent	97	(71.9%)
Sibling	7	(5.2%)
Nurse	1	(0.7%)
Other/Other Family	9	(6.7%)
Total	135	(100.0%)
Patient Sex		
Female	64	(47.4%)
Male	69	(51.1%)
Not Reported	2	(1.5%)
Total	135	(100.0%)
Patient Age		
Range	19 – 60	
Mean (SD)	30.16	(10.428)
Survey Language		
English	117	(86.7%)
Spanish	18	(13.3%)
Total	135	(100.0%)

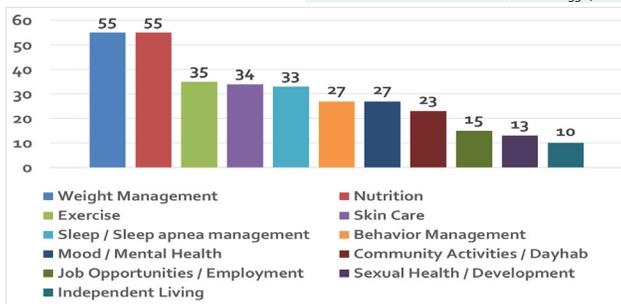


Figure 1. Frequency of Health Topic Selection by Patients/Caregivers

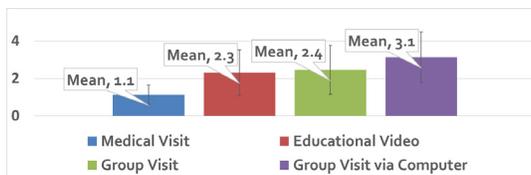


Figure 2. Preferred Education Method Ratings (1=Definitely Yes; 5=Definitely No)

Results (continued)

Table 2. Statistically Significant Differences for Various Survey Results

Variable	N	Mean	Std. Dev	p
Preference for Group Computer education				
Patient	15	2.28	1.534	.011
Parent	67	3.30	1.255	
Preference for Group Visit				
Patient	16	1.75	1.000	.030
Parent	75	2.52	1.298	

Discussion

The three health priorities most commonly rated by adults with Down syndrome and their caregivers were: weight management, nutrition, and exercise. These findings are not surprising given the prevalence of obesity and weight related issues in individuals with Down syndrome. Results also suggests that educational efforts may be best received face to face during an office visit.

Study limitations include small, non-randomized sample. Therefore findings may not be generalizable beyond this group. If, however, this sample more or less represents the clinic as a whole, then results could possibly generalize to the greater population of individuals with Down syndrome.

Conclusions

This study helps inform healthcare providers on issues of importance to and educational preferences of adults with Down syndrome and their caregivers. This study highlights the importance of asking patients/caregivers about concerns other than their presenting problems.

References

Tomsik, P., Witt, A., Raddock, M., DeGolia, P., Werner, J., Zyzanski, S., ... Flocke, S. (2014). How well do physician and patient visit priorities align? *Journal of Family Practice*, 63(8), E8–E13. Retrieved from https://mdedge-files-live.s3.us-east-2.amazonaws.com/files/s3fs-public/Document/September-2017/JFP_06308_ArticleW2.pdf.