

A Pilot study of short-term outcomes of a community based weight management program for culturally diverse children with Intellectual Disability

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Abstract

Aim: To describe the short-term outcomes of a pilot, community based weight management service for overweight and obese culturally diverse children and adolescents with intellectual disability

Methods: A retrospective review of case notes was conducted for patients seen by the dietitian and exercise physiologist over a 12-month period between 1 January 2017 and 31 December 2017. The main outcome measure was individual change in BMI z-score. Simple descriptive analysis of the data was performed.

Results: Of 60 patients attending the service, 41 (68.3%) were referred specifically for weight management, of which 32 patients had sufficient data for analysis. Nineteen of 32 patients (59%) achieved a reduction in BMI z-score, with a mean change of -0.1 points. Analysis showed that younger age at referral and higher initial BMI were significantly associated with a greater reduction in BMI z-score. There was a trend for patients on psychotropic medications to be less likely to achieve BMI z-score reduction. In addition, patients attending the service for prolonged periods trended towards better outcomes.

Conclusions: This pilot study improved access to care and demonstrates a trend towards positive short-term weight reduction in vulnerable children and adolescents with intellectual disability, and underscores the importance of early intervention. Future research should include larger sample sizes and longer study periods to understand long-term health and weight outcomes.

Introduction

Children and adolescents with Intellectual Disability (ID) are highly vulnerable and experience a higher prevalence of morbidity compared with the general population (Cooper, Melville and Morrison, 2004). Common health problems include vision and hearing impairments, dental health issues, respiratory illness, musculoskeletal, gastrointestinal, mental and neurological health problems. People with ID are at increased risk of lifestyle related health issues such as physical inactivity, poor nutrition and being in an unhealthy weight range (Health NDo, 2006). A range of biopsychosocial and developmental



factors are barriers to accessing health services for this group of children (Cooper, Melville and Morrison, 2004).

The burden of childhood obesity is a major public health issue globally. In 2015, in the state of New South Wales in Australia, a school based survey reported a quarter of children and adolescents to be overweight or obese (Hardy *et al*, 2017). In children with ID, the prevalence of overweight and obesity is even higher (De, Small and Baur, 2008; Emerson and Robertson, 2010). Unhealthy weight issues predispose children with significant physical and psychological health consequences in both the short and long-term (Sahoo *et al*, 2015; Schwimmer *et al*, 2003; Chisholm, Alexander and Barzi, 2014). They are at increased risk of developing cardiovascular disease, metabolic syndrome and diabetes at a younger age.

Lifestyle interventions promoting dietary modification and increased physical activity are recommended as the first line treatment for weight issues in children and adolescents (Goldschmidt, 2013). There is very limited evidence, however, regarding effective weight management strategies for children with intellectual disability, particularly for culturally and linguistically diverse populations (Must *et al*, 2014; Donnelly *et al*, 2016; Ptomey *et al*, 2016).

A pilot, community based weight management service was established in a highly culturally diverse region of South Western Sydney in Australia. This service is a component of one of the pilot health teams established and funded by the state government, to increase accessibility for health needs of children and adolescents with ID living in an area with high measures of social disadvantage (SWSLHD, 2016; SWSLHDb, 2016). The rationale of this service was based on the fact that socio-economic disadvantage will compound the likelihood of childhood obesity and barriers experienced by linguistically diverse families (Wang, Patterson and Hills, 2002; Cyril *et al*, 2017).

The aims of this report is to study the profile of children referred to the dietitian and exercise physiologist component of the team and identify the factors that may impact on the achieved outcomes.

Method

Ethics approval for the study was obtained from the quality improvement program run by the local health service (approval number 5924).

Participants and Intervention

A retrospective chart analysis was conducted for patients seen by the weight management team during the period 1 January 2017 to 31 December 2017. Patients typically attended combined dietitian and exercise physiologist appointments with their primary carer. A family-based, individualised counselling approach as summarised in

“They are at increased risk of developing cardiovascular disease, metabolic syndrome and diabetes at a younger age”

the report by Barlow, was used to promote behaviour change (Barlow, 2007). This involved education regarding nutrition and physical activity, identification of unhealthy lifestyle behaviours, realistic goal setting, and problem solving to help families implement and sustain lifestyle changes.

Patient involvement in this process was optimised as appropriate to their intellectual ability and willingness to engage. Interpreters were used for the appointments where patients and/or their families have low English proficiency. The allied health team also frequently **collaborated with the service’s medical team, school staff, case managers and other allied health therapists**. The majority of participants of the program also accessed nationally funded disability services, thus liaison with support coordinators for achieving health and wellbeing goals was important.

Interventions done by the weight management team

Exercise Physiology

Once the individual was cleared medically, a targeted exercise program was developed for the family and several communication, instructional strategies, activity modification and behavioural reinforcement methods such as motivational interviewing were employed. The program often started with walking or jogging for 30 minutes, followed by weekly increases in speed to promote physical endurance. Similarly riding a stationary bicycle and increasing the resistance at appropriate intervals was used using clinic appointments. Wherever, possible support workers were used for weekly walks on the weekends, and local community pools catering to programs such as swimming were encouraged. If the cognitive ability permitted, gentle lunges, and pushes and simple movement exercises of major joints were also encouraged. These were also developed in partnership with school teachers to incorporate as part of the **student’s physical activities learning plan at schools**. the program focussed on the suitability of exercise selection, sequence, and variety with physical fitness assessments that included the range of movements, strengths and posture.

Dietetics interventions

The dietary intervention was focused on parental health education, providing individualised information on the **patient’s dietary requirements for achieving a healthy balanced diet**. This included education on core food groups, portion sizes, improving kilojoule intake through

balanced carbohydrate, fat and protein distribution, increasing fruit and vegetable intake, healthy snack and meal options, environmental controls and managing food seeking behaviour. For many of the patients who presented with selective eating behaviours, education and support was provided on achieving positive family mealtime experiences and consideration of their sensory food preference to assist with acceptance and tolerance of new healthier foods. Health coaching methods were used by the dietitian to facilitate lifestyle changes, though goal setting and self-monitoring. The dietitian also worked collaboratively with some of the patient's school teachers to implement these goals within the school environment.

Data collection

Service related data and patient information was collected from the electronic medical records. This included total occasions of service, attending therapists, stage of intervention, appointment location and reasons for referral. Baseline patient data included age, gender, level of ID, presence of autism spectrum disorder (ASD), use of psychotropic medications, year of initial appointment, and whether an interpreter was required at appointments. Whenever available, pathology results were also collected, including blood glucose, insulin, lipid profile, and liver functions tests. Anthropometric data [Body Mass Index (BMI), BMI percentile and z-score using Centre for Disease Controls (CDC) Growth charts] was collected at initial and final visits (Ogden *et al*, 2002). Surveys of patient satisfaction on a Likert scale were provided to all parents who had attended at least one review appointment in 2017.

Statistical analysis

A simple descriptive analysis of the demographic data and weight management outcomes was performed. Continuous data on age, initial BMI, number of visits and duration of involvement with the service was categorised into quantile based groups for analysis. Univariate analysis was performed using Analysis of Variance (ANOVA). The factors affecting BMI z-score change was analysed using Chi-Square test for trend. MedCalc Statistical Software version 18.6 (MedCalc Software bvba, Ostend, Belgium) was used to perform the analysis.

Results

A total of 60 patients were seen by the service from 1 January 2017 to 31 December 2017, of which 73.3% (44) were male. The average age at initial appointment was 13.0 years (range 5.5-19.5 years). The majority of patients had moderate or severe ID as determined from cognitive and adaptive assessments by special school services.

Almost two-thirds (63%) had a diagnosis of autism, and all attended schools with significant supports. Participant characteristics are detailed in **Table 1**. The majority of appointments were conducted in English (65%) with a

Age at first appointment, mean (range)	13.0 (5.5-19.5%)
Year of initial appointment	
2017	24 (40%)
2013-2016	36 (60%)
Gender	
Male	44 (73%)
Female	16 (27%)
Interpreter used during appointment	
No	39 (65%)
Yes	21 (35%)
-Arabic	7 (12%)
-Vietnamese	7 (12%)
-Other	7 (12%)
Level of ID	
Mild	5 (8%)
Moderate	23 (38%)
Severe	22 (37%)
Profound	1 (2%)
Unknown	9 (15%)
Reason for referral	
Weight management	41 (68%)
Underweight	8 (13%)
Other	11 (18%)
Autism diagnosis	
Weight management (% of referral group)	38 (63%)
Underweight (% of referral group)	26 (63%)
Other (% of referral group)	2 (25%)
	10 (91%)
Baseline anthropometry - weight management (n=39)*	
BMI, mean (range)	31.2 (20.7-49.9%)
BMI percentile, mean (range)	97.0 (81.0-100%)
BMI z-score, mean (range)	2.2 (0.9-3.7%)

Table 1: Patient profile of weight management service for Intellectual disability children, n = 60

Unless otherwise stated n = 60, expressed as n (%), *Baseline data unavailable for 2 weight management patients



Vietnamese (11.7%) and an Arabic (11.7%) language interpreter being used in other consultations. Most appointments were conducted at the community clinic (73%).

A total of 41 of 60 patients (68.3%) were referred for the management of overweight or obesity. The average BMI z-score was 2.2 points at initial appointment and 85 % had obesity. The average median weight for the overweight/obese group was 76.3 kgs (Interquartile Range 56.6- 93.7 kgs).

Of these 41 patients, 32 patients attended at least one follow up visit. **Figure 1** shows the change in BMI percentile and z-score since commencement of weight management appointments. Nineteen of 32 patients (59%) experienced reduction in BMI z-score with a mean change in BMI z-score of -0.1 (range -1.17 – 0.81). A total of 10 patients achieved a change in BMI z-score greater than 0.25. The median change in BMI for the group that demonstrated weight loss was -2.0 (Interquartile range: -3.0 to -0.87).

A younger age at referral and higher initial BMI were associated with greater negative change in BMI z-scores ($p = 0.02$ and 0.04 , respectively) (**Figure 2, overpage**). Patients taking psychotropic medications and those

involved with the weight management program for a shorter duration were less likely to achieve a reduction in BMI z-score; however, these differences were not statistically significant. There was no association between level of ID, ASD diagnosis or interpreter use.

Six of the 32 (19%) of patient satisfaction surveys were returned. All patients surveyed indicated that they agreed or strongly agreed to the statement: ***“I am satisfied with the services I have received.”***

Discussion

This study demonstrates a trend towards positive short-term weight reduction in children and adolescents with intellectual disability by a pilot weight management service in a community setting. Findings of interest include that nearly 60% of patients, who attended at least two appointments, had a reduction in BMI z-score; and that those referred at a younger age or with a higher initial BMI z-score had a greater reduction.

We obtained a mean BMI z-score change of -0.1 points and almost one-third of children achieved a reduction in BMI z-score of greater than 0.25 points. This is a good outcome, as a BMI z-score reduction of as little as 0.25, can result in improvements in blood pressure, total cholesterol/high-density lipoprotein ratio and insulin sensitiv-

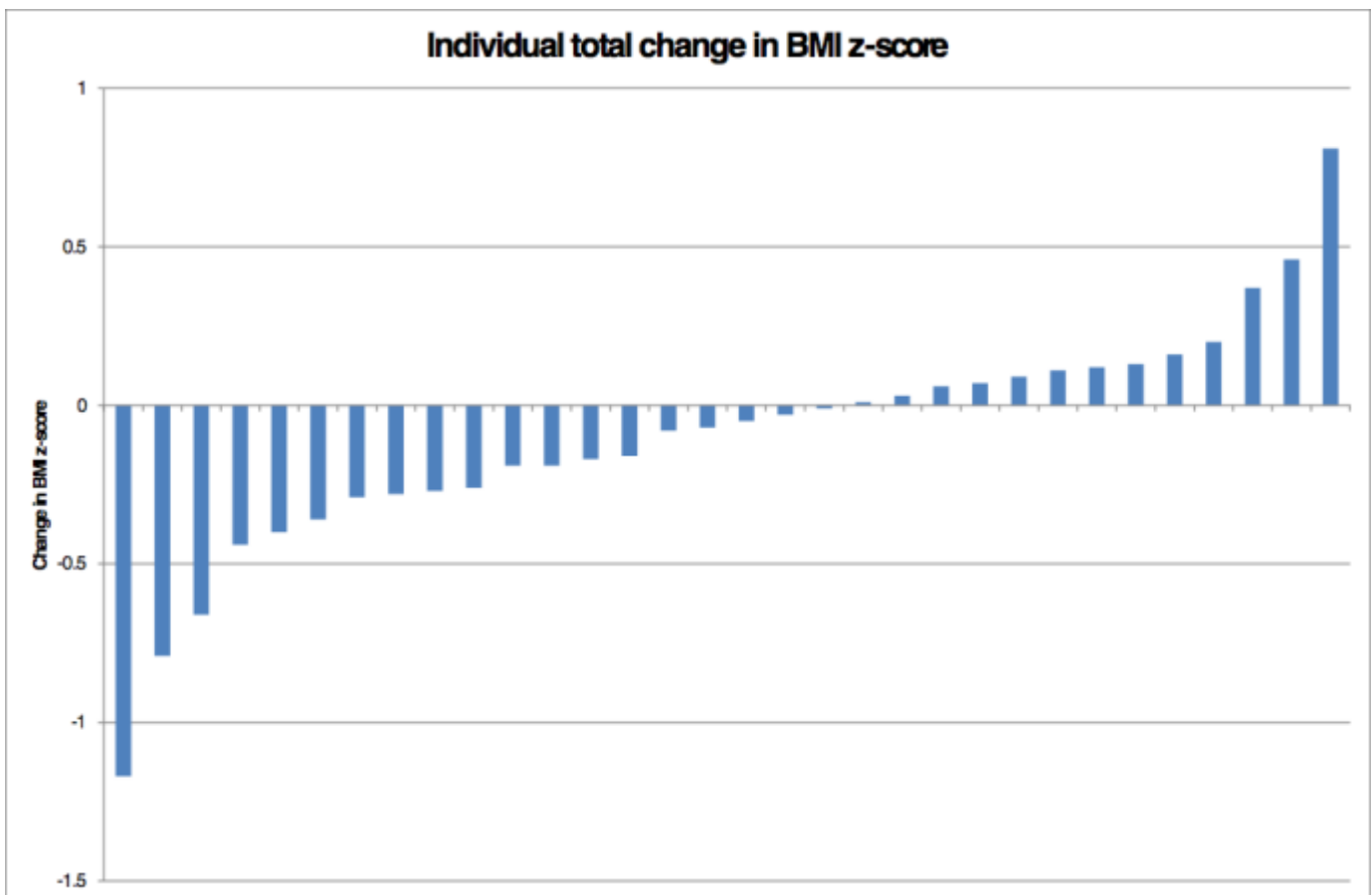


Figure 1: Individual total change in BMI z-score of overweight/obese children of the team (n=32)

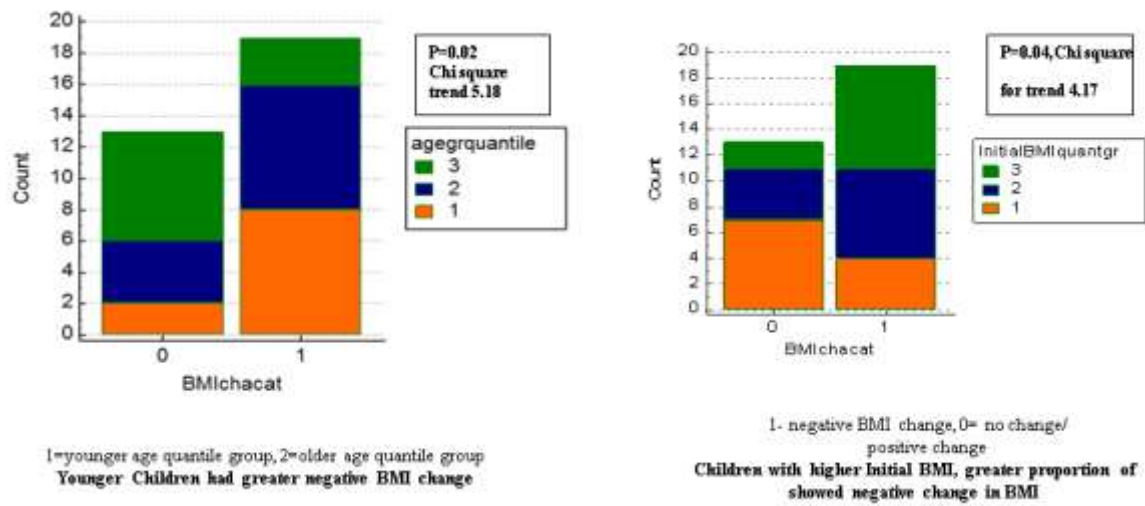


Figure 2. Factors affecting weight management outcomes

ity in obese adolescents (Ford, 2010). Unfortunately, we could not demonstrate this biochemical improvement in our cohort due to unavailability of serial measurements of blood pressure, serum lipid profile and other biochemistry, because of the challenges in obtaining cooperation of children for venipuncture and blood pressure measurements.

In the current study, younger age at initial appointment was associated with greater negative change in BMI z-score ($p=0.02$). This is consistent with previous research showing younger children to have better short-term weight loss and greater possibility of modifying life style behaviours before they become more ingrained in adolescent years (Goldschmidt *et al*, 2013; Reinehr *et al*, 2009; Gow *et al*, 2016).

Higher initial BMI was also associated with greater total negative change in BMI z-score ($p=0.04$) and this is consistent with previous studies in obese children and adolescents (Mameli *et al*, 2017; Braet, 2006). There was also a trend for those involved in the program for a longer duration to be more likely to achieve a negative change in BMI z-score, but this association was not statistically significant due to small size.

The majority of patients seen by the service had a moderate or severe level of ID and 63% of clients referred for weight management had a diagnosis of ASD. Our study found no significant association between severity of ID or ASD diagnosis and weight loss outcomes, however, previous studies have identified that adults with mild-moderate ID are more likely to be obese than those with moderate to severe ID (Fox and Rotatori, 1982).

Six of 39 (15.4%) weight management patients had diagnosed syndromes as the underlying cause of their ID (Lobstein, Baur and Uauy, 2004). Obesity is a clinical feature of some of these syndromes; however, again this

association could not be analysed due to the small sample size.

Centrally-acting medications such as psychotropic medications, often prescribed for managing difficult behaviours in children with ID are associated with excessive weight gain (Hellings *et al*, 2001; Leslie, Hankey and Lean, 2007). In this analysis, patients using psychotropic medications were less likely to achieve a reduction in their BMI compared with those not taking these medications, however this was not statistically significant due to sample size.

About one-third of patients required an interpreter at appointments and several English-speaking patients were from culturally and linguistically diverse backgrounds. This is reflective of the local population profile, where almost 40% of residents are born overseas, and the area is a region of settlement for refugees (SWSLHDb, 2016; SWSLHDc, 2016). Whilst the use of interpreters and the weight management service improved communication, accessibility, patient satisfaction and clinical outcomes, the families in our cohort continued to experience barriers in service engagement, due to psychosocial stressors that were not studied specifically in this report (Cyril *et al*, 2017; Karliner *et al*, 2007).

Strengths and Limitations

This is a first report from Australia that reports the findings of a weight management service working with a vulnerable population of children and adolescents living with ID in an area of disadvantage in Sydney. The limitations of small size and unavailability of biochemical tests limited the interpretation of the findings of our study.

The study cannot ascertain the level of dietary or physical activity change in children who achieved a reduction in BMI z-score compared to those who did not. There was significant heterogeneity in specific interventions due to

the differences in patient and family characteristics, readiness for change and barriers to change (George, Shacter and Johnson, 2011). This highlights that a “one size fits all” approach for this extremely vulnerable population may not necessarily work, and further research should look at groups for targeted interventions.

Another limitation of the study is that the duration of treatment and number of visits was highly variable, which makes comparisons of BMI z-score change challenging. Ongoing data collection and analysis is planned to understand the long-term outcomes of weight management for these children.

Potential factors that may impact body weight and program outcomes, such as socioeconomic status and parental weight status were not been collected hence could not be assessed. In future studies, it would be valuable to collate other physiological data such as waist circumference, blood pressure, pathology results, fitness tests and better markers for body composition.

Conclusions

The findings suggest that a weight management clinic run by a dietitian and exercise physiologist has the potential in reducing BMI z-scores in children and adolescents with ID who are overweight or obese. Sustained engagement and continuity of intervention is needed that has implications for resources. It has been demonstrated that earlier age of intervention and higher initial BMI z-score are factors positively associated with BMI z-score reduction in children and adolescents with ID. These findings highlight the importance of early intervention for weight management in this population, as well as the efficacy of treatment for those at the most extreme weight ranges. The current study should encourage other clinicians and researchers working with children and adults with ID to report their outcomes. There is also a

need for more collaborative research to obtain larger sample sizes. Future research in this population should include data on the level of lifestyle change achieved, multiple physiological outcomes and the impact of psychotropic medications on weight management.

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“These findings highlight the importance of early intervention for weight management in this population”

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