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To cite this article: Amy C. McPherson, Laura McAdam, Sarah Keenan, Heidi Schwellnus, Elaine Biddiss, Andrea DeFinney & Kirsten English (2017): A feasibility study using solution-focused coaching for health promotion in children and young people with Duchenne muscular dystrophy, Developmental Neurorehabilitation, DOI: 10.1080/17518423.2017.1289271

To link to this article: http://dx.doi.org/10.1080/17518423.2017.1289271

Published online: 08 Mar 2017.

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A feasibility study using solution-focused coaching for health promotion in children and young people with Duchenne muscular dystrophy

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\textbf{ABSTRACT}

\textbf{Purpose:} To evaluate the feasibility and acceptability of a coaching intervention (Solution-Focused Coaching in pediatric rehabilitation [SFC-Peds]) related to physical activity and diet in males with Duchenne muscular dystrophy. \textbf{Methods:} A pre-post design was employed. Participants had five coaching sessions over 8 weeks. The first session was face-to-face, followed by four virtual sessions. Feasibility criteria included recruitment rates, attrition, and intervention fidelity. The Canadian Occupational Performance Measure (COPM) and Goal Attainment Scaling (GAS) were employed to look at outcome trends. The acceptability was assessed using a survey. \textbf{Results:} Five males (11–19 years) participated. All feasibility criteria were met. Clinically significant increases were observed for GAS and COPM scores. Participants reported SFC-Peds to be acceptable. Broad barriers and facilitators to coaching success were identified. \textbf{Conclusions:} A SFC-Peds intervention for health promotion is feasible and acceptable in children with DMD and their families. A rigorous efficacy study assessing SFC-Peds intervention is warranted.

\textbf{Introduction}

The World Health Organization’s “Global Strategy on Diet, Physical Activity and Health Promotion” highlighted the key roles that health behaviors related to physical activity (PA) and diet play in disease prevention and promotion of health.\textsuperscript{1} Children with disabilities often experience a range of physical, social, and psychological restrictions leading to sub-optimal health behaviors.\textsuperscript{2–4} Fatigue, pain, incontinence, lack of professional support, and inaccessible fitness/recreational facilities have all been cited as PA barriers.\textsuperscript{5–9} Low PA can lead to mobility and functional restrictions, osteoporosis, depression, social isolation, and reduced overall health and well-being.\textsuperscript{9,10} The current obesogenic environment provides easy access to energy-dense food for all children, but those with disabilities report eating less fresh produce, more “fast food,” more high-fat food, and more chocolate than their non-disabled peers.\textsuperscript{2–4} It is, therefore, both unsurprising and concerning that children with disabilities are 2–3 times more likely to be classified as overweight or obese than those without disabilities.\textsuperscript{11}

One group for whom this is particularly salient is children with Duchenne muscular dystrophy (DMD), a progressive condition affecting approximately 1 in 8400 male births in North America between 2006 and 2010.\textsuperscript{12} Once a disease with a predicted lifespan into the early teen years, management advancements have resulted in the majority of boys living into adulthood,\textsuperscript{13} with one study showing a mean age of death at 27.9 years (range 23–38.6 years) when mechanical ventilatory support was used.\textsuperscript{14,15}

DMD is characterized by muscle degeneration and progressive weakness, resulting in contractures, spinal deformity, restrictive lung function patterns, cardiomyopathy, and variable degrees of cognitive involvement.\textsuperscript{16} Affected individuals typically lose ambulation by approximately 12 years of age, with the natural history of the disease leading to respiratory and cardiac failure.\textsuperscript{13,17,18} Overall, energy expenditure decreases as muscles deteriorate and boys become non-ambulatory and less active, which contributes to sedentary lifestyles, reduced muscle strength and increased fatigue. This in turn leads to functional decline and lowered quality of life.\textsuperscript{19,20} Other limitations on physical activities include decreased muscle extensibility and the presence of joint contractures, so that only sub-maximal activities (e.g., gentle swimming) are recommended.\textsuperscript{15}

Glucocorticoid therapy has been associated with many positive health outcomes for this population, but comes with significant side effects including weight gain, reduced height, glucose intolerance and systemic hypertension.\textsuperscript{17,21,22} Excessive weight gain can prematurely cease ambulation and functional ability, as it fatigues already weak skeletal, respiratory and cardiac muscles.\textsuperscript{13,17,23} It has been suggested that slightly higher weights in early adolescence may potentially prevent later underweight for boys with DMD.\textsuperscript{20} However, this does not negate the benefits of both engaging in positive health behaviors and maintaining a weight that allows optimal functioning.
Practice recommendations highlight the importance of addressing psychosocial functioning in boys with DMD. Given the progressive nature of DMD, the child’s ability to perform everyday tasks declines over time, which can also lead to a lack of independence and social isolation. This in turn results in fewer opportunities to engage in healthy lifestyle behaviors and participate in the community, which in addition to cognitive impairments, can lead to anxiety and depression. Anti-depressant and other mood-stabilizing medications may help promote emotional adjustment and regulation, but can also be associated with weight gain, especially in combination with other medications used in DMD treatment.

The longer lives now seen in boys with DMD have therefore brought new challenges, especially around health promotion. When addressing obesity, simply reducing dietary intake and increasing energy expenditure may result in micronutrient deficiencies and a reduction in lean body mass, with substantial implications for nutritional status and energy in children with DMD. There is currently a lack of evidence-based guidelines around PA for boys with DMD, amid concerns that exercise may cause muscle tissue damage. Much of the work looking at the impact of activity on muscle tissue has been conducted in mouse models, which cannot be directly applied to humans. However, there is a consensus in the literature based on currently available evidence that sub-maximal activities employing concentric exercises (i.e., where a contraction shortens a muscle) can be of benefit to boys with DMD, although eccentric exercises (i.e., where a contraction lengthens the muscle) should be avoided given the vulnerable nature of muscle tissue. A recent RCT of assisted bicycle training in boys with DMD demonstrated greater maintenance of function than those in the control group, with no adverse events reported. Although promising, it underscores the need for carefully tailored health promotion advice.

Methods

An exploratory mixed methods feasibility study was conducted, using a pre-post design. Feasibility studies can fulfill...
multiple purposes. They help evaluate essential methodological components that will inform the later design of a full trial (e.g., processes, resources, management etc.), can examine whether selected outcome measures are appropriate, and explore how acceptable the intervention and trial participation is to participants.51–53

Sample

Formal sample size calculations are inappropriate for feasibility studies, as they are not designed to evaluate intervention efficacy.51,53 We aimed to recruit five participants, which would be sufficient to evaluate the feasibility of recruitment procedures, study coordination requirements and intervention implementation processes.46 All participants attended the neuromuscular clinic at a large urban teaching hospital in Ontario, Canada. Following Research Ethics Board approval, children and youth meeting the inclusion criteria were identified from clinic records, which were screened for suitability by a healthcare professional who knew the clients and was not a member of the research team. Inclusion criteria: (a) primary diagnosis of DMD confirmed by genetic testing; (b) 10–19 years (10 years judged to be the minimum age able to engage with coaching54; 19 years is the maximum age seen by clinic); (c) live within 50 km of the hospital (to make first coaching visit feasible); (d) safe to participate in some form of physical exercise (indicated by physician); (e) able to raise their arms (rating less than 5 on the Brooke Upper Extremity Scale55); (f) able to eat and drink without assistance (to have some autonomy over their dietary intake); (g) able to converse in English; (h) willing to set goals around diet1 and/or PA (to enhance engagement with coaching, judged by the Research Assistant (RA) through conversation with the participant); (i) home has telephone and internet connection (for scheduling sessions and conducting remote coaching sessions, respectively); and (j) child aware of their DMD diagnosis. Exclusion criteria: (a) intellectual disability that precluded goal-setting, judged by medical team members.

Recruitment

Information letters were sent to families with an “opt-out” telephone number. The Research Assistant (RA) telephoned anyone who had not opted out after 10 days, screened children using the full inclusion and exclusion criteria and scheduled a 30-minute appointment during the child’s next hospital visit if they wished to participate.

Measures

For all participants, brief demographic data were collected, including age, medications, use of orthoses or mobility device(s) and sports involvement (both current and previously). Levels of weekday and weekend activity were rated as very inactive, inactive, somewhat inactive, somewhat active, active, very active, modeled on the Habitual Activity Estimation Scale.56 Participants completed these themselves where possible, with parents offering support where needed.

In addition, each study objective employed specific measures:

Objective 1. To determine the feasibility of a full randomized controlled trial of SFC-Peds in boys with DMD

The measures used to determine feasibility were identified a priori, according to best practices.57 These “success criteria” included:

1. A minimum of 10% response rate from all eligible participants (the minimum feasible response rate for RCTs58);
2. 85% of the participants successfully completed the study (i.e., completed outcome measures at both baseline and follow-up);
3. All participants were able to set at least one PA and/or one dietary goal;
4. Participants participated in at least four of the five coaching sessions;
5. Coaches achieved minimum scores of 5 on the Solution-Focused Fidelity Instrument (SFFI), demonstrating high fidelity.59 The scale has 13 items addressing different solution-focused coaching components on a 7-point scale from 1 (not at all) to 7 (yes, clearly and specifically). An example questions is “I complimented the client’s strengths/resources during today’s session”. It has a reported internal consistency of 0.83.59

Objective 2. To explore the potential impact of SFC-Peds coaching on goal attainment

SFC-Peds is operationalized through goal-setting, and therefore two validated and complementary measures were employed to examine any potential impact of coaching on goal attainment. Both are conducted through conversation between a skilled clinician and the child. The Canadian Occupational Performance Measure (COPM) helps to identify person-centered goal performance issues they wish to improve.60 In this study, performance issues were all related to PA and/or diet. Clients rated themselves on both performance and satisfaction with their current ability on a scale of 1 (unable to perform/unsatisfied) to 10 (able to perform/ extremely satisfied). A score change of at least two points is considered to be clinically significant.60 For Goal Attainment Scaling (GAS), the clinician and client take a broad issue (such as one identified using the COPM) and together define five levels of possible outcomes, ranging from −2 (individual’s current level) to +2 (exceeds expectations) and ensures that all levels of attainment are mutually exclusive and measurable.61 The middle level (0) represents the expected level of attainment after intervention.62 GAS and COPM provide the flexibility of an individualized assessment but with standard scores that can be compared across participants.63,64 Given the standardized nature of these measures, both can be used with a range of ages and cognitive abilities. The use of COPM and GAS has also been recommended for evaluating coaching interventions. See Table 1 for example goals and scaling.

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The term “healthy eating” was used with participants at all times.
Objective 3. To understand the acceptability of a SFC-Peds intervention to children with DMD and their families

To identify how acceptable the SFC-Peds intervention was to participants, children and parents completed a survey with both Likert scale responses and semi-structured questions at their follow-up visit, designed to assess the core components of SFC-Peds and the study design. Likert-scale questions were rated on a 5-point scale (strongly disagree, disagree, neutral, agree, strongly agree) and included questions such as how helpful participants perceived their coach to be in meeting their diet and PA goals, how personally meaningful their goals were, and whether they would recommend coaching to others. Open response questions included questions that related to barriers and facilitators to goal attainment with and without the coach, and improvements to the coaching experience. Parents contributed to the open questions where appropriate.

The coaches were two certified Therapeutic Recreation Specialists from the host institution. Therapeutic Recreation Specialists use meaningful recreation and leisure education, counseling and experiences to promote, restore, rehabilitate, and/or maintain quality of life and well-being. The coaches in this study had received education and rigorous training for determining the capacities of the population being served and appropriate personalized interventions to ensure safety and best practice. This included in-depth guidance on diagnosis-specific considerations associated with DMD. Both coaches had previously led recreation programs focused on healthy lifestyles for children and youth with disabilities, which necessitated an in-depth understanding of Canadian physical activity and nutrition guidelines. A Nurse Practitioner specializing in pediatric DMD care provided additional training in nutrition and diet specific to DMD, and both she and the Physician Lead for the DMD clinic were available for consultation at any point in the research study in the case of safety concerns. Coaches attended an intensive two-day training course in SFC-Peds provided by an external, certified SFC-Peds trainer. The coaches had access to team members with SFC-Peds expertise during the study for support.

Procedure

There is no legal age of consent for research in Ontario, where the research took place. Therefore, consent was obtained from either the child or their parent, depending upon whether the child was judged by the researcher to demonstrate capacity to provide their own consent, assessed by a tool commonly used in the host institution and approved by the Research Ethics Board. If the child did not demonstrate consent but was happy to take part in the study, they provided assent and their parent provided consent. The client (with help from their family if necessary) then completed the demographic information form. Participants were assigned one of the coaches by the RA using a coin-toss and the first coaching session organized at their home within 2 weeks of their recruitment visit. The participant and their coach engaged in coaching sessions up to 60 minutes every week for 3 weeks, followed by one session 2 weeks later, and a final session after another 4 weeks to “taper” the intervention (5 sessions in total over 8 weeks). The child then had a further 4 weeks to work on their goals without the coach before attending the follow-up visit, 12 weeks after enrolment (see Table 2 for study schedule).

Following SFC-Peds guidelines, at the first in-person coaching session the coach worked with the participant to identify their “preferred future,” and to set one to two personally meaningful goals related to PA and/or diet using the COPM and GAS. Both coaches were skilled clinicians who had extensive experience of setting COPM and GAS goals in a pediatric rehabilitation setting with clients varying in age and cognitive ability. They conducted an in-depth discussion of the child’s strengths and abilities to ensure that participant-generated goals were both realistic and safe. Coaches supported participants to use their current strengths, past successes, resources and ideas to develop strategies and determine an action plan to work toward their goal(s), tailored to the child’s needs. At no time was a specific activity or exercise “prescribed” or recommended by the coaches. All PA

Table 1. Sample COPM and GAS goals set during the study.

<table>
<thead>
<tr>
<th>COPM goal: To be involved in decisions about food</th>
<th>GAS goal: To increase physical activity by attending a dance program</th>
</tr>
</thead>
<tbody>
<tr>
<td>GAS goal: Present level</td>
<td>COPM goal: Increase physical activity by attending a dance program</td>
</tr>
<tr>
<td>$-2$</td>
<td>I am active once per week (swimming)</td>
</tr>
<tr>
<td>Expected level</td>
<td>I search for information about a dance program that I can participate in</td>
</tr>
<tr>
<td>$0$</td>
<td>I attend a dance program to try it out</td>
</tr>
<tr>
<td>Expected level</td>
<td>I register to attend a dance program</td>
</tr>
<tr>
<td>program goal</td>
<td>I am active 2/week (swimming and dance program)</td>
</tr>
<tr>
<td>$+2$</td>
<td>I am involved in decisions about my meals 1–2 days/week</td>
</tr>
<tr>
<td>Much better than expected</td>
<td>I am involved in decisions about my meals 3 days/week</td>
</tr>
<tr>
<td>$+1$</td>
<td>I am involved in decisions about my meals 4 days/week</td>
</tr>
<tr>
<td>Somewhat better than expected</td>
<td>I am involved in decisions about my meals every day</td>
</tr>
</tbody>
</table>

Table 2. Schedule of study.

<table>
<thead>
<tr>
<th>Time</th>
<th>Baseline</th>
<th>1 week</th>
<th>2 weeks</th>
<th>3 weeks</th>
<th>5 weeks</th>
<th>8 weeks</th>
<th>12 weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activity</td>
<td>Consent &amp; recruitment</td>
<td>Coaching session #1</td>
<td>Coaching session #2</td>
<td>Coaching session #3</td>
<td>Coaching session #4</td>
<td>Coaching session #5</td>
<td>Follow-up measures COPM &amp; GAS Survey</td>
</tr>
<tr>
<td>Demographic info</td>
<td>COPM &amp; GAS</td>
<td>Via Kinect</td>
<td>Via Kinect</td>
<td>Via Kinect</td>
<td>Via Kinect</td>
<td>Via Kinect</td>
<td>Clinic</td>
</tr>
<tr>
<td>Location</td>
<td>Clinic</td>
<td>Client home</td>
<td>Client home</td>
<td>Client home</td>
<td>Client home</td>
<td>Client home</td>
<td>Client home</td>
</tr>
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</tr>
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<td>COPM &amp; GAS</td>
<td>Via Kinect</td>
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<td>Via Kinect</td>
<td>Via Kinect</td>
<td>Clinic</td>
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<tr>
<td>Location</td>
<td>Clinic</td>
<td>Client home</td>
<td>Client home</td>
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<td>Client home</td>
<td>Client home</td>
<td>Client home</td>
</tr>
</tbody>
</table>

Table 1. Sample COPM and GAS goals set during the study.
goals were generated by the participants themselves, although the coaches determined whether their chosen activities were in line with their current level of ability and emphasized concentric exercises rather than eccentric exercises, as recommended in the current evidence. Although the participant was the focus of the coaching intervention, parents were present so that they could support the participant’s goal attainment strategies. Depending upon the participants’ age and abilities, parents could be an appropriate resource for participants to draw upon to facilitate goal attainment.

To reduce burden on families, after the first at-home coaching session, the four remaining sessions were conducted remotely via an X-Box Kinect with videoconferencing capabilities, loaned to the family for the duration of the study and installed by the coach. During these sessions, coaches used the SFC-Peds approach to acknowledge progress and strengths through the use of feedback and feedforward loops, and reinforce and refine strategies to support goal attainment. Participants could select a range of strategies to attain their physical activity goals(s), depending upon their strengths, interests and abilities and resources (e.g., identifying accessible community facilities or friends with whom to exercise). The Kinect aimed to ensure that they had at least one accessible means of participating in PA. They were given 2–3 games requiring some degree of PA (e.g., swinging arms, stepping, dancing), appropriate to their functional level, to play on the Kinect if they chose. Feedback on the participants’ use of the Kinect was captured in the survey at the 12-week follow-up visit.

After each coaching session, the coach completed the fidelity measure, which was reviewed by a member of the research team with coaching expertise. At the 12-week follow-up visit, the participant’s COPM and GAS goal(s) were reassessed by a different coach to reduce bias. The RA completed the acceptability survey with the child. Each child who attended the follow-up assessment was given a gift card as a token of appreciation (required by the Research Ethics Board).

**Analysis**

Demographic data were summarized using descriptive statistics. GAS scores were transformed into T-scores to summarize goal attainment, with an expected T-score of 50 corresponding to achievement of the 0 level i.e., the level the participant is expected to attain if their goal has been met. Raw COPM scores were examined for changes between baseline and follow-up. Paired t-tests were used to examine the responsiveness of GAS and COPM in this coaching intervention, although statistical significance was not calculated as feasibility studies are not powered to detect such differences. The mean fidelity scores on the SFFI were computed. The 5-point quantitative responses on the follow-up survey were collapsed into agree, neutral, disagree and analyzed descriptively. Answers to the semi-structured questions were analyzed using content analysis, using open coding on the written materials, followed by grouping codes into categories and then under higher-order headings.

**Results**

**Sample**

Nineteen clients who met the inclusion criteria and had upcoming appointments were sent an information letter, of whom nine declined to participate and five were unable to be contacted. Five participants were recruited, with a median age of 13 years (range 11–19 years). All were currently taking corticosteroid medication and they reported a range of previous and current activity levels (see Table 3). All participants were male as DMD predominantly affects that sex.

**Objective 1: To determine the feasibility of a full randomized controlled trial of SFC-Peds**

The recruitment of five participants from 19 invited represented a 26.3% response rate. All five participants (100%) completed both baseline and follow-up assessments. All participants were able to set at least one goal related to physical activity or diet. The attendance rate at coaching sessions was 100% for all participants, although one participant had to reschedule a session, which he subsequently attended. The two coaches scored a mean of 93% on the SFFI across all coaching sessions indicating excellent fidelity. Coach 1 had a significantly higher mean score of 96.3% compared with Coach 2’s mean of 89.9% (t = −4.95, df = 3, p = 0.016). However, the participants’ performance and satisfaction change scores did not differ across the two coaches (Performance: t = −1.78, df = 3, p = 0.17; Satisfaction: t = −6.2, df = 3, t = 0.58). See Table 4 for all feasibility criteria.

**Objective 2. To explore the potential impact of SFC-Peds coaching on goal attainment**

Mean COPM performance scores increased by 5 points, from 3 at baseline to 8 at follow-up, indicating that participants perceived that they had become more skilled at their chosen goal activity at follow-up. The mean COPM satisfaction scores increased by 2.8 points, from 5 at baseline to 7.8 at follow-up, indicating that participants were more satisfied with their performance on their chosen goal activity. The mean GAS scores at 12 weeks exceeded the expected level (i.e., a T-Score of 50), with a mean T-score of 54. All goal attainment measures therefore indicated clinically significant gains.

### Table 3. Sample characteristics.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Age at diagnosis</th>
<th>Current medication</th>
<th>Current sports/activities</th>
<th>Previous sports</th>
<th>Activity rating (week)</th>
<th>Activity rating (weekend)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>13 years</td>
<td>3 years</td>
<td>Deflazacort</td>
<td>None</td>
<td>None</td>
<td>Very active</td>
<td>Very active</td>
</tr>
<tr>
<td>2</td>
<td>13 years</td>
<td>4 years</td>
<td>Deflazacort</td>
<td>None</td>
<td>Sledge hockey</td>
<td>Somewhat inactive</td>
<td>Somewhat active</td>
</tr>
<tr>
<td>3</td>
<td>12 years</td>
<td>4 years</td>
<td>Deflazacort</td>
<td>None</td>
<td>Swimming, gym</td>
<td>Active</td>
<td>Active</td>
</tr>
<tr>
<td>4</td>
<td>11 years</td>
<td>8 years*</td>
<td>Deflazacort</td>
<td>Swimming</td>
<td>Swimming</td>
<td>Very active</td>
<td>Active</td>
</tr>
<tr>
<td>5</td>
<td>19 years</td>
<td>8 years*</td>
<td>Deflazacort</td>
<td>Swimming</td>
<td>None</td>
<td>Somewhat inactive</td>
<td>Somewhat active</td>
</tr>
</tbody>
</table>

*These clients came from countries that did not offer testing for DMD and only received the diagnosis upon arriving in Canada.
Objective 3. To understand the acceptability of a SFC-Peds intervention to children with DMD and their families

In the Likert rating section of the follow-up questionnaire, all participants reported that they felt the goals they set were personally meaningful. In addition, four of the five participants agreed that they would tell other people with DMD to try coaching. Three of the five participants reported that the coach had been helpful in achieving their goals, with two ambivalent (neither helpful nor unhelpful). The number of sessions was deemed acceptable by four of the five participants. Two participants reported the remote nature of the coaching as acceptable, while three wished to meet face-to-face. Full acceptability data can be found in Table 5.

Responses to the semi-structured questions in the survey clustered into facilitators and barriers for goal attainment during the coaching process.

Facilitators of goal attainment

Of the two participants who set diet goals, developing a greater awareness of healthy foods enabled them to engage in their identified goal attainment strategies (e.g., help make shopping list including healthy foods from supermarkets), which in turn was perceived to have facilitated their goal attainment (e.g., being more involved in decisions about meals). Children also reported that their family members were key facilitators for these diet goals, for example, purchasing fruits and vegetables requested by the participants. PA goals were facilitated largely through recreational activities rather than structured exercise, for example, wrestling with siblings, taking short walks and playing gentle soccer with family members (e.g., to meet the goal: identify after-school PA that I enjoy). Four of the five participants felt confident that they could continue with healthy behaviors without the coach, demonstrating self-efficacy, a key element of self-determination. However, one participant reported that the support of a coach would be important for them to continue their healthy behaviors.

Barriers to goal attainment

A dominant theme concerned the technology utilized in the study for the virtual coaching sessions. Participants were frustrated that they were unable to connect visually with their coach for many coaching sessions, and reported being disappointed when they were unable to use the Kinect for PA. For example, participants who used a wheelchair were often not registered by the Kinect sensors. Another participant reported that they found the hand controls awkward to use. The father of one participant reported that his son’s engagement waned significantly after the first 3 weeks of the study, although unfortunately, no further explanation was provided.

Discussion

SFC-Peds appears a promising approach for promoting health behaviors such as PA and diet in children and youth with DMD. Establishing feasibility is critical for complex interventions (like SFC-Peds) that have multiple interacting components and/or target multiple behaviors, before launching into a full efficacy trial. The a priori feasibility criteria in this study were all met, indicating that SFC-Peds is a feasible approach with this population and can be delivered with high fidelity.

All participants reported that the goals they set were personally meaningful, an integral feature of SFC-Peds and a key factor in behavior change. Clinically significant increases in goal attainment scores were demonstrated by all participants. Some participants were ambivalent regarding the coach’s role in attaining their goals. However, SFC-Peds aims to enhance self-determination in participants along with feelings of competence and autonomy in decision-making. It is therefore desirable that children felt a sense of control over their achievements. Indeed, there was some evidence in the follow-up survey that participants felt confident about maintaining health behaviors after the coaching finished, demonstrating high self-efficacy, another important part of self-determination. This theoretical underpinning is one reason why SFC-Peds is so promising, but the conceptual constructs require explicit assessment in order to draw firm conclusions about the mechanisms of behavior change.

Although this study focused on PA and diet, a coaching approach could be used for a number of different activities relevant to DMD care. For example, clinical staff frequently recommend stretching of upper and lower extremities, and respiratory exercises. Using a solution-focused approach with clients to identify personally important goals related to these areas (e.g., prolonging safe ambulation, participation in

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Table 4. Feasibility criteria overview.

<table>
<thead>
<tr>
<th>Feasibility criteria</th>
<th>Actual (%)</th>
<th>Criteria met?</th>
</tr>
</thead>
<tbody>
<tr>
<td>A minimum 10% response rate from all eligible participants</td>
<td>26.3%</td>
<td>✓</td>
</tr>
<tr>
<td>85% of the participants successfully completed the study</td>
<td>100%</td>
<td>✓</td>
</tr>
<tr>
<td>All participants able to set one PA goal and/or one diet goal</td>
<td>100%</td>
<td>✓</td>
</tr>
<tr>
<td>Participants completing the study participated in at least four of the five coaching sessions (80%)</td>
<td>100%</td>
<td>✓</td>
</tr>
<tr>
<td>Coaches achieve minimum scores of 50% on fidelity measures</td>
<td>93%</td>
<td>✓</td>
</tr>
</tbody>
</table>

Table 5. Responses to acceptability survey.

<table>
<thead>
<tr>
<th>Acceptability criteria</th>
<th>Agree (%)</th>
<th>Neither (%)</th>
<th>Disagree (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The goals I worked toward were important to me</td>
<td>100</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>I would tell other people with DMD to try coaching</td>
<td>80</td>
<td>–</td>
<td>20</td>
</tr>
<tr>
<td>Coaching was fun</td>
<td>80</td>
<td>–</td>
<td>20</td>
</tr>
<tr>
<td>I liked using the Kinect to connect with my coach</td>
<td>40</td>
<td>20</td>
<td>40</td>
</tr>
<tr>
<td>The coach was helpful in working toward my healthy eating goals</td>
<td>60</td>
<td>40</td>
<td>–</td>
</tr>
<tr>
<td>The coach was helpful in working toward my physical activity goals</td>
<td>60</td>
<td>40</td>
<td>–</td>
</tr>
<tr>
<td>Coaching was a waste of time</td>
<td>–</td>
<td>20</td>
<td>80</td>
</tr>
<tr>
<td>The number of sessions was about right</td>
<td>80</td>
<td>20</td>
<td>–</td>
</tr>
<tr>
<td>Coaching would be a good way for all kids to become healthier</td>
<td>40</td>
<td>40</td>
<td>20</td>
</tr>
<tr>
<td>It would have been better to meet my coach face-to-face</td>
<td>60</td>
<td>–</td>
<td>40</td>
</tr>
<tr>
<td>Having the Kinect made it easier to be physically active</td>
<td>60</td>
<td>20</td>
<td>20</td>
</tr>
</tbody>
</table>
activities with peers) may be more fruitful than the more traditional didactic model of healthcare communication. Because SFC-Peds utilizes the child’s existing strengths and resources, it can also be used as the condition progresses and goals need to become reimagined. Healthcare professionals from a range of disciplines can potentially be trained in SFC-Peds and integrate it into the clinical care they provide. This is important because optimal management of DMD requires a multidisciplinary approach, although the exact composition of the clinical team may vary.15

The coaches in this study, who had existing experience working clinically with youth with disabilities (as Therapeutic Recreation Specialists), demonstrated excellent intervention fidelity after just two days’ intensive training and with some ongoing light-touch support from a colleague with SFC-Peds expertise. Therefore, a relatively modest investment is required to potentially optimize clinical care, especially given that strengths-based coaching approaches such as SFC-Peds have been demonstrated to result in quicker, less costly behavior change than problem-based approaches.72

The type of coaching employed in this study (SFC-Peds) enabled young people to identify their own goals, which in the cases of PA goals, were often successfully met through recreational activities rather than specific structured sports. This is a very different model than “prescribed” exercise28 and is particularly relevant for boys with DMD, given the current lack of definitive PA guidelines. Setting goals through SFC-Peds allowed them to remain active at whatever level was appropriate for their current level of functioning. The coaches ensured that their planned goal attainment strategy did not include activities that are known to be damaging to muscle tissue (e.g., eccentric exercises) and no adverse events were reported.

**Strengths and considerations**

Following best practice, the study used pre-identified success criteria against which to measure the feasibility of the study.52 Establishing feasibility can greatly decrease the likelihood of failure in a future RCT because of issues such as low recruitment, high participant attrition, low intervention adherence and lack of intervention fidelity.50 Given the scarcity of literature in this area, it is critical to disseminate these early findings to inform other studies, both with DMD and other populations experiencing significant health promotion needs. Many of the learnings are generalizable to other contexts, such as the challenges of communicating with participants “virtually.” Using assessments that take into account variability between children is key when evaluating coaching interventions for children with disabilities, including those with DMD. The lack of consistent measures across participants in previous research has made generalizing their results challenging.73 In contrast, GAS and COPM are both highly reliable and widely used, and have been recommended for evaluating coaching interventions where the evidence base is not yet known,74 such as with health promotion. The reassessment at follow-up of participants’ goals by a coach who wasn’t their allocated coach minimized bias. In a future trial, using additional objective measures such as functional mobility and anthropometrics (e.g., BMI, waist circumference, etc.) could identify whether behavior changes assessed by COPM and GAS are reflected in physical indicators, although it should be noted that the use of BMI as a primary outcome for children with disabilities has been criticized.75,76

There are a number of considerations when interpreting our findings, most of which are features of feasibility studies and would be addressed in a fuller trial. For example, the study involved a small number of participants, although the sample was sufficient for the aims of feasibility work.46 We could not test whether the increased goal scores were statistically significant as feasibility studies are not powered to detect such differences.53 However, information gained during this study can inform the sample size of a future study to ensure adequate power. Due to funding constraints, we were only able to follow participants for 4 weeks after their final coaching session (12 weeks post study enrolment), which did not provide information on whether health behaviors were maintained in the long-term. This would be a key outcome to assess in a larger study. In order to describe our sample, we collected information on the participants’ current and past activity levels using questions modeled on the HAES. The HAES has been used with a number of patient populations, including children with the progressive pulmonary condition cystic fibrosis,77 but it has not to our knowledge been used with boys with DMD. Some of the responses indicated that they were “very active” at ages where ambulation is typically limited, indicating that children’s perceptions of “very active” may be quite different to those of healthcare professionals or researchers. Therefore, not only should a fuller study involve larger samples, comparison groups, and longer follow-up, but validated objective behavioral outcome measures are required in order to fully assess intervention efficacy and maintenance. The open-ended questions on our survey unfortunately did not elicit detailed responses from the participants, making interpretation challenging. More in-depth qualitative interviews would help explore participants’ experiences, identify the most engaging aspects of SFC-Peds, and highlight why some participants’ engagement waned over time. To reduce cognitive load, nine of the eleven survey items were worded positively, which may have biased participants’ responses. However, a number of responses disagreed with the positive items, suggesting that this was not a major concern.

Although SFC-Peds focuses on the child, the role of their environment cannot be ignored. Parents were involved in the coaching process, as they are often one of the child’s greatest “resources,” especially for younger children. Indeed, children’s responses to the follow-up survey identified their parents (and other family members) as having facilitated their goal attainment. Parents typically provide transport and financial support for activities and also usually provide food for family members, potentially restricting children’s control over their own dietary intake. However, children can have a positive influence on their parents.78 The dietary goals created by participants in this study involved working with their parents to increase healthy choices, providing them with the opportunity to influence the family’s diet. Exploring parental behavior over the course of the coaching intervention would provide additional insight into the processes of behavior change.
We restricted participants’ goals to PA and diet, so it is possible that other goal areas may have been more important to participants. However, all participants rated their goals as personally meaningful, a key component of SFC-Peds. To reduce family burden, we employed videoconferencing technology to connect coaches and participants virtually, but experienced a high rate of technology failure, and coaching sessions often ended up being conducted by telephone. Although studies with adults with physical disabilities have demonstrated improvements in BMI after telephone coaching, this communication method may not be as appropriate with children and young people, as three participants reported that would have preferred to meet in person. Exploring more reliable technology to facilitate face-to-face coaching (albeit virtual) may be beneficial, especially as children have previously reported that using home-based technology for rehabilitation to be a substantial motivator. The feasibility of providing large numbers of technologies such as Kinects (e.g., during a larger trial) may also be prohibitive, even if recruitment was staggered. However, many youth already possess their own gaming technologies, which could be potentially leveraged if necessary. The Kinect was not intended to fulfill the participants’ PA needs, but was provided as one potential option, although participants were rarely able to take advantage of it due to the technology failure. Given all of these considerations, it is notable that we still saw positive indicators of goal attainment.

Conclusion

This study demonstrated that a SFC-Peds intervention for PA and diet is feasible and acceptable for children with DMD and their families. Encouraging goal attainment data also indicate that a rigorous efficacy study assessing SFC-Peds intervention is warranted. A solution-focused coaching approach for health promotion with other populations may hold promise.

Acknowledgments

We wish to thank all of the participants and families who took part in this study. We thank Joan Walker for providing research assistant support and Kathleen Macleod for her clinical input.

Funding

Funding was provided by the Centre for Leadership in Participation and Inclusion with the support of the Holland Bloorview Kids Rehabilitation Hospital Foundation.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

References


