Team IMPACT Program Evaluation
Derek Gravholt, MS
Rachel Rogovin, MSW, LICSW

INTRODUCTION

Background

It has been well established that children with chronic medical conditions have an increased risk of developing a mental illness such as depression or anxiety compared to their healthy peers (Adams, 2019; Brady, 2021). Children and teens with a chronic illness often experience social isolation, school absenteeism, and an inability to participate in extra-curricular activities. As such, they can feel alienated and separated from their peers (Yeo & Sawyer, 2005), which can have long-term negative effects on adult social and mental health (Caspi et al., 2006). Furthermore, families with children with chronic illness may experience some burden related to the care of the child (Caicedo, 2014), making the child's cooperation and independence with their care important in relieving stress.

Physical activity has been shown to enhance quality of life in healthy children, as well as in children with chronic diseases (Riner & Sellhorst, 2013). For example, significant benefits of routine physical activity have been documented for children with cystic fibrosis including improvements in cardiovascular endurance and quality of life (West, 2019). In addition, for childhood cancer survivors, higher levels of physical activity are associated with better health-related quality of life around physical, social, and cognitive functioning (Gilliam, 2013).

Team IMPACT

Team IMPACT provides children and adolescents with the opportunity to engage in normative developmental activities, with the intention of helping them overcome loneliness, isolation, and emotional distress by matching them with a college athletic team for inclusion and purpose. The organization's mission is to guide children and teams alike in a mutually beneficial relationship of belonging, empowerment, and resilience.

Since its founding in 2011, Team IMPACT has matched 3,200 children across 50 states, serving children with over 300 rare diseases and conditions. To date, more than 70,000 collegiate student-athletes have had a Team IMPACT player on their roster.

In a previous evaluation of the Team IMPACT program, participants' parents reported that the program has helped their children start talking about their illness with their classmates, increase their interest in physical activity, reduce their reliance on parents in social settings, and manage their stress related to executing daily activities.

The overarching goal of this paper is to quantitatively examine the effects of participating in Team IMPACT on participants' cooperation and independence in their own care, their physical activity, ability to manage emotions, and feelings of stigma related to their medical illness.

METHODS

The Team IMPACT Program

All participating families complete a comprehensive psychosocial assessment with an Intake Coordinator to determine eligibility for participation. Then, a Match-Up Specialist focuses on identifying the appropriate

team for each child and family. by evaluate interested teams' capacity to fully participate in Team IMPACT. Other criteria for team selection include coaching philosophy, team cohesion and culture, and proximity to family's home.

Selected teams must complete an online, self-guided orientation prior to finalizing their match. The orientation includes information on program guidelines, boundaries and confidentiality, strategies for building connection with their match, and recommended activities. Every matched team has a small group of student-athlete leaders who serve as the primary contacts for the family and the Team IMPACT Case Manager.

Case Managers, all of whom are either master's level social workers or certified child life specialists, guide the relationships between families and their teams, providing psychoeducation and therapeutic support at every stage of the match.

They routinely assess the health of each match, based on four domains – communication, connection, goals, and expectations. The weight of each domain varies based on the match phase and the level of impact that they have on the quality of the relationship. For instance, the frequency and consistency of communication is critical at the beginning of a match, while it is expected that interpersonal connectedness will grow as the match progresses.

Evaluation
Participants in the program are asked to complete a survey at baseline (before starting the program), and again at 12 months and 24 months of involvement with the program. This data has been collected since January 2021, with many participants completing the 24-month survey at the time of writing. All survey items were completed by the participants' parents/guardians.

Measures
Previous qualitative data collected from parents of children who participated in Team IMPACT showed that participants exhibited growth in several areas including improved ability to manage emotions, increased feelings of belonging, increased independence, and increased interest in physical activity. For this project, we chose measures which evaluated these domains. When a validated measure could not be found, we developed our own measure.

Two of the survey's primary purposes were to assess participants' self-efficacy in managing emotions (referred to as "emotion management" herein) (Gruber-Baldini et al., 2017) and the social stigma they feel from their peers related to their medical condition (referred to as "stigma" herein) (Lai et al., 2015). These instruments have been previously validated and have normative data that we were able to use to compare our participants' progress with that of others like them. This normative data allows us to use what are called "t-scores," which are standardized scores used to compare one individual's score to the population of all similar pediatric patients.

Another purpose of the survey was to measure participants' cooperation and independence with health-related behaviors (referred to as Cooperation herein). This instrument was developed by the authors and does not have normative data available.

Basic information about the main instruments can be found in **Figure 1**, and the full survey is available in **Appendix A**.

Figure 1: Instrument properties

Construct	Instrument	Number of Items	Scale	Anchors
Emotion management	PROMIS: Self-Efficacy for Managing Chronic Conditions – Managing Emotions – Short Form 8a	8	Likert 1-5	1 = I am not at all confident 5 = I am very confident
Stigma	Neuro-QoL: Pediatric Stigma – Short Form	8	Likert 1-5	1 = Never 5 = Always
Cooperation*	Author-developed	5	Likert 1-5	1 = Never 5 = Always

*One item ("How would you rate your child's independence with their medical care (taking medication, breathing treatments, diet changes)") used the following anchors: 1 = Fully dependent on caregiver; 5 = Fully independent with care.

We also report participant demographics, Net Promoter Score (which is a measure that measures participants' satisfaction with and enthusiasm for the organization), and items that ask whether participants improved in their physical activity.

Sample

This was a retrospective analysis of data collected from participants enrolled in the Team IMPACT program from January 2021 to June 2023; however, data collection is ongoing and will be updated periodically.

First, for this report, it should be noted that analysis was conducted by separating the data into two cohorts: 1) Baseline to 12-month participants, and 2) 12-month to 24-month participants (See **Figure 2**). This was done to keep paired data together because the majority of participants had only completed either the baseline and 12-month surveys, or the 12-month and 24-month surveys, with the third timepoint missing. This is a result of the survey beginning after the program had started; some participants had already participated in the program for some time, resulting in availability of only the 12- and 24-month surveys. On the other hand, some participants have only recently started the program, resulting in availability of only the Baseline and 12-month surveys. Because the data is split into two cohorts, tables and figures will show findings from each cohort side-by-side.

Figure 2: Distribution of paired data
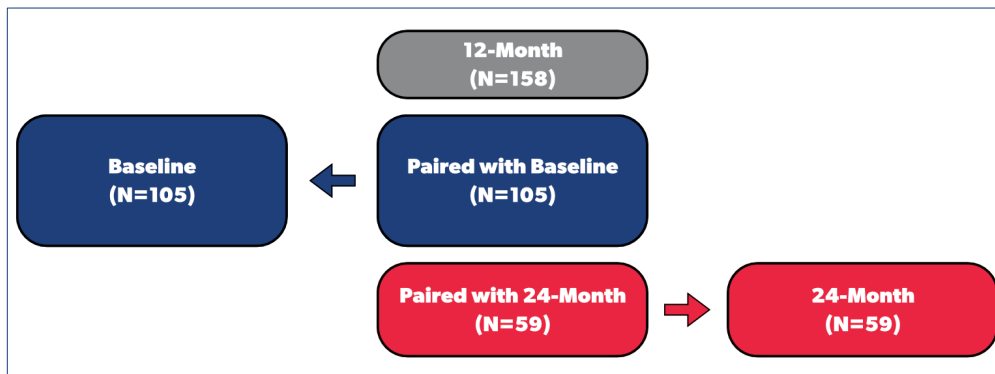
Analyses

Participant characteristics

Participant characteristics were reported, including age, gender, diagnosis (cancer/transplant vs. non cancer/transplant), race/ethnicity, and household income.

Descriptive statistics

All descriptive statistics were reported separately at each timepoint for applicable timepoints (i.e. baseline, 12-month, and/or 24-month). Emotion management, Stigma, and Cooperation were reported at all three timepoints while Improvement in Physical Activity Items and Net Promoter Score were reported only at 12-month and 24-month because the wording of these items refers to improvement since the previous timepoint.

Raw means, standard deviations, and ranges were reported for the Emotion management, Stigma, and Cooperation instruments. Additionally, considering normative data is available for Emotion management and Stigma instruments, their mean t-scores were reported along with their range.

Four improvement items were also reported for Cooperation (see *Measures* section) along with the improvement in actual physical activity and improvement in interest in physical activity. These items were reported as the percentage of participants that improved at least slightly, that improved slightly or moderately, and improved very much or extremely.

T-test

Paired t-tests were performed on three constructs (Emotion management, Stigma, and Cooperation) to test whether there was significant improvement in mean scores from Time 1 to Time 2 (baseline to 12-month and 12-month to 24-month). Prior to running the paired t-tests, the Shapiro-Wilk test of normality was conducted to assure that data was distributed normally for each variable.

Linear models

Linear models were constructed for three constructs (Emotion management, Stigma, and Cooperation) in order to understand factors that may influence their change over time aside from the Team IMPACT program. Predictor variables included age, gender, diagnosis (cancer/transplant vs non cancer/transplant), household income, race/ethnicity, match quality*, and base score for the respective measure. The outcome variable was the difference between Time 2 and Time 1 raw scores for the respective measure.

*Match quality is a rating by the participant's Case Manager (a Team IMPACT employee that facilitates the relationship between a participant and their team) that evaluates the health of each specific match. It is assessed every 6-8 weeks and includes domains related to communication, connection, goals, and guidelines/expectations which are weighted scores depending on the time of evaluation. The lowest possible score is 55 and the highest possible score is 100.

Logistic models

Logistic models were constructed for the two items related to improvement in physical activity and interest in physical activity to understand factors that may influence whether there was an improvement that could be explained outside of the effect of participation in the Team IMPACT program. Predictor variables

included age, gender, diagnosis (cancer/transplant vs non-cancer/transplant), household income, race/ethnicity, match quality, and base score for the respective measure. The outcome variable was "Yes" or "No" depending on whether the participant reported improvement in each item.

For logistic models, the estimate seen is what's called an "odds ratio." Essentially this shows the difference in likelihood that the outcome will be "Yes" based on a change in the predictor variable. The reason for doing this is because the outcome variable is categorical; in this case "Yes" or "No" regarding whether participants improved on the respective measure.

Additional analyses
Because two of our measures (Emotion management and Stigma) have normative data, we were also able to examine the number of participants that experienced a clinical improvement or decline in these constructs. Participants with a t-score that increased by 10 or more were considered to have clinically improved while participants that experienced a t-score that decreased by 10 or more were considered to have clinically declined (Gruber-Baldini et al., 2017; Lai et al., 2015).

We also reported Net Promoter Score (NPS) at 12-months and 24-months. NPS is a one-item instrument measured on a scale of 0-10 (0 = Not at all likely; 10 = Extremely likely) that asks participants "How likely is it that you would recommend Team IMPACT to another family." It is calculated by subtracting the percentage of "detractors" (those that score from 0-6) from the percentage of "promoters" (those that score 9-10). This score can range from -100 to 100 and the original creators suggest a score above 0 is "good", above 20 is "favorable", above 50 is "excellent", and above 80 is "world class." (Carpenter, n.d.).

All analyses were conducted using R/RStudio (R Core Team, 2021).

RESULTS

Participant characteristics
Table 1 shows participant characteristics for each of the cohorts, along with the total. Six participants completed surveys at all three timepoints and were included in both cohorts. There was little variation in participant characteristics between the two cohorts, which allowed for comparison between the cohorts, and inspires confidence that any differences are unlikely to be due to participant characteristics.

Table 1: Participant Characteristics

Characteristic	Baseline – 12m (n = 105)	12m – 24m (n = 59)	Total (n = 158)*
Age, mean (SD)	11.53 (3.11)	13.32 (2.87)	12.18 (3.12)
Age, n (%)			
<12	56 (53%)	17 (29%)	70 (44%)
≥12	49 (47%)	42 (71%)	88 (56%)
Gender, n (%)			
Male	71 (67%)	41 (69%)	107 (68%)
Female	34 (32%)	18 (31%)	51 (32%)
Diagnosis, n (%)			
Cancer/Transplant	26 (25%)	14 (24%)	37 (23%)
Other	79 (75%)	45 (76%)	121 (77%)
Race, n (%)			
White	68 (65%)	40 (68%%)	104 (66%)
Black or African American	5 (5%)	5 (8%)	10 (6%)
Asian/Pacific Islander	2 (2%)	0	2 (1%)
Latino	3 (3%)	4 (7%)	7 (4%)
Multiracial/Other	3 (3%)	1 (2%)	4 (3%)
Unknown	24 (23%)	9 (15%)	31 (20%)
Household income ($), n (%)			
0-24,999	4 (4%)	5 (8%)	8 (5%)
25,000-49,999	9 (9%)	11 (19%)	18 (11%)
50,000-74,999	9 (9%)	7 (12%)	16 (10%)
75,000-99,999	11 (10%)	4 (7%)	15 (9%)
100,000-149,000	18 (17%)	7 (12%)	25 (16%)
150,000-199,999	8 (8%)	4 (7%)	11 (7%)
More than 200,000	8 (8%)	2 (3%)	10 (6%)
Unknown	38 (36%)	19 (32%)	55 (35%)

*6 participants completed all 3 timepoints.

Note: Values are taken at earliest available timepoint (e.g. for Baseline – 12 month, values are taken at baseline)

Age, match quality, and base score are all continuous variables with varying scales:
- **Age** is simply the participant's age in years
- **Match Quality** is a rating between 55 and 100 by Team IMPACT Case Managers regarding their perception of the quality of the match between the child and their team
- **Base Score** is the mean score for the respective measure at Time 1 (Baseline in the Baseline – 12-month cohort, and 12-month in the 12-month to 24-month cohort).

Gender, diagnosis, household income, and race are all categorical variable with varying levels:
- **Gender*** includes two levels: Male and Female
- **Diagnosis** includes two levels: Cancer/Transplant and Non-Cancer/Transplant
- **Household Income** includes three levels: <$50,000, $50,000 - $99,999, and >$100,000
- **Race** includes two levels: White and Not white

*At the time of this report there were not any participants who indicated a different gender identity

Descriptive Statistics
Table 2a shows descriptive statistics for Emotion management, Stigma, and Cooperation measures at each timepoint. For all three instruments, the mean score was reported per item, along with the standard deviation and range. Because they have normative data, for Emotion management and Stigma measures, the mean and range of t-scores were also reported. Based on the eye-test, we can see that Emotion management and Cooperation measures trend toward improvement in mean score over time while Stigma does not change drastically.

Table 2a: Descriptive statistics across analyzed participants

Outcome	Baseline (n = 105)	12-month (n = 158)	24-month (n = 59)
Emotion management; Likert, mean (SD) [Range]	3.09 (0.76) [1.25,5.00]	3.29 (0.81) [1.38,5.00]	3.42 (0.81) [1.50,5.00]
Emotion management; T-score [Range]	42.85 [27.82,64.98]	44.58 [29.34,64.98]	45.63 [30.63,64.98]
Stigma; Likert, mean (SD) [Range]	2.51 (0.75) [1.00,4.50]	2.53 (0.80) [1.00,5.00]	2.58 (0.98) [1.00,4.75]
Stigma; T-score, mean [Range]	54.45 [37.10,67.70]	54.47 [37.10,75.80]	54.39 [37.10,70.40]
Cooperation Likert, mean (SD) [Range]	3.72 (0.65) [2.00-5.00]	3.93 (0.61) [2.00-5.00]	3.97 (0.71) [1.60-5.00]

Note: Mean scores are shown as aggregate score for the measure divided by the number of items on the measure.

In **Table 2b**, we also report frequencies for the items that directly ask participants' parents whether their child improved. These items were related to the Cooperation measure along with two separate items that measure participants' interest in physical activity and their actual physical activity.

Table 2b

Improvement at 12-month (n=158)	Improved at least Slightly	Improved Slightly or Moderately	Improved Very Much or Extremely
Has your child's cooperation with routine medical treatment improved?	82%	54%	27%
Has child's cooperation with medical care during doctor/clinic visits or hospital admissions improved?	82%	54%	27%
Has your child's independence with their medical care (taking medications, breathing treatments, diet changes) improved?	78%	54%	24%
Has your child's ability to advocate for themselves with the medical team improved?	78%	51%	27%
Has your child's interest in physical activity increased?	91%	49%	42%
Has your child's physical activity level increased?	87%	54%	32%

Improvement at 24-month (n=59)	Improved at least Slightly	Improved Slightly or Moderately	Improved Very Much or Extremely
Has your child's cooperation with routine medical treatment improved?	78%	49%	29%
Has child's cooperation with medical care during doctor/clinic visits or hospital admissions improved?	81%	53%	29%
Has your child's independence with their medical care (taking medications, breathing treatments, diet changes) improved?	80%	53%	27%
Has your child's ability to advocate for themselves with the medical team improved?	81%	58%	24%
Has your child's interest in physical activity increased?	83%	42%	41%
Has your child's physical activity level increased?	80%	47%	32%

T-test

To go beyond the eye-test and investigate whether there was a significant improvement in any of the three measures, data was separated into two cohorts and a paired samples t-test was run with participants that completed surveys for at least two timepoints. The data is "paired" in the sense that data at both timepoints have some relationship to each other; in this case, they are from the same participant.

As shown in **Table 3**, there was a significant improvement in Emotion management in both cohorts. There was no change in Stigma after involvement with the program for either cohort. For Cooperation, there was a significant improvement in the Baseline to 12-month cohort, but no change in the 12-month to 24-month cohort.

Table 3: T-test

Outcome	Baseline – 12m (n = 105)	12m – 24m (n = 59)
Emotion management	Baseline Mean (SD): 3.09 (0.76) 12m Mean (SD): 3.30 (0.83) $t = -2.93$ (p = .004)**	12m Mean (SD): 3.21 (0.80) 24m Mean (SD): 3.42 (0.81) $t = 2.52$ (p = .014)*
Stigma	Baseline Mean (SD): 2.51 (0.75) 12m Mean (SD): 2.53 (0.76) $t = -0.24$ (p = .810)	12m Mean (SD): 2.58 (0.91) 24m Mean (SD): 2.58 (0.98) $t = 0.00$ (p = 1.000)
Cooperation	Baseline Mean (SD): 3.72 (0.65) 12m Mean (SD): 3.89 (0.62) $t = -3.27$ (p = .001)**	12m Mean (SD): 3.98 (0.61) 24m Mean (SD): 3.97 (0.71) $t = -0.09$ (p = .928)

*Indicates significance at p<0.05
**Indicates significance at p<0.01

Linear models

Linear models are helpful for understanding which variables can predict changes in an outcome variable. In this case, the outcome variable is the change in a participant score between Time 1 and Time 2. For example, in the Baseline to 12-month cohort on the Emotion management measure, if a participant scored 3.5 at Baseline and 3.7 at 12-month, their outcome variable in this scenario would be 0.2. Predictor variables include: age, match quality, base score, gender, diagnosis, household income, and race.

Table 4: Linear Models (Univariate)

Outcome	Baseline – 12m (n = 105)	12m – 24m (n = 59)
Emotion management, estimate (p-value)	**Age**, -.01 (=.78) **Gender (Male)**, -.54 (<.001)*** **Diagnosis (Other)**, .10 (=.54) **Income (100+)**, .67 (<.01)** **Income (50-99)**, .70 (<.05)* **Race (White)**, -.04 (=.86) **Match Quality**, .00 (=.83) **Base Score**, -.38 (<.001)***	**Age**, -.01 (=.86) **Gender (Male)**, -.39 (<.05)* **Diagnosis (Other)**, .35 (<.10)[1] **Income (100+)**, .07 (=.72) **Income (50-99)**, .71 (<.01)** **Race (White)**, .38 (<.10)[1] **Match Quality**, .02 (<.10)[1] **Base Score**, -.31 (<.01)**

Stigma, estimate (p-value)	**Age**, .00 (=.84) **Gender (Male)**, .09 (=.45) **Diagnosis (Other)**, -.09 (=.52) **Income (100+)**, .14 (=.49) **Income (50-99)**, .23 (=.31) **Race (White)**, -.02 (=.93) **Match Quality**, .01 (=.24) **Base Score**, -.32 (<.001)***	**Age**, -.01 (=.60) **Gender (Male)**, .19 (=.21) **Diagnosis (Other)**, -.05 (=.78) **Income (100+)**, -.09 (=.68) **Income (50-99)**, -.14 (=.52) **Race (White)**, .03 (=.90) **Match Quality**, .00 (=.73) **Base Score**, -.09 (=.23)
Cooperation, estimate (p-value)	**Age**, -.03 (<.10)[1] **Gender (Male)**, -.09 (.43) **Diagnosis (Other)**, .13 (=.27) **Income (100+)**, .32 (<.10)[1] **Income (50-99)**, .07 (=.70) **Race (White)**, -.19 (=.26) **Match Quality**, .01 (=.13) **Base Score**, -.39 (<.001)***	**Age**, -.02 (=.38) **Gender (Male)**, -.35 (<.05)* **Diagnosis (Other)**, -.05 (=.79) **Income (100+)**, .17 (=.46) **Income (50-99)**, .26 (=.27) **Race (White)**, .36 (<.10)[1] **Match Quality**, .02 (<.05)* **Base Score**, -.26 (<.05)*

Model results indicated possible influences of **Gender**, **Household Income**, and **Base Score** for the Emotion management measure, **Base Score** for the Stigma measure, and **Gender**, **Match Quality**, and **Base Score** for the Cooperation measure.

For Emotion management, we found that there was a large difference for **Gender** in both cohorts, with female participants tending to improve much more than male participants. Additionally, higher income may predict improvement for Emotion management, with **Income 50-99** significantly predicting higher improvement in both cohorts and **Income 100+** predicting higher improvement in the Baseline to 12-month cohort as compared to **Income <50**. Higher **Base Score** predicted lower improvement in Emotion management for both cohorts, which is expected considering there is less room for improvement if the score is already high at Time 1.

For Stigma, the only significant predictor of improvement that we found from the model was **Base Score** in the Baseline to 12-month cohort. Surprisingly, better **Base Score** predicted better improvement for this measure.

For Cooperation, **Gender** predicted improvement in the 12-month to 24-month cohort, but not in the Baseline to 12-month cohort, with female participants tending to improve more than male participants. Higher **Match Quality** also predicted improvement in Cooperation for only the 12-month to 24-month cohort. Lastly, for both cohorts, higher **Base Score** predicted lower improvement in Cooperation. Again, this is expected considering less room for improvement if the score is high at Time 1. Linear model results are shown in **Table 4**.

Overall, we found that **Gender** and **Income** are important predictors of Emotion management improvement, there are no important predictors of Stigma improvement, and **Gender** and **Match Quality** might predict improvement in Cooperation.

Logistic models

Logistic models were chosen to understand predictors of two outcomes, **Improvement in Actual Physical Activity,** and **Improvement in Interest in Physical Activity,** as they were not measured at each timepoint (only at 12-month and 24-month), and within the wording of these items, there is a reference point already included ("improved"). Because of this, the difference between two timepoints does not provide the value needed to confirm improvement as it is already baked into the question itself. In this case, a model that predicts a categorical outcome variable was used: whether or not the participant improved at one timepoint.

Predictor variables include: age, match quality, base score, gender, diagnosis, household income, and race.

Table 5: Logistic Models (Univariate)

Outcome	12-month (n = 158)	24-month (n = 59)
Physical activity actual improved, Odds Ratio (p-value)	**Age** ~-.25 (<.01)** **Gender (Male)** ~-1.17 (<.10)[1] **Diagnosis (Other)** ~-1.96 (<.10)[1] **Income (100+)** ~.67 (=.33) **Income (50-99)** ~.80 (=.31) **Race (White)** ~-.41 (=.61) **Match Quality** ~.04 (=.23)	**Age** ~-.21 (<.10)[1] **Gender (Male)** ~.62 (=.35) **Diagnosis (Other)** ~.62 (=.39) **Income (100+)** ~.92 (=.33) **Income (50-99)** ~1.51 (=.20) **Race (White)** ~.00 (=1.00) **Match Quality** ~.00 (=.94)
Physical activity interest improved, Estimate (p-value)	**Age** ~-.14 (=.14) **Gender (Male)** ~-1.13 (=.15) **Diagnosis (Other)** ~-1.47 (=.16) **Income (100+)** ~.31 (=.70) **Income (50-99)** ~.64 (=.50) **Race (White)** ~.13 (=.87) **Match Quality** ~.03 (=.39)	**Age** ~-.06 (=.65) **Gender (Male)** ~-.03 (=.97) **Diagnosis (Other)** ~1.49 (<.05)* **Income (100+)** ~1.70 (=.15) **Income (50-99)** ~.72 (=.45) **Race (White)** ~.35 (=.70) **Match Quality** ~.07 (=.12)

In the model, results indicated a potential influence of **Age** for actual physical activity improvement and **Diagnosis** for interest in physical activity improvement.

Age was a significant predictor of actual physical activity improvement at the 12-month timepoint and a marginally (not quite) significant predictor at the 24-month timepoint. Because the values of both estimates for **Age** were quite similar, -0.25 and -0.21, we can be fairly certain that it has an impact based on this analysis even though the 24-month timepoint was not quite significant.

On the other hand, **Diagnosis** was a significant predictor of improvement in Interest in Physical Activity for the 24-month timepoint, but not for the 12-month timepoint. Additionally, the estimate was opposite between the timepoints (1.49 for 24-month and -1.47 for 12-month). This makes it difficult to be sure there is an effect of **Diagnosis** predicting participants' improvement in Interest in Physical Activity, unless there is a difference in the intervention (the Team IMPACT program) at that timepoint. Logistic model results are shown in **Table 5.**

Overall, it is likely that **Age** predicts Actual Physical Activity Improvement such that older participants are less likely to improve in their Actual Physical Activity.

Clinical Improvement Counts

Using the t-scores that were available for Emotion management and Stigma measures, we were able to look at the number of participants that clinically improved from Time 1 to Time 2. A t-score difference of 10 is considered a clinically significant change for both Emotion management (Gruber-Baldini et al., 2017) and Stigma (Lai et al., 2015), with an increase indicating improvement and a decrease indicating decline for Emotion management and the opposite for Stigma as it is scored negatively. **Figure 3** shows the number of participants that improved and declined in each cohort for both Emotion management and Stigma measures.

Overall, we can see that most participants who had a clinical change for these measures improved after participating in Team IMPACT, especially for Emotion management.

Figure 3: Clinical Improvement Rates

12-month to 24-month cohort (n=59)

Emotion management

7%
3%
90%

Stigma

3%
97%

Improved   Declined   No change
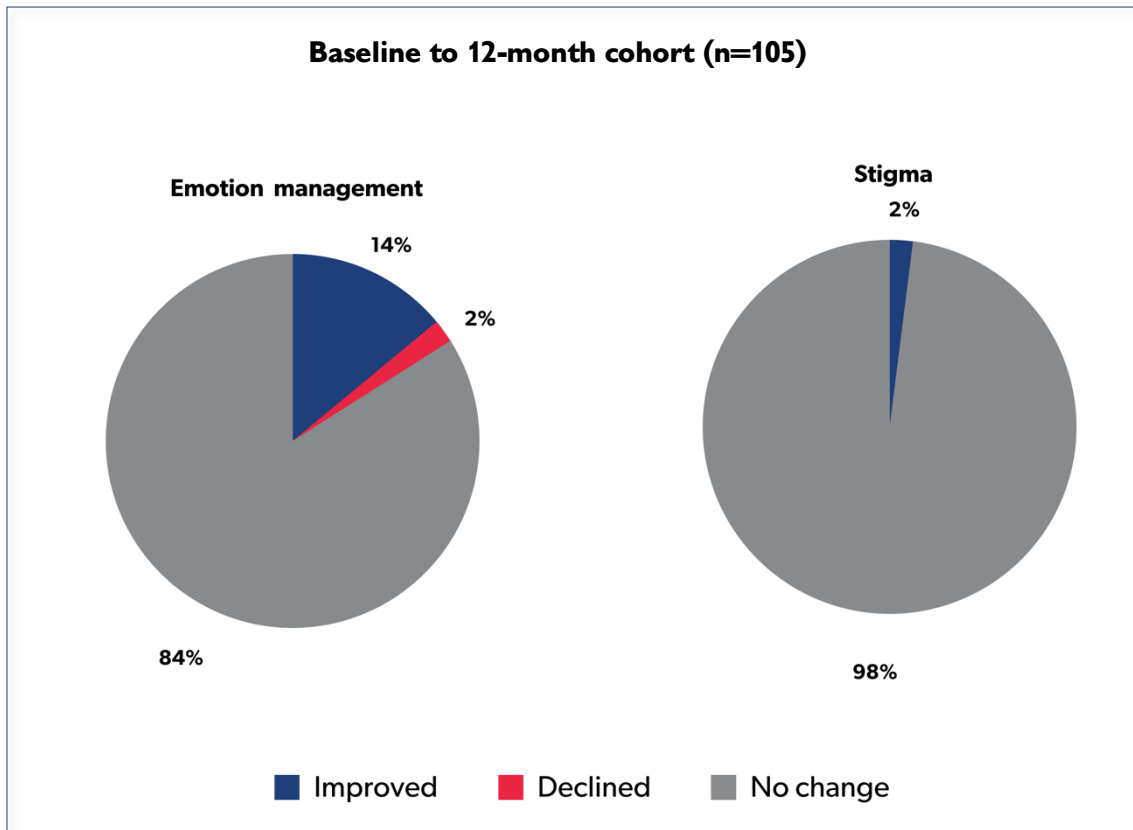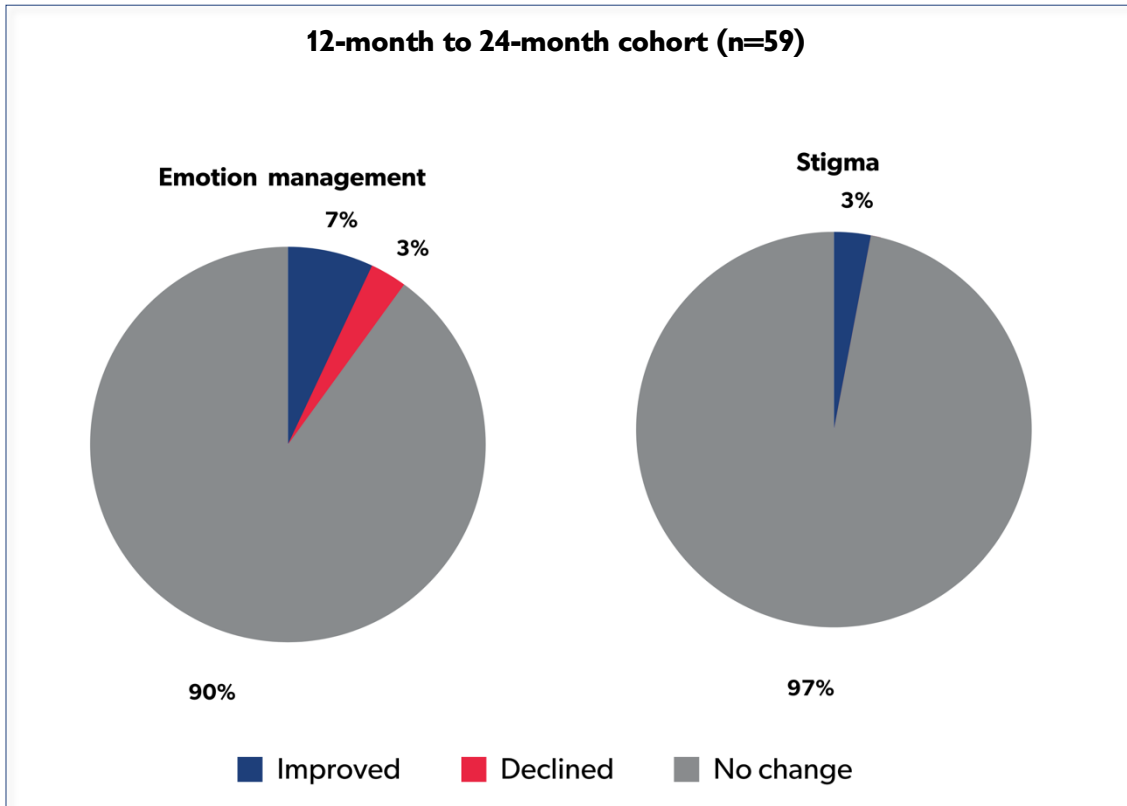
Net Promoter Score

Parents of participants in Team IMPACT reported an NPS of 85 at 12-months and 74 at 24-months involvement with the program. These scores range between the "Excellent" and "World Class" categories as suggested by the developers of the instrument (Carpenter, n.d.).

DISCUSSION

This report highlights some promising findings related to the effectiveness of the Team IMPACT program.

First, we found that participants improve in their self-efficacy to manage emotions after being involved with the program. One goal of the program is to improve children's emotional lives, and this finding suggests that many participants experience a significant improvement in this area. Other studies illustrate that this finding is in line with current research regarding the effects of social interventions for children with chronic illnesses. For example, an assessment of a wish intervention found that participants improved in their general distress, depression, and anxiety after completion (Shoshani, et al., 2016).

Second, participants significantly improved in their cooperation and independence with medical care after involvement with the program. This is important considering our participants (children with chronic illnesses) and their parents may experience treatment or caregiver burden, respectively (Caicedo, 2014). After participating in Team IMPACT, children may be more prepared to cooperate with their medical care and gain independence in their daily requirements of living with their illness.

We also investigated whether participant characteristics could predict these results. For Emotion management, we found that female participants tend to significantly improve more than male participants and that participants with higher Household Income tend to improve more than those whose Household Income is less than $50,000. For Cooperation, we also found that female participants may tend to improve more than male participants. Additionally, participants' Match Quality score may be a significant predictor of improvement in this measure.

For physical activity measures, we also found that Age predicts Actual Physical Activity Improvement such that older participants are less likely to improve in their Actual Physical Activity.

With our findings showing consistent significant differences in improvement between Genders and Household Incomes, there is also opportunity to investigate these differences further. Future studies could take advantage of qualitative methods to help understand the nuances of what parts of the program help each individual participant, and thus, help tailor the program to the needs of each family.

Third, we found no significant differences for our Stigma measure after involvement with the Team IMPACT program. At the outset of this study, we intended to measure some aspect of social acceptance. However, after seeing these results, it may be more appropriate to investigate the impact that the program has on something like social isolation as a form of social acceptance. We will consider a new measure for our survey in future data collection.

Last, we found that parents of participants in Team IMPACT are highly likely to recommend the program to their friends and colleagues as is reflected in the Net Promoter Scores at both the 12-month and 24-month timepoints. Based on cutoff scores suggested by the original developers of the Net Promoter Score, our families rate Team IMPACT in the "Excellent" to "World Class" range.

In conclusion, we found that the Team IMPACT program helps participants improve in their self-efficacy to manage emotions and their cooperation and independence with their care. Parents of children are highly likely to recommend the program to their friends and colleagues, further indicating the utility of the program and the joy it can bring to participating families.

REFERENCES

Adams, J. S., Chien, A. T., & Wisk, L. E. (2019). Mental Illness Among Youth With Chronic Physical Conditions. *Pediatrics*, *144*(1). https://doi.org/10.1542/peds.2018-1819

Bhatia, S., Landier, W., Hageman, L., Kim, H., Chen, Y., Crews, K. R., Evans, W. E., Bostrom, B., Casillas, J., Dickens, D., Maloney, K. W., Neglia, J. P., Ravindranath, Y., Ritchey, A. K., Wong, F. L., & Relling, M. V. (2014). 6MP adherence in a multiracial cohort of children with acute lymphoblastic leukemia: a Children's Oncology Group study. *Blood*, *124*(15), 2345–2353. https://doi.org/10.1182/blood-2014-01-552166

Brady, A. M., Deighton, J., & Stansfeld, S. (2020). Chronic illness in childhood and early adolescence: A longitudinal exploration of co-occurring mental illness. *Development and Psychopathology*, *33*(3), 885-898. https://doi.org/10.1017/s0954579420000206

Caicedo, C. (2014). Families with special needs children. *Journal of the American Psychiatric Nurses Association*, *20*(6), 398–407. https://doi.org/10.1177/1078390314561326

Carpenter, A. (n.d.) *What is a good Net Promoter Score*. Qualtrics. *https://www.qualtrics.com/experience-management/customer/good-net-promoter-score*

Caspi, A., Harrington, H., Moffitt, T. E., Milne, B., & Poulton, R. (2006). Socially isolated children 20 years later. *Archives of Pediatrics & Adolescent Medicine*, *160*(8), 805. https://doi.org/10.1001/archpedi.160.8.805

Gilliam, M. B., & Schwebel, D. C. (2013). Physical activity in child and adolescent cancer survivors: a review. *Health Psychology Review*, *7*(1), 92-110. https://doi.org/10.1080/17437199.2011.603641

Goodfellow, N., Hawwa, A. F., Reid, A., Horne, R., Shields, M., & McElnay, J. (2015). Adherence to treatment in children and adolescents with cystic fibrosis: a cross-sectional, multi-method study investigating the influence of beliefs about treatment and parental depressive symptoms. *BMC Pulmonary Medicine*, *15*(1). https://doi.org/10.1186/s12890-015-0038-7

Gruber-Baldini, A.L., Velozo, C., Romero, S., & Shulman, L.M. (2017). Validation of the PROMIS® Measures of Self-Efficacy for Managing Chronic Conditions. Quality of Life Research, 1- 10.

Lai, J. S., Nowinski, C. J., Zelko, F., Wortman, K., Burns, J., Nordli, D. R., & Cella, D. (2015). Validation of the Neuro-QoL measurement system in children with epilepsy. Epilepsy & Behavior, 46, 209-214.

R Core Team (2021). *R: A language and environment for statistical computing*. R Foundation for Statistical Computing, Vienna, Austria. https://www.R-project.org/

Riner, W. F., & Sellhorst, S. H. (2013). Physical activity and exercise in children with chronic health conditions. *Journal of Sport and Health Science*, *2*(1), 12–20. https://doi.org/10.1016/j.jshs.2012.11.005

Shoshani, A., Mifano, K., & Czamanski-Cohen, J. (2015). The effects of the Make a Wish intervention on psychiatric symptoms and health-related quality of life of children with cancer: a randomized controlled trial. *Quality of Life Research*, *25*(5), 1209–1218. https://doi.org/10.1007/s11136-015-1148-7

West, S., Banks, L., Schneiderman, J. E., Caterini, J. E., Stephens, S., White, G., Dogra, S., & Wells, G. D. (2019). Physical activity for children with chronic disease; a narrative review and practical applications. *BMC Pediatrics*, *19*(1). https://doi.org/10.1186/s12887-018-1377-3

Yeo, M., & Sawyer, S. M. (2005). Chronic illness and disability. *BMJ, 330*(7493), 721 - 723. https://doi.org/10.1136/bmj.330.7493.721

APPENDIX A: SURVEY

Please respond to each question or statement by marking one box per row.

Your current level of confidence:

	I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
My child can handle negative feelings	1	2	3	4	5
My child can find ways to manage stress	1	2	3	4	5
My child can handle upsetting situations	1	2	3	4	5
My child can avoid feeling discouraged	1	2	3	4	5
My child can keep emotional distress from interfering with things they want to do	1	2	3	4	5
My child can bounce back from disappointment	1	2	3	4	5
My child can relax their body to reduce anxiety	1	2	3	4	5
My child can handle the stress of going for treatment of their medical conditions	1	2	3	4	5

Adapted from PROMIS: Self-Efficacy for Managing Chronic Conditions – Managing Emotions – Short Form 8a

Lately, because of my child's illness…

	Never	Rarely	Sometimes	Often	Always
Others their age avoided them	1	2	3	4	5
They felt left out of things	1	2	3	4	5
Others their age made fun of them	1	2	3	4	5
They felt embarrassed when they were in front of others their age	1	2	3	4	5
They were treated unfairly by others their age	1	2	3	4	5
Others their age tended to ignore their good points	1	2	3	4	5
They felt different from others their age	1	2	3	4	5
My child avoided making new friends to avoid talking about their illness	1	2	3	4	5

Adapted from Neuro-QoL: Pediatric Stigma – Short Form

TEAM IMPACT PROGRAM EVALUATION

Lately…

	Never	Rarely	Sometimes	Often	Always
My child cooperates with their routine medical treatments	1	2	3	4	5
My child cooperates with their medical care during doctor/clinic visits or hospital admissions	1	2	3	4	5
My child is able to advocate for themselves with the medical team	1	2	3	4	5
My child cooperatively participates in physical activity and/or PT/OT	1	2	3	4	5
How would you rate your child's independence with their medical care (taking medication, breathing treatments, diet changes)?	Fully dependent on caregiver	Mostly dependent on caregiver	Somewhat independent with care	Mostly independent with care	Fully independent with care

Measure self-developed

The following questions are included at 12 and 24 months:

Because of participating in Team IMPACT…

	Not at all	Slightly	Moderately	Very	Extremely
Has your child's cooperation with their routine medical treatments improved?	1	2	3	4	5
Has your child's cooperation with doctor/clinic visits or hospital admissions improved?	1	2	3	4	5
Has your child's ability to advocate for themselves with the medical team improved?	1	2	3	4	5
Has your child's interest in physical activity increased?	1	2	3	4	5
Has your child's physical activity level increased?	1	2	3	4	5
Has your child's independence with their medical care (taking medication, breathing treatments, diet changes) improved?	1	2	3	4	5

Measure self-developed

- What has been the biggest change you've seen in your child since the start of their participation in Team IMPACT?
- What has been the most challenging part of participating in Team IMPACT?
- How likely are you to recommend Team IMPACT to other families? *(from 0 – 10)*
  - Please explain why you rated the last question the way you did.