



Evaluating Health-Related Quality of Life and School Attendance in a Multidisciplinary School Program for Youth with Significant Medical Needs

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Abstract

Many youth with significant medical needs have difficulty attending traditional schools due to academic, physical, and psychosocial challenges. To meet the needs of these youth and prepare them for a successful transition to a traditional school, a multidisciplinary school program (MSP) provides support in these three domains. The aims of this program evaluation are to describe the operation of the novel MSP, characterize participants, and determine the impact of participation as related to school attendance and health-related quality of life (HRQoL). Attendance in the MSP was significantly higher than school attendance estimates provided by caregivers prior to participation in the program. Youth reported significant improvement in physical functioning and total HRQoL. Caregivers reported significant improvement in academic functioning and total HRQoL of youth. The MSP represents a unique educational model for youth with significant medical issues that also provides physical and psychosocial support. Initial findings highlight the potential positive impact of this model for this population of youth.

Keywords Health-related quality of life (HRQoL) · Pediatric · School reintegration · Health outcomes · Program evaluation

Introduction

In the United States, 15 to 30% of children and adolescents have significant medical challenges (Denny et al., 2014; Van Cleave, Gortmaker, & Perrin, 2010). Advances in medical care result in shorter hospitalizations, but youth are increasingly returning to home and school environments with substantial, ongoing medical needs (Cohen et al., 2011). Given

these advances, mortality is no longer considered the only indicator of effective medical interventions (Eiser & Morse, 2001). Rather, health-related quality of life (HRQoL), a multidimensional construct that assesses subjective well-being and functioning across domains (Eiser & Varni, 2013), including academic, physical, and psychosocial (social and emotional) functioning, is considered a more comprehensive indicator of outcomes (Eiser & Morse, 2001). As such, many argue that improvement in quality of life should be a key outcome and goal of health care interventions (Kaplan, 2001), especially for youth with chronic health conditions (Ingerski et al., 2010; Varni, Limbers, & Burwinkle, 2007a).

Chronic health conditions can adversely affect the quality of life of youth across various domains, including academic functioning. Youth with significant medical illnesses may experience a number of challenges that negatively affect their school experiences, including increased risk for absenteeism and academic underachievement (Kearney, 2008; Shiu, 2001) that may consequently compromise future educational and vocational attainment (Maslow, Haydon, McRee, Ford, & Halpern, 2011). Factors that may influence attendance and educational outcomes include ongoing illness symptoms (e.g., pain, fatigue, vomiting), lack of physical stamina to

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attend school after a prolonged illness or intensive treatment regimen (e.g., radiation or chemotherapy), and school avoidance after absences secondary to health challenges. Homebound education, a common alternative to attending a traditional school, attempts to address these challenges but can be considered isolating and academically inadequate (Bessell, 2001; Searle, Askins, & Bleyer, 2003). Notably, youth with significant medical issues often want to attend school to maintain a sense of normalcy in a life that can seem dominated by illness and its treatment (Sullivan, Fulmer, & Zigmond, 2001). Therefore, attending school may be one avenue to provide normalization and promote positive HRQoL for these youth in multiple domains.

Youth with significant medical needs may experience a number of physical challenges such as exercise intolerance (West et al., 2017) or sequelae that may limit physical activity (e.g., Yeo & Sawyer, 2005) and impact their quality of life. As a result, there are concerns about the extent to which traditional school settings can adequately provide medical services and physical accommodations. For example, some youth may require more medical supervision than a single school nurse can provide within a large traditional school setting (e.g., a child with poorly controlled diabetes who has frequent episodes of hypoglycemia). Parents of youth with significant medical issues commonly worry about inadequate medical supervision during the school day and teachers' ability to recognize and manage acute illness symptoms (Notaras et al., 2002). Similarly, teachers endorse concerns about helping their students manage medical symptoms within the classroom, especially since they frequently receive limited training in this area (Hinton & Kirk, 2015).

Psychosocial quality of life can also be significantly impacted, and youth with chronic medical needs are at heightened risk for mental health concerns such as depression, anxiety, and behavioral disorders (Shaw & McCabe, 2008). Although traditional schools have counselors available to students, it is typically beyond a counselor's scope to provide psychotherapeutic intervention from a lens that includes an understanding and knowledge base about the student's medical needs. Additionally, school counselors may be responsible for hundreds or thousands of students, which makes it difficult to provide the level of social and emotional support that youth with significant medical needs may require.

Existing Programs

Since significant medical illness can negatively affect the academic, physical, and psychosocial domains of HRQoL, it is important to consider alternatives to homebound education and traditional public school for these school-age youth, and particularly for those who are demonstrating concerns with their HRQoL. A variety of school reintegration programs

have been documented in the literature (see Canter & Roberts, 2012; Prevatt, Heffer, & Lowe, 2000 for reviews); however, none systematically provide supports to improve all domains of HRQoL. The most cited model to support school attendance in chronically ill youth is the school reintegration program (see Canter & Roberts, 2012; Lindsay et al., 2015 for reviews). This type of program typically offers short-term services to youth returning to school after an extended hospital stay. School reintegration programs have demonstrated increases in teachers' illness-related knowledge and improvement of patients' psychological functioning (Canter & Roberts, 2012; Lindsay et al., 2015); however, they typically exclude youth with illnesses that do not require extended hospitalizations (Shaw & McCabe, 2008). These programs are also usually short-term and do not offer the comprehensive care and multidisciplinary collaboration that youth in this population may need (Lindsay et al., 2015). Moreover, most of the research supporting the efficacy of these programs has been conducted on youth with cancer (Canter & Roberts, 2012) and thus may not be generalizable to those with other health conditions.

While education is not the primary focus of more intensive psychiatric programs for youth, these programs often provide some degree of educational support during psychiatric care. This model of care is typically arranged within a partial or full psychiatric hospitalization program and provides multiple hours of psychiatric treatment per day (DeMaso, Martini, & Cahen, 2009). Rather than focusing on education, these programs focus on stabilization of psychiatric symptoms for youth that demonstrate higher acuity mental health concerns. However, although psychosocial factors certainly play a large part in an effective return to school, only a small subset of youth with significant medical illness have acute psychiatric issues that would require emergent services (Wallander, Thompson, & Alriksson-Schmidt, 2003). Therefore, the focus of psychosocial intervention for many of these youth should include other important areas related to HRQoL (e.g., academic motivation, locus of control, and feelings of helplessness; Shaw & McCabe, 2008) that can be delivered in a lower level of care. Moreover, these programs are often not equipped to accept patients with significant medical needs (e.g., requiring g-tube feeds).

A Novel Model

In summary, the extant literature focuses primarily on school reintegration programs for youth returning to school after long hospital stays and psychiatric hospitalization programs for youth who require acute psychiatric care. While these programs can have beneficial effects for subsets of youth needing targeted services, they do not meet the complex needs of those with significant medical illness who require supportive interventions in academic, physical, and

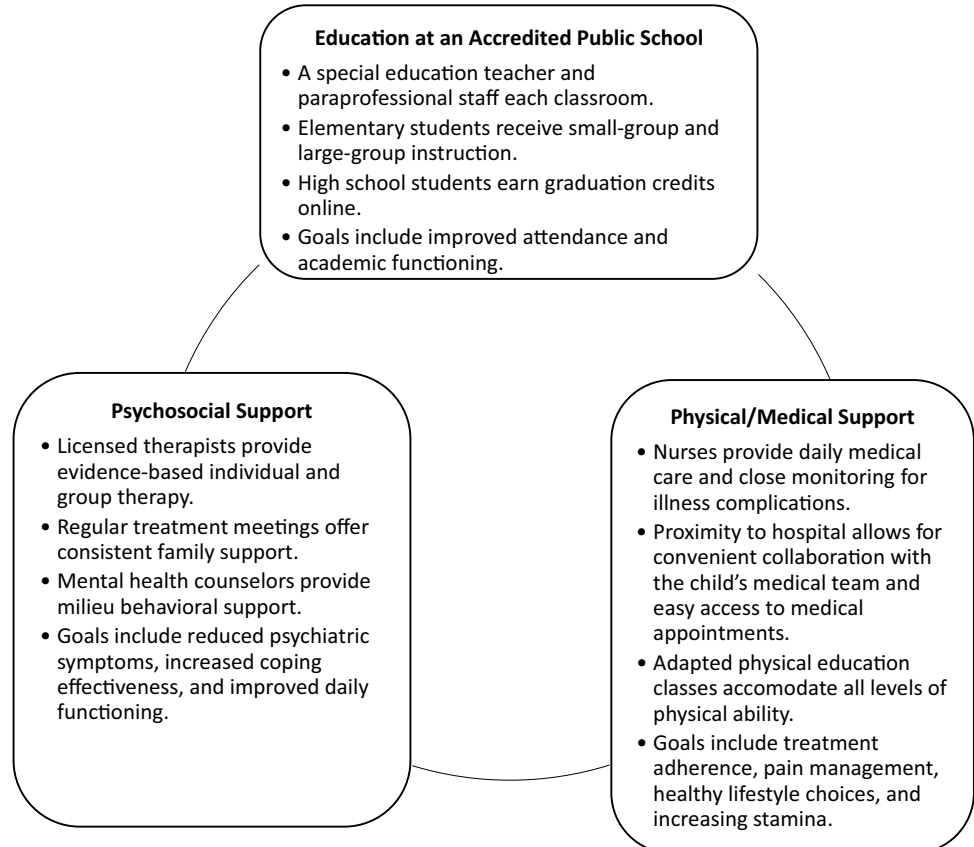
psychosocial domains. They also do not provide an ideal setting for the delivery of closely coordinated, comprehensive care across providers. Given these limitations, we will illustrate an alternative model, which is a hospital-based, multidisciplinary school program (MSP) that provides collaborative academic, physical, and psychosocial services to promote improvement in HRQoL of youth with significant medical needs. At this juncture, creating and implementing program evaluation efforts are critical steps toward better understanding the youth served in the MSP and outcomes of these youth. In this program evaluation, we aim to describe the operation of the novel MSP, characterize participants, and preliminarily examine school attendance and HRQoL of youth as outcomes of this comprehensive, multidisciplinary program. Ultimately, findings of this evaluation inform ways to address the academic development of youth with significant medical diagnoses while also supporting their physical and psychosocial needs, and concurrently improving their HRQoL.

Characterization of the Multidisciplinary School Program (MSP)

Program Overview

The MSP is housed within the Department of Psychiatry at a large children's hospital and is affiliated with the local school district. As an accredited school that functions as a multidisciplinary outpatient program, the MSP provides services in three treatment domains: academic, physical, and psychosocial (see Fig. 1). Despite experiencing changes in local school district affiliation, partnership, programming, and staff throughout its operation, the MSP has consistently included the three aforementioned treatment domains. Students from regional school districts enroll in the affiliated public school district for the duration of admission to the MSP, and then re-enroll in their home school district after meeting academic, physical, and psychosocial goals that prepare them for a successful transition to a traditional school in the community. Since the MSP operates throughout the year, it is open when the school district is closed. Thus, the MSP is able to provide consistent structure and support for these youth, as well as facilitate ongoing access to academic, physical, and psychosocial interventions. Their length of

Fig. 1 The three-pronged MSP program structure



stay is variable, depending on progress made toward their individualized goals. In general, youth are enrolled at the MSP for an academic year or longer.

The state budget allocates funds annually to support the MSP. Due to this arrangement, youth with Medicaid (as primary or secondary insurance coverage) are eligible for the program. Of note, efforts to serve individuals with private insurance exclusively have been challenged by private payers who report not having a billing code that fits this unique service; therefore, this is a barrier to serving youth in the MSP. The hospital financially supports the program as one of its behavioral health services, providing the physical space for the program and contributing to costs for operation and staffing. The partnering school district provides salary support for teaching staff and materials for the program, as would occur for any other school in the district. Door-to-door transportation is provided for students through services that are contracted through Medicaid or through the school district.

Eligibility Criteria

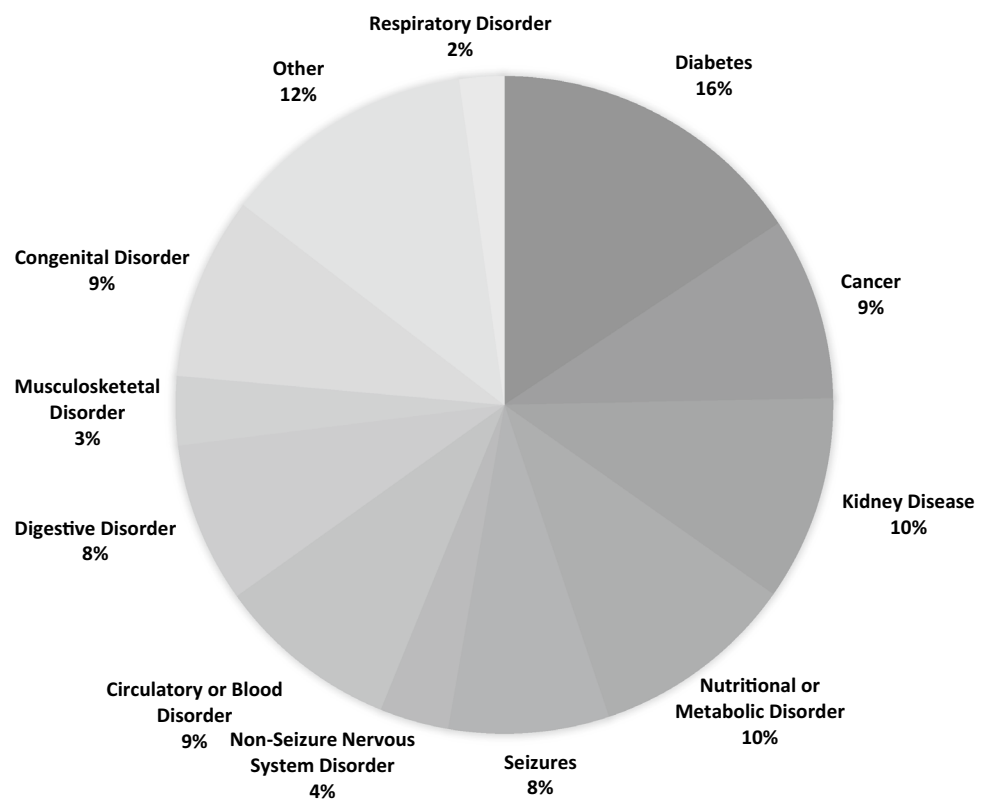
Youth who are seven to 21 years old are eligible to attend the MSP if they have difficulty accessing educational services in a traditional school setting as a consequence of having a significant medical illness and/or other medical problems interfering with their schooling (e.g., high frequency of medical appointments, illness-related fatigue). Broad categories

of medical diagnoses have included cancer, diabetes, metabolic disorder, central nervous system disorder, circulatory or blood disorder, digestive disorder, congenital disorder, respiratory disorder, and kidney disease (see Fig. 2). Exclusion criteria for admission into the program include significant needs in any one of the three treatment areas that cannot be met within the parameters of the program (e.g., requiring a one-on-one personal aide in the classroom for significant cognitive or learning challenges, needing one-on-one nursing care, or having a history of aggressive behavior or safety concerns warranting one-to-one supervision from a mental health counselor). Community providers, school personnel, and families can initially refer youth to the MSP. An order from a medical provider within the children's hospital is required for admission to ensure that the program can adequately meet the youth's medical needs. Formal approval by the home school district for students who have IEPs is also necessary.

MSP Staff and Services

The MSP is comprised of academic, medical, and psychosocial teams. The MSP staff frequently consult and collaborate with health care providers in the children's hospital, including physicians, nurses, psychologists, psychiatrists, social workers, and rehabilitation therapists. Youth in the program may also receive other types of supportive services, such

Fig. 2 Categories of primary medical diagnoses ($N=89$)



as physical, occupational, or speech therapy, from the children's hospital and/or from the school district.

The academic team includes two full-time special education teachers, two full-time classroom paraprofessionals, and a special education liaison from the partnering school district. Other staff from the school district (e.g., teachers from the online high school within the school district) are available to provide consultation and to work with students face-to-face. The MSP has two classrooms, each staffed by a special education teacher and a paraprofessional. One classroom serves grades one through six (elementary and early middle school), while the other classroom serves grades 7 through 12 (later middle school and high school). To enhance academic HRQoL, teachers identify educational goals for each youth, which commonly include regaining academic functioning disrupted by medical barriers and, for high school youth, earning credits toward graduation. Teachers work closely with the youth's school district to match curriculum that they would otherwise receive in a traditional school setting. For elementary school students, the teacher and paraprofessional provide individualized and small-group instruction for reading, writing, and math. An online curriculum is used for middle and high school youth, with support from the MSP teachers and teachers from the online high school. Larger-group instruction targets other areas such as social sciences. Teachers are closely involved with IEP initial or re-evaluation as needed, and they work with the district's school psychologist to complete testing and conduct IEP meetings.

The medical team, which provides support for the physical health goals of youth, includes a certified pediatric nurse who is also the Program Manager, three staff nurses, and a consulting advanced practice nurse. Each youth is assigned to a primary nurse who tracks medical goals and coordinates care with involved medical teams. Specific nursing interventions include medication administration (e.g., oral, intramuscular, and intravenous), central line care, gastrostomy tube care, dressing changes, lab draws, and daily assessment of pain and other symptoms. Nurses also support students in completing components of their daily treatment regimens (e.g., checking blood sugar, monitoring carbohydrate intake, and administering insulin for a youth with diabetes). The program's location on the hospital campus allows for youth to attend medical appointments during the school day, minimizing time away from school for these appointments. It also allows for more direct communication with other health care professionals involved in each student's care. Finally, daily physical education classes include modified activities to ensure there is not exclusion based on physical limitations.

The psychosocial team includes a psychologist, a clinical social worker, a mental health counselor, and a consulting psychiatrist. Each youth is assigned a primary psychotherapist who identifies psychosocial goals for treatment that are

addressed in weekly individual therapy sessions. These sessions may focus on providing support related to the stressors of managing a significant medical issue(s), strengthening coping skills for managing medical and psychological challenges, reducing psychiatric symptoms, supporting overall psychosocial development, improving treatment adherence, and classroom functioning. Given the unique mental and behavioral health goals for each student, individual therapy is tailored to meet these goals and is grounded in evidence-based treatments. Examples of psychological interventions or strategies that may be used during individual therapy include cognitive-behavioral therapy; behavioral therapy; acceptance and commitment therapy; motivational interviewing techniques; and dialectical behavior therapy. If behavioral problems arise during the school day, the mental health counselor and therapists are readily available for support. The psychosocial team can observe youth in the classroom, during unstructured social time (e.g., meals), and while undergoing medical procedures (e.g., dialysis, needle sticks) to better inform treatment planning and practice skills learned in therapy. In addition to receiving individual therapy, youth participate in group therapy twice weekly. One group is creative arts therapy provided by a consulting team, and the second group focuses on building social-emotional and coping skills and is provided by the MSP mental health providers. Finally, the psychologist and social worker facilitate monthly family treatment meetings which provide an opportunity to review treatment progress and offer additional family support, intervention, and consultation. Common targets of evidence-based, family-focused therapeutic intervention include increasing household structure, improving effectiveness of discipline strategies, facilitating communication, and helping to align youth and family goals to improve HRQoL.

Program Goals and Progress Monitoring

The overarching focus of the MSP is attaining stability in academic, physical, and psychosocial domains that would prepare youth for transitioning into a traditional school within their home school district. Therefore, discharge criteria include meeting goals related to each of the aforementioned areas, which in essence mirror the domains of HRQoL. Specifically, progress within the academic domain may include an improvement in school attendance and decreased time out of the classroom due to medical symptom interference. From a physical perspective, discharge requires that physical symptoms do not significantly interfere with school attendance and academic functioning. In addition, the monthly tracking of progress toward individualized medical goals provides data to substantiate level of medical need and progress with medical goals. For example, reduced frequency of rest breaks may be documented as evidence of

improved stamina. Finally, criteria for demonstrating psychosocial progress might include consistent use of effective coping skills for managing anxiety, improved social skills, decreased symptoms of depression or anxiety, and increased use of behavioral strategies to promote medical adherence. Upon discharge from the program, the MSP team consults on an as-needed basis with community mental health clinicians, medical providers, and staff at the youth's home school to facilitate a successful transition.

Methods

Procedures

A clinical registry (i.e., database of patient information) for the MSP was established in 2013, and information for all analyses in the program evaluation was obtained from the database. As part of the standard of clinical care to inform treatment and discharge planning, youth and their caregivers complete a battery of psychosocial measures at intake, regular intervals (e.g., beginning, middle, and end of each school year), and discharge. The standardized assessment battery includes measures of social, emotional, and behavioral symptoms, health-related quality of life, coping strategies, resiliency, and family functioning.

The Institutional Review Board at the program site designated this work as a program evaluation. Program evaluations are projects in which the intent is to improve a specific program within the institution. Program evaluations do not involve randomization of participants, are largely observational, and are based on data from all or most participants receiving an intervention or treatment within the program. Essentially, the goals of program evaluations are to facilitate program improvements, clarify needs and impact, and to evaluate whether the specific program should continue. Collectively, these descriptions fit the overall aims of this project. Although the goal of publication is presumed at the initiation of program evaluation efforts, the intent of this publication is to suggest effective models, strategies, and assessments rather than to be generalized to other populations or programs. This project represents the first systematic attempt to conduct a program evaluation of the MSP.

Measures

The program does not have access to pre-MSP school attendance records; however, upon admission to the MSP, caregivers are asked to provide estimates of school attendance on a standard intake form. Since previous research has documented strong correlations between caregiver and youth report of attendance and official school attendance records (Logan, Simons, Stein, & Chastain, 2008), estimates from

caregivers were used to characterize prior school attendance. Categorical estimates of attendance are utilized, as many caregivers cannot accurately report the exact amount of school missed or do not readily have this information. Caregivers report attendance using the following scale: attending school less than 25% of the time, attending school 25–49% of the time, attending school 50–74% of the time, or attending school 75% or more of the time. Attendance data are also collected during admission in the MSP, and total percentage of days attended is coded according to the scale described above.

The pediatric quality of life inventory (PedsQL) Generic Core Scales (Varni, Seid, & Kurtin, 2001) quantified HRQoL in the youth. The PedsQL has been shown to be reliable and valid in youth with acute and chronic medical conditions as well as in their healthy counterparts (Varni et al., 2001). The scales correlate with measures of both morbidity and illness burden (Varni et al., 2001). They also demonstrate sensitivity to disease severity and change over time as well as significant relationships with disease-specific symptom scales (Varni et al., 2001). The PedsQL includes twenty-three items across four subscales: academic, physical, emotional, and social functioning. A Total Scale score is also provided and represents the average of all items. Scores range from 0 to 100, with higher scores indicating better functioning within each domain. Self-report and caregiver-proxy (i.e., caregiver perception of youth quality of life) report forms were used.

Statistical Methods

Demographic variables of all program participants were analyzed using descriptive statistics ($n = 89$). Preliminary examination of school attendance and HRQoL of youth included a sub-sample of youth who entered the program after the clinical registry was established and formalized psychosocial screening was implemented at admission (47 caregivers and 48 youth). Missing data were excluded from analyses, and pre-post analyses included 36 caregivers and 40 youth, as some participants did not complete the PedsQL at discharge. This was because the PedsQL was not administered at discharge for those who were admitted for less than a month or because the caregiver was not present at the discharge meeting. Paired samples t tests compared estimated school attendance prior to enrollment at the MSP to attendance while participating in the MSP. Paired sample t tests also measured change in PedsQL scores from admission to discharge from the MSP, as assessed by youth and caregiver report. PedsQL improvement scores were computed by calculating the difference between admission and discharge scores within each domain and comparing to reported estimates of Minimally Clinically Important Difference (MCID). The MCID is the smallest difference in scores that patients perceive to be beneficial and that would

mandate a change in patient management (Varni, Burwinkle, Seid, & Skarr, 2003). Follow-up analyses compared demographic variables and PedsQL change scores (e.g., gender, age, race/ethnicity), which were computed by subtracting admission PedsQL scores from discharge scores across domains. Between-subjects *t* tests compared youth with only one medical diagnosis to those with one or more medical comorbidities. All analyses were performed using SPSS, with significance levels set at $p < 0.05$.

Results

Characterization of the MSP Participants

As of August of 2016, the MSP clinical registry database included 89 youth ranging in age from 7 to 18 years ($SD = 2.93$). Most patients identified as female (52% female;

47% male; 1% transgender). The majority were Caucasian (37%) or Latino (35%), though participants also included African American (15%) or multiracial (8%) individuals. The primary insurance source was Medicaid (80.9%), followed by private insurance with secondary Medicaid (13.5%). Table 1 provides a summary of demographic information (13.5%). Categories of primary medical diagnoses that characterize youth in the MSP are depicted in Fig. 2. Notably, around 75% of youth have at least one medical comorbidity. Mean duration of admission to the MSP was 482 days, but ranged from 16 to 2907 days.

All youth in the program had some level of psychiatric symptomatology at admission. Approximately 42% met criteria for one psychiatric diagnosis, around 37% met criteria for two psychiatric diagnoses, and around 20% met criteria for three or more psychiatric diagnoses. Anxiety and depression were the most common psychiatric diagnoses (29% each), followed by attention deficit hyperactivity disorder

Table 1 Participant demographics

Patient characteristic	Full cohort ($N = 89$)			Sample subset ($n = 36$)		
	Percentage	$M + SD$	Range	Percentage	$M + SD$	Range
Youth Age		12.22 ± 2.9	7–18		12.19 ± 3.0	7–17
Gender						
Male	47			50		
Female	52			47		
Transgender	1			3		
Race/Ethnicity						
Caucasian	37			36		
Hispanic/Latino	35			36		
African American	15			14		
Multiracial	8			8		
Pacific Islander	1			–		
Asian	1			–		
Other	3			6		
Insurance						
Medicaid	81			81		
Secondary Medicaid	14			9		
Private	1			3		
Other Public	2			3		
Unknown	2			6		
Admission duration		481.70 ± 532.55	16–2907		357.14 ± 271.29	49–1009
At least one medical comorbidity	70.8			83.7		
Total psychiatric diagnoses		1.85 ± .96	1–6		1.78 ± 1.03	1–6
Psychosocial stressors*	94.4**	3.48 ± 2.02	0–9	94.9**	4.02 ± 2.24	0–9
Individualized education plan	39			39		
504 plan	19			28		

*Psychosocial stressors include the following: Immediate family member with physical or mental illness, separation from at least one biological parent, single caregiver, caregiver unemployment, receipt of financial assistance beyond Medicaid, family involvement in the legal system, non-English-speaking caregiver, relocation for medical reasons, parental concerns related to immigration status, and homelessness

**Percent experiencing at least one psychosocial stressor

(ADHD; approximately 13%; see Table 2 for more information). Additionally, approximately 94% of youth experienced significant psychosocial stressors (as identified in the initial assessment on a list of stressors common to the population). The most common stressors included having an immediate family member with a mental or physical illness (65%), having a single caregiver (56%), or involvement with Child Protective Services (current or historic; 52%).

Thirty-nine percent of participants had Individualized Education Plans (IEP) to address deficits significantly interfering with learning and requiring educational supports. Of note, not all of the MSP participants require IEPs because not all presenting illnesses are associated with learning problems. Although illness symptoms and treatment have typically interfered with school attendance, this interference

does not automatically qualify a student for an IEP. Nineteen percent had a 504 plan at the time of admission due to previously established needs for accommodations in the school setting due to health conditions.

Examination of School Attendance and HRQoL of the MSP Participants

Attendance in the MSP was significantly higher than attendance estimates provided by caregivers prior to participation in the program ($t(49) = -0.945, p < 0.000, d = -1.45$), and results represent a large effect size. Figure 3 illustrates pre- and post-MSP attendance estimates. Prior to enrolling in the MSP, approximately half of participants were attending school less than 25% of the time. While attending the MSP, most participants attended more than 75% of the time and all participants attended school at least 25% of the time. Of note, approximately 28% of caregivers did not provide attendance estimates at admission.

Youth reported significant improvements in physical functioning and total HRQoL between admission and discharge and results represented a small to medium effect size ($t(39) = -3.29, p < 0.05, d = -0.53; t(39) = -2.18, p < 0.05, d = -0.35$, respectively). Caregivers reported significant improvements in academic functioning and total HRQoL ($t(35) = -3.54, p = 0.001, d = -0.60; t(35) = -2.42, p < 0.05, d = -0.40$, respectively), with results representing a small to medium effect size. Youth physical and total functioning met criteria for MCID. Caregiver emotional, academic, and total functioning also met criteria for MCID. See Table 3 for full results.

Additional analyses examined the relationship between demographic variables (e.g., age, gender, race/ethnicity,

Table 2 Psychiatric diagnoses of youth at MSP admission ($N = 89$)

Diagnosis	Percentage
Depression	29.7
Anxiety	29.1
Attention deficit hyperactivity disorder (ADHD)	12.7
Adjustment problem, general	7.3
Behavioral disorder (oppositional defiant disorder or conduct disorder)	3.6
Psychotic disorder	1.8
Bipolar disorder/mania	0.6
Substance abuse	0.6
Intellectual disability	0.6
Autism spectrum disorder	0.6
PTSD/acute stress disorder	0.6
Other	7.9

Fig. 3 Pre-MSP and MSP attendance estimates ($N = 78$)

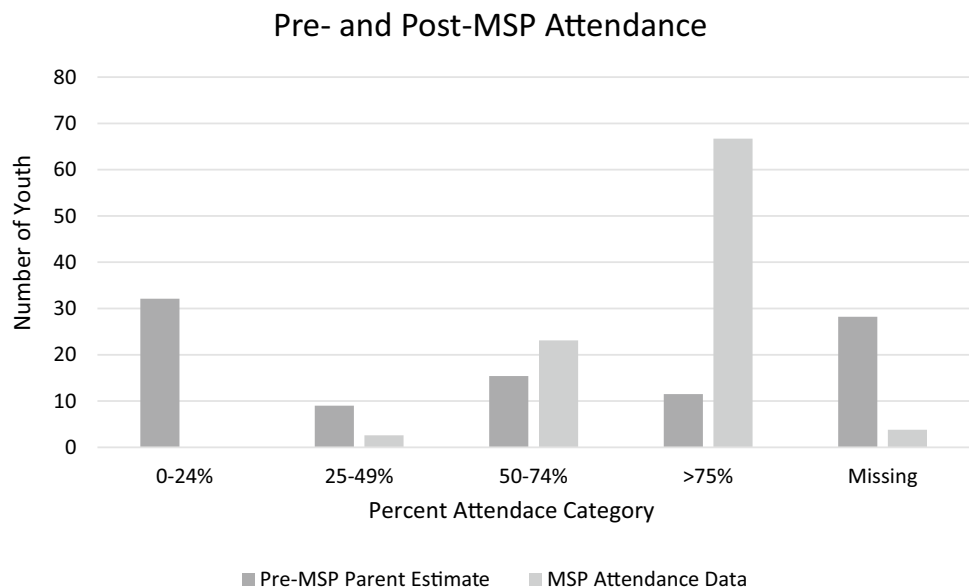


Table 3 Paired samples *t* tests between admission and discharge HRQoL scores in youth in the MDT program

	Admission Scores		Discharge Scores		<i>T</i>	<i>d</i>	Improvement Scores ^a	Minimum clinically important difference (Varni et al., 2003)
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>				
Youth (<i>n</i> = 40)								
Physical	56.95	21.95	66.71	20.13	− 3.29*	− 0.53	9.76 ^b	6.66
Emotional	58.16	23.83	59.97	29.53	− .55	− 0.36	1.81	8.94
Social	62.50	20.44	67.50	22.36	− 1.49	− 0.24	5	8.36
School	52.88	22.16	55.25	20.57	− .55	− 0.09	2.37	9.12
Total	57.49	17.25	62.95	17.15	− 2.18*	− 0.35	5.46 ^b	4.36
Caregiver (<i>n</i> = 36)								
Physical	51.62	25.28	56.25	23.12	− 1.21	− 0.20	4.63	6.92
Emotional	54.86	23.68	63.33	21.28	− 1.91	− 0.32	8.47 ^b	7.79
Social	57.08	22.15	62.11	23.23	− 1.09	− 0.17	5.03	8.98
School	41.67	22.83	55.61	17.24	− 3.54***	− 0.60	13.94 ^b	9.67
Total	51.33	18.30	59.05	15.61	− 2.42*	− 0.39	7.72 ^b	4.50

* $p \leq .05$, ** $p \leq .01$, *** $p \leq .001$

^aChange scores from pre-test to post-test

^bMeets minimally clinically important difference cut-off (Varni et al., 2003)

insurance type) and PedsQL scores. At the MSP admission, only youth report of physical functioning was significantly related to age ($r = -0.34$, $p = 0.02$). Similarly, only youth report of physical functioning significantly differed by gender (male $M = 50.88$, female $M = 65.79$; $t(42) = -2.29$, $p = 0.03$). Group differences were not observed between race/ethnicities or insurance type on any admission PedsQL subscales. With regard to change in PedsQL scores, neither length of admission nor age at admission was significantly related to PedsQL change scores by either caregiver or youth report. Demographic variables were also unrelated to change scores. Youth with at least one medical comorbidity reported higher improvement in physical HRQoL than those with no comorbidities ($t(39) = 2.39$, $p < 0.01$, $d = 0.76$), representing a medium to large effect size. Other domains of HRQoL did not differ significantly between groups based on data from either caregiver or youth report.

Discussion

The aims of this program evaluation were to describe a comprehensive MSP that provides academic, physical, and psychosocial support to youth with significant illnesses, to characterize the youth attending the program, and to evaluate key outcomes of participation such as attendance and HRQoL. The overarching goal of the MSP is to promote academic, physical, and psychosocial stability to prepare youth for reintegration into the home school district. Therefore, they receive intensive services throughout MSP enrollment, with the goal of improved HRQoL across domains and a need

for less intensive services at discharge. However, ongoing support in these areas is recommended, as needed, to help support a successful transition to a traditional school setting (e.g., referral to the school counselor or an outpatient mental health provider, special education services, or involvement of the school nurse).

It has long been recognized that youth with significant medical issues are absent from school more frequently than their healthy counterparts (e.g., Fowler, Johnson, & Atkinson, 1985). Drawing from models of school reintegration, school attendance is cited as a primary goal for reintegrating youth into an academic setting and creating a sense of return to normalcy (Kaffenberger, 2006). In the current program evaluation, school attendance significantly improved during admission when compared to the period before admission. Although reports of pre-MSP admission were based on caregiver recall, this finding remains encouraging given that these youth often experience significant barriers to attending school. While it is beyond the scope of this program evaluation to examine why attendance improved while students attended the MSP, improvement was potentially driven in part by the program's emphasis on consistent school attendance during times of higher physical and psychosocial need. For example, if youth experience exacerbations in their illnesses, nurses can provide additional accommodations to promote attendance (e.g., increased monitoring during the day, assessment from the consulting advanced practice nurse). If youth experience emotional difficulties, therapists can provide psychotherapy sessions that day to help the patients cope. These immediate supports are understandably difficult to provide for students with higher physical

and psychosocial needs in a traditional school setting where counselors and nurses may be responsible for hundreds or even thousands of students each day.

Youth that participated in the MSP reported significant increases in their physical and total HRQoL from admission to discharge, and these improvements met the criteria for clinically meaningful change (Varni, Limbers, & Burwinkle, 2007b). The MSP interventions that focused on increasing treatment adherence and improving coping with significant medical issues may have contributed to these gains. The provision of physical and occupational therapy and nursing support for increasing student's daily stamina may have also contributed to the improvements. It is notable that youth did not report significant gains in the other domains of functioning (e.g., academic, emotional, social). This finding suggests that the MSP should continue reviewing and consider strengthening the interventions provided in these areas. The current results highlight, however, the centrality of physical functioning for these youth, as this subscale had the highest correlation with the total HRQoL subscale. It should also be noted that the physical subscale has eight items compared to five items in each of the other subscales, thus contributing more to the total score.

Caregivers reported significant improvements in academic functioning and total HRQoL, which also met the criteria for clinically meaningful change (Varni et al., 2007b). Caregiver-reported improvements in academic functioning may be due to increased school attendance at the MSP, facilitating greater participation in academic activities. Caregivers also likely experienced a reduced personal burden due to better school attendance, contributing to their reports of improved academic functioning overall. However, it is interesting to note that caregivers did not report significant improvement in physical functioning as youth did. This is consistent with previously described findings whereby caregivers tend to report more concerns about their child or adolescent's physical well-being than youth self-report (Varni et al., 2003). Previous research has also shown that caregivers reporting higher levels of emotional distress tend to report lower overall youth HRQoL (Janicke et al., 2007; Kobayashi & Kamibeppu, 2011). Consistent with these findings, it is also possible that some caregivers may have provided low ratings at the time of discharge due to their distress anticipating the transition of youth from the program.

Although there was not clinically significant improvement across all individual domains of HRQoL in either youth or caregivers, it is encouraging that total HRQoL showed both statistical significance and clinically meaningful improvement at the time of discharge as rated by both youth and caregivers. Lack of change across all categories may highlight the physical and psychosocial complexity of this group of youth with significant illness, who may be less likely to show significant gains in functioning due to their substantial

challenges at baseline. Specifically, from a physical functioning standpoint, the MSP population has a greater need for intervention services than other youth with significant medical issues. Notably, youth and caregivers in our population consistently rated youth's HRQoL 15 to 25 points lower than their counterparts in previously published estimates (e.g., Varni et al., 2001). To put this into perspective, Varni et al. (2001) reported discrepancies in HRQoL of only about five points between healthy and chronically ill youth across domains, and MCID estimates reported by Varni et al. (2003) ranged from 4.36 to 9.67. That is, youth in the MSP reported scores several times lower than MCID estimates, highlighting the impairments in HRQoL in this population. Thus, the establishment of multidisciplinary, collaborative treatment models such as the MSP is even more critical to effectively serve the marked needs of this population.

It is notable from our data that neither caregiver nor youth report suggested significant improvements in psychosocial (i.e., social or emotional) functioning. This may be due, at least in part, to the significant psychosocial adversity that characterizes the MSP population. This observation is consistent with previous studies that showed a positive correlation between early childhood adverse events and poor health outcomes (Cronholm et al., 2015). Specifically, the majority of youth enrolled in the MSP had some level of psychiatric symptomatology at admission, though the most common diagnoses are typically treated in outpatient settings (e.g., depression, anxiety). Approximately 95% of youth in the MSP also experienced at least one adverse event, and over one-third endorsed four or more stressors during their lifetime. For example, approximately half of the youth had a current or past history with child protective services. Moreover, a high rate of parental neglect among the MSP students could be attributed to the complexity of the medical issues in these youth. Caring for youth with chronic medical complexities can be understandably taxing to caregivers who may have limited resources to cope with the multiple stressors (e.g., financial hardship, increased days missed at work), making it more likely for these caregivers to be involved with social services. Overall, given the significant psychosocial adversity that characterizes the MSP population, it is not surprising that this cohort continues to have low HRQoL across psychosocial domains, even after participating in the intensive MSP.

One additional reason for lack of significant improvement in psychosocial functioning may be the absence of extracurricular offerings. Youth often establish friendships through these activities, and the extant literature documents the importance of extracurricular activities for meaningful adolescent development (Eccles et al., 1999; Larson & Verma, 1999). In addition, a sizable minority of the youth demonstrated social skill deficits related to cognitive impairments, developmental delays, or lack of exposure to socialization

with peers. Thus, the peer group structure of the MSP may not have included sufficient modeling of appropriate social skills to develop positive relationships.

Limitations and Future Directions

There are several limitations associated with program evaluation methodology that should be considered when interpreting the results. First, this type of work does not allow for having a control sample for comparison. This would have added empirical weight to findings that participation in the program improves outcomes. Given the current small sample size, these data represent preliminary efforts to characterize the MSP population's attendance and HRQoL pre- and post-admission. As the number of youth included in the clinical database increases, additional analyses can be performed in subsequent studies to further describe youth characteristics and program outcomes, with a larger power to detect more subtle differences. As previously mentioned, follow-up data on attendance and HRQoL after discharge from the program would also be helpful.

Currently, there is no consensus regarding appropriate metrics to evaluate the outcomes of school reintegration programs. In this study, HRQoL and attendance were chosen as proxy measures given that these indicators are important outcomes regardless of medical diagnosis. However, the extant literature has identified a number of additional potential outcomes that can be utilized for evaluating school reentry programs which may serve as an exemplar for the MSP moving forward. For example, Prevatt et al. (2000) identified outcome measures such as pre-post medical knowledge, attitudes and perceptions, program satisfaction, and ratings of youth behavior and interpersonal functioning. Given the limitations of subjective, self-report data, future program evaluations should also seek to measure and analyze objective outcomes (e.g., academic progress, health care utilization) in conjunction with HRQoL to allow for a better understanding of the impact of treatment on functioning-related trends. Moreover, although we were able to examine pre-MSP attendance estimates and MSP attendance data, we did not have access to school records of attendance, and approximately 28% of caregivers did not report pre-MSP attendance. This points to the importance of collecting attendance data in a more objective and systematic manner in order to better monitor outcomes.

The current project evaluated whether youth demographic variables (e.g., age, gender, race/ethnicity, insurance type) were related to changes in HRQoL at admission. Key findings suggest that only youth report of physical functioning differed by gender (i.e., males reported more physical symptoms on admission than females) and age (i.e., older age associated with worse physical functioning). However, only number of medical comorbidities was

related to youth report of changes in physical functioning over time. Future work should continue to examine the complex relationships between demographic and illness-related variables, as identifying and exploring factors associated with poorer HRQoL may help suggest other potential treatment targets. Alternatively, identifying factors associated with higher HRQoL may help to determine protective or resiliency factors that can then inform interventions to promote these positive characteristics in youth.

Further program evaluation efforts may also consider examining trends in PedsQL scores over the course of admission rather than evaluating scores only at admission and discharge, and longitudinal designs exploring patterns of score fluctuations may be useful to better understand changes in HRQoL. This has not been well established in the HRQoL literature up to this point (Meade & Dowswell, 2016). Examining these trends could help inform decisions about the optimal length of stay by identifying whether there are points at which improvements in HRQoL scores plateau or even decline. Any decreases in HRQoL could also be evaluated to determine whether certain types of stressors contribute to faster declines in functioning (e.g., acute health crisis, discrete family stressors).

Another future direction would be to collect follow-up data at regular intervals post-discharge. These data could be used to examine the likelihood of youth experiencing greater difficulty once being placed in a traditional school setting. Such work could also inform ongoing program development efforts related to discharge processes.

Further work is also needed to gain a better understanding of the discrepancy between youth and caregiver report in the domain of physical functioning. Moreover, it may be useful to examine specific social deficits of youth in the MSP and design targeted interventions to address these difficulties. For example, in some cases, it may be appropriate to include involvement in extracurricular activities outside of the program as a treatment goal. Qualitative data from interviews with youth and caregivers should also be gathered since it may offer richer contextual data beyond what quantitative data can provide. For example, qualitative data will be useful in understanding youth and family experiences participating in the MSP, identifying areas of strength and areas for improvement from the perspectives of youth and caregivers, and learning about changes in daily functioning from youth and caregivers after participating in the MSP that may not be captured by current quantitative program evaluation measures.

Finally, the current project did not examine tolerability, acceptability, or feasibility of the program. Systematic collection of data to specifically investigate these variables (e.g., youth and caregiver satisfaction, dropout rate, fidelity to treatment, agreement to enroll) could suggest ways

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