Short-term Pediatric Rehabilitation Intensive Therapy (SPRINT) Pilot Study: functional inpatient outcomes in pediatric hematologic and oncologic disorders

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Abstract

Background Pediatric patients with oncologic and hematologic diagnoses who experience functional decline during a hospitalization may benefit from intensive therapies. However, acute medical issues or disease treatment plans may prevent a safe transfer to the inpatient rehabilitation unit. Accordingly, an alternative inpatient rehabilitation program was developed. Procedure Short-term Pediatric Rehabilitation Intensive Therapy ("SPRINT") is a 2-week inpatient intensive therapy program developed for pediatric patients on hematology-oncology and bone marrow transplant units at a pediatric tertiary care hospital. This pilot study evaluates functional outcomes of SPRINT participants measured by the Caregiver Assistance section of the Pediatric Evaluation of Disability Inventory (PEDI) and differences in participants' symptoms with a questionnaire. Results Eighteen pediatric patients (50% female, age 1.9-17.8 years) participated in SPRINT, and 11 parents and 4 children completed questionnaires. Common diagnoses included leukemia and lymphoma (N=9, 50%) and central nervous system tumor (N=6, 33%). Deconditioning (N=18, 100%) and peripheral neuropathy (N=8, 44.4%) were common rehabilitation diagnoses. Significant gains were found in tasks in self-care and mobility domains of PEDI (all p<0.05), as well as functional expression in social function domain (p=0.03). No adverse events related to SPRINT participation were identified. There was no significant difference between pre- and post-SPRINT questionnaire responses. Conclusion SPRINT is an alternative model for intensive rehabilitation care delivery. Data suggest that SPRINT participation can result in significant functional gains in mobility, self-care, and functional expression for pediatric patients with hematologic and oncologic diagnoses during hospitalizations. No difference was found in questionnaire responses after SPRINT participation.

Title Page

Short-term Pediatric Rehabilitation Intensive Therapy (SPRINT) Pilot Study: functional inpatient outcomes in pediatric hematologic and oncologic disorders

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Fax: (206)987-2651 Email: elaine.tsao@seattlechildrens.org Megan Flanigan, MD Pediatric Physiatrist Mary Bridge Children's Hospital 311 South L Street MS: 311-1-PMR Tacoma, WA 98405 Lindsay Johnson, MOT, OTR/L **Occupational Therapist** Seattle Children's Hospital 4800 Sand Point Way NE Seattle, WA 98105 Melissa Toy, MPT Physical Therapist Seattle Children's Hospital 4800 Sand Point Way NE Seattle, WA 98105 Eboli Giannini, MS, CCC-SLP Speech and Language Pathologist Seattle Children's Hospital 4800 Sand Point Way NE Seattle, WA 98105 Kristie Bjornson, PT, PhD, MS Associate Professor in Pediatrics, Adjunct Associate Research Professor in Rehabilitation Medicine Seattle Children's Research Institute, University of Washington M/S CURE-3 PO Box 5371 Seattle, WA 98145-5005 Word Count: Abstract - 248 Main text -2951 Keywords: rehabilitation, pediatric hematology/oncology, late effects of cancer treatment

Short running title: Pediatric Rehabilitation Intensive Therapy

Abbreviation key:

ADLS PT OT ST SPRINT Hem-Onc BMT LOS ICU PEDI Activities of daily living Physical therapy Occupational thera

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Abstract

Background

Pediatric patients with oncologic and hematologic diagnoses who experience functional decline during a hospitalization may benefit from intensive therapies. However, acute medical issues or disease treatment plans may prevent a safe transfer to the inpatient rehabilitation unit. Accordingly, an alternative inpatient rehabilitation program was developed.

Procedure

Short-term Pediatric Rehabilitation Intensive Therapy ("SPRINT") is a 2-week inpatient intensive therapy program developed for pediatric patients on hematology-oncology and bone marrow transplant units at a pediatric tertiary care hospital. This pilot study evaluates functional outcomes of SPRINT participants measured by the Caregiver Assistance section of the Pediatric Evaluation of Disability Inventory (PEDI) and differences in participants' symptoms with a questionnaire.

Results

Eighteen pediatric patients (50% female, age 1.9-17.8 years) participated in SPRINT, and 11 parents and 4 children completed questionnaires. Common diagnoses included leukemia and lymphoma (N=9, 50%) and central nervous system tumor (N=6, 33%). Deconditioning (N=18, 100%) and peripheral neuropathy (N=8, 44.4%) were common rehabilitation diagnoses. Significant gains were found in tasks in self-care and mobility domains of PEDI (all p < 0.05), as well as functional expression in social function domain (p = 0.03). No adverse events related to SPRINT participation were identified. There was no significant difference between pre- and post-SPRINT questionnaire responses.

Conclusion

SPRINT is an alternative model for intensive rehabilitation care delivery. Data suggest that SPRINT participation can result in significant functional gains in mobility, self-care, and functional expression for pediatric patients with hematologic and oncologic diagnoses during hospitalizations. No difference was found in questionnaire responses after SPRINT participation.

Introduction

As survival rates of childhood cancers increase in the last decades, short- and long-term adverse effects of oncologic diseases and treatments have resulted in diminished physical activity and motor performance of patients and survivors.¹⁻⁸ Children and adolescents with oncologic diagnoses demonstrate reduced strength, balance and functional mobility^{4-6,9} with self-report of cancer-related fatigue⁹ when compared to control norms or healthy peers. During hospitalizations for cancer-related care, less than half of children mobilized 3-5 days a week and 18% less than 3 days per week in a retrospective study.¹⁰ Levels of physical activity, including number of strides and activity intensity, were significantly lower during inpatient stays compared to that at home in pediatric patients with oncologic diagnoses in another study.¹¹

Physical exercise training interventions have been demonstrated to improve cardiopulmonary fitness, muscle strength, and flexibility for children with cancer.^{12,13} Reduced fatigue and improved physical function are among other potential benefits of exercise for patients with childhood cancer.^{12,14} In a meta-analysis study, incorporation of exercise training during cancer treatment significantly improves children's functional mobility and their ability to participate in activities of daily living (ADLs) without affecting the risk of mortality or relapse.⁷For patients who experience functional deficits during a hospitalization due to adverse effects of treatment or disease, intensive therapies supported by an admission to inpatient rehabilitation may promote their functional progress. Patients on inpatient rehabilitation may receive physical therapy (PT), occupational therapy (OT), speech therapy (ST), and several other services addressing their neurocognitive, psychological, recreational, educational and/or vocational needs. Children and adolescents with cancer diagnoses undergoing inpatient rehabilitation demonstrate significant functional gains in domains of self-care, mobility, and cognition.¹⁵

While pediatric patients with functional deficits may benefit from intensive therapies during inpatient stays, cancer treatment plans or medical care related to disease or treatment complications may prevent patients from transferring to the inpatient rehabilitation unit safely. This retrospective study evaluates a pilot program named Short-term Pediatric Rehabilitation Intensive Therapy (SPRINT), which provides intensive therapies for pediatric patients hospitalized on the hematology-oncology (Hem-Onc) and bone marrow transplant (BMT) units at a regional tertiary pediatric hospital. This evaluation of SPRINT includes an assessment of functional outcomes of participants, adverse events associated with the program, as well as measures of patients' fatigue, sadness, nervousness, and pain by parents and patients at the start and end of SPRINT.

Methods

Study Design

After obtaining institutional review board approval, a retrospective chart review of electronic medical records was conducted for all participants of SPRINT from January 1, 2017 to October 10, 2018 in a regional tertiary pediatric hospital. Information extracted from chart review included demographic data, oncologic or hematologic diagnosis, cancer treatment phase, length of stay (LOS) in the intensive care unit (ICU) prior to SPRINT, hospital LOS, Pediatric Evaluation of Disability Inventory (PEDI) caregiver assistance scores, adverse events during the course of SPRINT, number of SPRINT therapy sessions and minutes, events or complaints recorded in therapy notes that limited patient participation, and questionnaire responses

Program Description

SPRINT is an inpatient intensive therapy program developed for pediatric patients on Hem-Onc and BMT units at a regional pediatric tertiary care hospital. Therapy goals address functional impairments, including functional mobility, gross and fine motor skills, strength, range of motion, ADLs, cognitive-linguistic, swallow, and/or feeding function.

Participant Selection

Selection of SPRINT participants requires multidisciplinary effort. Patients on the Hem-Onc and BMT units receive OT, PT, and/or ST at various frequencies during the hospitalization and are identified as SPRINT candidates by their therapists and/or a consulting rehabilitation physician. Inclusion criteria for SPRINT include that a patient 1) has experienced a significant functional decline during the hospitalization, 2) requires two or more therapies (PT, OT, or ST) to meet functional goals, 3) is willing and able to participate in >30 minutes per therapy type per day, 4) would otherwise be considered for inpatient rehabilitation services but are unable due to ongoing acute medical needs and/or cancer treatments, and 5) has a parent or guardian agreeable to the child's participation in the program to support the child in recommended activities and exercises outside of therapy sessions. In addition to assessing participants' medical stability, Hem-Onc and BMT physicians help determine the timing of SPRINT for patients in order to minimize factors that may negatively impact SPRINT participation and completion, such as major procedures or surgeries. Of note, participation in SPRINT does not preclude a patient from receiving inpatient rehabilitation services later in the hospitalization once medically stable, if the patient continues to demonstrate the need for intensive therapies to address his or her functional impairments.

Program Structure

A SPRINT schedule consists of 2-3 hours of daily PT, OT, and/or ST on weekdays for 2 weeks. The goal duration of each therapy session is 60 minutes; however, for young patients or those with lower endurance, therapy sessions are 45 minutes in duration. Other therapeutic services such as Psychology, Music Therapy, Art Therapy, and Child Life may also be incorporated into one's SPRINT program. On day 1 of SPRINT, a meeting involving the patient, parents or guardians, therapists, rehabilitation and Hem-Onc or BMT care providers, and the patient's nurse is conducted in the patient's hospital room. The purpose of the meeting is to review expectations of program participation, establish patient- and family-centered functional goals, discuss activities and exercises the patient can practice outside of therapy sessions, formulate a daily therapy schedule, and review and, if possible, adjust the timing of medication administration, feedings, or planned procedures to promote uninterrupted therapy and patient participation. On the last day of SPRINT, another meeting is conducted with objectives of reviewing and celebrating the child's functional progress and discussing additional short-term and long-term functional goals and rehabilitation plans. At the start of SPRINT, a daily therapy schedule is displayed in the participant's hospital room, with a SPRINT sign posted on the door to indicate when therapy is in session in attempt to minimize any unnecessary interruptions.

Functional Outcome Measures

The Pediatric Evaluation of Disability Inventory, or PEDI, is utilized as a functional measure tool for each patient at the start and end of SPRINT. PEDI is a validated tool that measures the functional status of children and adolescents in self-care, mobility, and social function. Within PEDI are three measurement scales assessing functional skills of the child, caregiver assistance level, and modifications required for complex functional activities. In its entirety with 197 items, PEDI may require a therapist 45-60 minutes to complete, which would consume an entire therapy session. Therefore, only the caregiver assistance section of PEDI was adapted for functional evaluation of SPRINT participants. A rating scale from 0 (total dependence) to 5 (independent) indicates the level of caregiver assistance for each task within domains of self-care, mobility, and social function, scored by SPRINT program OT, PT and ST respectively.

Questionnaire

A short four-item questionnaire is administered to parents and patients [?]7 years of age, if willing and able, at the start and end of SPRINT to inquire about patients' subjective symptoms. Questionnaire inquiries include, "In the last 7 days: How often has your child felt tired? How often has your child felt sad? How often has your child felt nervous? How often has your child had pain?" Response options consist of "never", "rarely", "sometimes", "often", and "always". For statistical analysis, responses were converted to nominal values, with "never" assigned as 5 to "always" as 1.

Statistical Analyses

Utilizing the IBM SPSS($\hat{\mathbf{R}}$) Statistics software (version 22), data analyses were conducted to descriptively quantify demographic data, diagnoses, LOS, adverse events, and number of therapy sessions and minutes. Paired sample t-tests were conducted to detect changes in pre- and post-SPRINT PEDI scores. A p value of [?]0.05 indicated statistical significance. Differences between pre- and post-SPRINT questionnaire responses were tested using a non-parametric Kruskal-Wallis test.

Results

Between January 1, 2017 and October 10, 2018, 18 children and adolescents, 50% female, between the ages of 1.9-17.8 years (median 4.78 years) participated in SPRINT program. Majority of patients live >11 miles away from the facility, 38.9% with homes >50 miles away. All patients had generalized muscle weakness or deconditioning as a rehabilitation diagnosis, and 44.4% carried an additional diagnosis of peripheral neuropathy (Table 1). Leukemia, lymphoma, and CNS tumor consisted of the most common oncologic diagnoses for SPRINT participants, and 10 participants received chemotherapy while participating in SPRINT program (Table 2). During their hospitalization prior to SPRINT course, 16 patients experienced medical complications (Table 1), and 13 patients required ICU-level care, ranging 3-25 ICU days with an average of 10.6 days. Hospital LOS varied widely from 8 to 404 days, with a median of 68 days.

The change in PEDI caregiver assistance levels at the start and end of-SPRINT was significant in all tasks under Self-Care and Mobility domains (p = 0.001-0.048), demonstrating an overall reduction in assistance needs of participants after completion of SPRINT (Table 3). Functional expression was the only task under Social Function domain that reached significance (t(6) = -2.83, p = 0.030).

All 18 patients received PT and OT in SPRINT. Average number of PT sessions was 8.39 across SPRINT courses, which was 84% of planned PT sessions, with overall average of 377 minutes of total PT minutes. Average OT session number was 8.83, which was 88% of planned OT sessions with an average of 467 total OT minutes. Only 7 patients required ST as part of their SPRINT program, receiving an average of 7.14 sessions, which consisted of 88% of planned ST sessions for an average total of 306.43 minutes.

Regarding barriers to therapy participation as documented in therapy notes, either resulting in reduction of planned therapy minutes or cancellation of entire sessions, 71% consisted of patients' symptoms or complaints (pain, fatigue, nausea or vomiting, general unwell feeling, being asleep, irritability, and poor participation), 22% of patient care (procedure, medication administration, care provider discussion, diaper change/bathroom use), and 7% of unexpected transfer to ICU or discharge from hospitalization before completion of the two-week SPRINT course.

No adverse events related to SPRINT participation were identified for all patients. At the end of hospitalizations after SPRINT completion, 9 patients were able to eventually discharge home, 6 patients transitioned to inpatient rehabilitation for additional intensive therapies, 2 were transferred to other acute care facilities closer to home, and 1 patient died after an extraordinarily prolonged hospitalization due to infection progression and neurologic deterioration with eventual withdrawal of care.

Only 11 parents and 4 patients completed both pre- and post-SPRINT questionnaires (Table 4). No significant difference between the pre- and post-SPRINT questionnaire responses was documented; however, trends toward reduced report of sadness by parent report and of tiredness by self report were appreciated.

Discussion

Pediatric patients who participated in SPRINT made significant functional gains in the domains of selfcare and mobility. These findings are similar to those in studies evaluating functional outcomes of pediatric patients undergoing inpatient rehabilitation. Studies have shown that children and adolescent with oncologic diagnoses make significant functional improvements in self-care and mobility domains after receiving inpatient rehabilitation services.^{15,16,17} In the domain of social function, functional expression was the only activity that demonstrated a significant gain at the end of SPRINT. While this may be related to the small number of children requiring ST services during SPRINT and possibly under-evaluation of the social function domain by ST as a result, a study by Tsao et al also demonstrated no significant change in a cognition domain of a functional measurement scale that includes language and social tasks in patients with cancer diagnoses undergoing inpatient rehabilitation.

Consisting of a wide range of children in age, race, and hematologic and oncologic diagnoses, SPRINT participants all have experienced significant functional decline during their hospitalizations to require intensive therapies prior to their discharge. The functional deficits of these patients are likely reflective of the cumulative effects of their disease process, treatment side effects, and/or other medical complications. Compared to healthy controls, children with acute lymphoblastic leukemia have demonstrated impairment in balance⁶, fine and gross motor performance^{5,9,18,19} before, during, and after cancer treatment. Weakness, gait abnormalities, scoliosis, neurogenic bowel and bladder can be presenting symptoms and sequelae of disease and treatment in children with spinal cord tumors.²⁰ A study of children with brain tumors reported an impaired ability of patients to perform self-care tasks and domestic activities, as well as reduced engagement in play and leisure and interpersonal relationships in the first six months after surgery.²¹ Neurocognitive dysfunction is also common for children with cancer, with multiple contributing factors related to disease or treatment, personal characteristics, and psychosocial impacts.^{22,23}

Hospitalizations also contribute to reduced mobilization in pediatric patients. In a retrospective study eval-

uating mobilization patterns of hospitalized children in a Hem-Onc inpatient unit, 43% and 18% patients mobilized between 3-5 days and <3 days per week respectively, and caregiver assistance was required for mobilization 91% of the time. Isolation and fever correlated with later and less frequent mobilization during hospitalizations.¹⁰ In another study, pediatric patients with oncologic diagnoses engaged in 58% of activities recorded by accelerometry during inpatient stays compared to home, and in contrast to healthy controls, patients took 23% gait cycles per day during inpatient stays and 40% at home.¹¹ With all SPRINT participants demonstrating generalized weakness or deconditioning, long hospitalizations with a median LOS of 68 days in this study may have contributed to these patients' functional decline in addition to the effects related to their disease or treatments.

Despite having received PT, OT, and/or ST during the hospitalization prior to SPRINT, children and adolescents in this study still demonstrated significant functional impairments and were recommended for intensive therapies. This highlights the severity of these patients' functional impairments and possibly reflects the difficulty with making steady functional progress while receiving acute medical care without intensive therapies. Conventionally, inpatient rehabilitation service in acute care hospitals or in standalone facilities provide intensive rehabilitation programs to address patients' functional needs across multiple therapy disciplines. However, considerations for the timing and model of rehabilitative care delivery for patients hospitalized for acute medical care need to incorporate patients' medical stability and treatment plans as well as their own functional goals. When a patient does not meet criteria to discharge from an acute care service yet demonstrates the ability to participate in intensive rehabilitation, SPRINT is an example of an intensive therapy program that can address functional needs without interfering with the patient's acute medical care needs.

In addition to daily therapies, the efficacy of SPRINT is likely bolstered by the structure and multidisciplinary involvement of the program, which include a discussion of the patient's functional goals at the start and end of the program, expectations for active engagement from patients and families, and scheduling of therapy sessions to minimize interruptions. Therapy sessions and exercises outside of therapy sessions are conducted under direct supervision and guidance of SPRINT therapists. In a systematic review and meta-analysis of randomized control trials of exercise training in childhood cancers, adolescents demonstrated better adherence to the training program and training-induced adaptations with supervision.²⁴ In a consensus statement on exercise guidelines for cancer survivors, supervised exercise programs appear to be more effective than unsupervised or home-based programs.²⁵ Receiving direct guidance from therapists likely contributed to the success of SPRINT participants in attaining functional goals. Half of the patients in this study cohort were able to discharge home without requiring additional intensive therapies after SPRINT completion.

Six patients required ongoing intensive therapies after SPRINT to address their functional deficits and were able to eventually transition to inpatient rehabilitation. For many, SPRINT is not a substitute for inpatient rehabilitation, which provides additional services as part of comprehensive rehabilitative care, such as rehabilitation psychology, neuropsychology, therapeutic recreation, and education. The specialists of these services address patients' adjustment to illness and disability, evaluate neurobehavioral and cognitive deficits, provide opportunities for community reintegration with outings and adaptive leisurely activities, as well as formulate supportive school plans to optimize children's return to school. Rehabilitation nurses are also essential in providing skilled care and training for patient and families on neurogenic bowel, bladder, and skin management.

While the benefits of SPRINT in patients' functional gains are delineated in this study, there remain room for improvement in the program and limitations to this study. The two-week length of SPRINT program may be a limitation, as some participants benefitted from a longer duration of intensive therapies to achieve additional functional goals and eventually transitioned to inpatient rehabilitation. The small number of available questionnaire responses from parents and patients likely was insufficient in detecting changes in patients' subjective symptoms. The brevity and lack of validation of the questionnaire in this study may not have captured the breadth of symptoms and emotions experienced by hospitalized children with oncologic and hematologic diagnoses. Furthermore, parents' report of their child's symptoms may also differ from the child's self report, which would be important to differentiate in order to better understand the effects of intensive therapy on children during hospitalizations.

Conclusion

SPRINT is a pilot rehabilitation program that provides inpatient intensive therapies for pediatric patients with hematologic and oncologic diagnoses with significant functional deficits while hospitalized for acute medical care. For patients who cannot safely transition to inpatient rehabilitation due to acute medical issues, participation in SPRINT can result in significant functional gains. Despite therapy participation barriers mostly related to patient complaints and symptoms, participation in SPRINT is generally safe with no adverse events associated with the program. No significant difference in the levels of patients' tiredness, sadness, nervousness, or pain between the start and end of SPRINT was detected on parent and self report.

Future directions of this study include ongoing data collection of additional SPRINT participants and potential subgroup analyses to characterize factors associated with functional outcomes. Utilization of a validated measure of subjective symptoms of children and adolescents with oncologic and hematologic diagnoses will also be considered.

Conflict of Interest statement

Lindsay Johnson, MOT, OTR/L, Melissa Toy, MPT, and Eboli Giannini, MS, CCC-SLP are some of the therapists providing treatment in the SPRINT program. Elaine Tsao, MD is one of the rehabilitation providers who administered the questionnaire to parents and patients in this study.

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