

BACKGROUND

Adolescents, teens, and young adults with complex medical conditions represent a small percentage of those treated in children’s hospitals. This population prefers to perform sedentary activities and is difficult to engage in therapy. Subtle cognitive changes that are difficult to detect can take place due to a complex medical condition. They can feel socially isolated and anxious. These individuals are frequent patients causing them to fall behind in school. One study determined an overall lower cognitive performance in the combined transplant group is associated with medical morbidity in the first year of life (Stein et al., 2012). Cognitive dysfunction can negatively impact the completion of self-care activities and how discharge instructions are learned (Cireddu et al., 2015). In this population, it is also important to monitor the social-emotional status of the patient during their hospital stay, because many experience attitude and behavior changes before, during, and after surgery (i.e. increased anxiety, eating disturbances, fear). It is important to assist the patients in developing successful coping skills for a successful transition (Gabriel et al., 2018).

PROGRAM DETAILS

This program was created to support adolescents, teens, and young adults in the Heart Center that demonstrate poor social- emotional skills and declines in cognitive skills due to their cardiac or pulmonary condition. A social-emotional and energy chart serves as a way to measure feelings through an emoji mood chart and a modified RPE chart. A goal and weekly headline box provide the family an opportunity to discuss their goals for the week and what procedures/special events are happening. A Mantra sheet was created to help the patient build confidence. The Leppy- Asbell Neurocognitive Screening Examination for Children and Adolescents (LANSE- (C) (A) was added to the program to screen this population for changes in cognition during its hospital stay. This screener can assist the therapy team in implementing the correct disciplines prior to the patients discharge. This age group is notorious for lack of participation during therapy session or not properly using their coping skills. A therapy activity chart was created to help guide early mobilization, self-care tasks, and assist in communicating preferred tasks. The coping skills guide helps patients figure out what skill is right for them with therapist guidance.

FOCUSED QUESTION

How can an occupational therapist (OT) provide social emotional and cognitive support to promote independence and engagement in therapy while helping an adolescent, teen, or young adult manage their chronic condition?

METHODS

An exhaustive search of pertinent literature was completed in the areas of cognition, psychosocial skills, social emotional skills, support systems, and transitions that addressed adolescents, teens, and young adults with a cardiac and/or pulmonary condition. A needs assessment was completed to review current practices for social-emotional support of adolescent, teen, and young adult patients and determine how screening for cognition was performed in Heart Center at St. Louis Children’s Hospital. A list of stakeholders was determined and interviews with this group were completed. These interviews played a key role in determining the supports that could be implemented. Current practice information was also gathered from the two primary occupational therapists and one primary physical therapist on the floor. Observation and assistance with the caseload was completed to gain insight from the patients and their families. A parent questionnaire was collected before discharge. This revealed that the parents had not thought about the need for discharge instructions, return to school, and coping skills. The key stakeholders reported that the following areas can be improved: communication, patient social-emotional skills, and identifying cognition changes more quickly. Another concern is that this patient population lacks control of decision making, lacks display of immediate engagement, and can become socially isolated. The program was developed based off the results from the current literature, the needs assessment, and the parent questionnaire. Five patients participated in the trial for the program. Two males and three females between the ages 9-18 participated. A binder was created to help improve these specific areas, provide supplemental activities for therapy, and provide easy access for the therapists.

RESULTS

Development	Results
<p>Mood Chart An emoji chart was created to assist the patient in specifying how they are feeling, not just reply that they are tired. Their responses can help start a conversation about how they are feeling, allow their emotions to be validated, and can assist in appropriate interdisciplinary referrals. The goal is to assist in teaching social-emotional skills to this population.</p>	<p>At a point during the trial, all patients demonstrated a positive mood after therapy sessions. A 9-year-old patient demonstrated a significant change from a negative mood prior to therapy to a positive mood post therapy. This reveals that mood levels change as patients accomplished ADLs, preferred tasks, and engaged in movement during the intervention. It also allowed the patients’ feelings to be acknowledged and validated.</p>
<p>Modified Rating of Perceived Exertion Scale (RPE) The patients that were observed would underestimate the amount of activities they could complete each day. This scale was developed to be used with more advanced, older patients who benefited from a visual scale to recognize their energy levels. The goal is to use this chart shortly after an activity of daily living (ADL) to gauge their energy exertion in order to demonstrate the amount of energy they are gaining each day.</p>	<p>The 18- year-old and 13-year-old patients demonstrated the ability to complete more activities at the same number or a lower number on the modified RPE scale. Patients reported that they enjoyed seeing their improvements by completing more activities throughout their stay.</p>
<p>Patient and Family Goals The parents reported wanting to know their child’s goals and wanted to contribute more in planning weekly goals. Patients also demonstrated difficulty formulating their own goals and can be left out of this conversation. This model increases family-centered care and ensures the patient was involved with their care.</p>	<p>Families reported feeling more involved by discussing goals every week for their child. Most patients were able to set realistic goals with assistance. A few patients demonstrated difficulty due to increased anxious feelings when discussing goal setting and the activities the ADLs that they had to practice in preparation for discharge.</p>
<p>Cognition Screen Many cognition screens take more than 30 minutes to administer, do not address this age group, or are more outpatient based assessments. The LANSE- (C)(A) addresses many different areas of cognition and takes about 30 minutes to administer. This assessment is for children 6-11.11 years old and adolescents 12- 17.11 years old. This screen assesses judgement, number- letter sequencing (foreword & backwards), verbal auditory memory, and orientation. This screen is designed to find subtle cognitive changes or limitations. It can be administered over many sessions and can use different subtests if the whole screen is not necessary. The neurocognitive screener will be used at admission and discharge to track the cognitive changes with future patients.</p>	<p>The LANSE- A was trialed with a 13- year-old female. This patient had the FLU, on extracorporeal membrane oxygen (ECMO), stroke, and myocarditis. This patient had reported her mind was feeling cloudy. The results from this screen demonstrated that this patient scored below the cut off for her age in visual motor and visual spatial skills. As part of her discharge plan, she was sent home with the supplemental visual motor, spatial, and perception packet to work on until she was able to start her outpatient services. Without this screen, this would have been missed due to the fact the patient could complete her activities of daily living (ADLs) and her self- care steps without faltering.</p>

BOTTOM LINE FOR OT

Occupational therapy (OT) plays an important role in pediatric inpatient clinics and hospitals. OT is a key component of getting the child mobilized after an injury or illness to focus on ADLs, play, and to facilitate quality of life. Families are a key component in the child’s recovery. It is important for OTs to help the family and child learn to manage their health needs, as well as their new social- emotional needs, that may have changed since their current hospital stay. OTs can help the child learn to take care of themselves, manage their new health needs, develop/maintain cognitive skills, and help them find new activities to help the child/teen continue to be successful at school and overall engagement in life. OT is also responsible in aiding the family and child find outside sources to help them manage their conditions and stay active in society. As the child ages, it is important to assist them in finding their new passions within society to increase their participation and increase their opportunities, as well as quality of life. Overall, it is important to help the family and child establish different opportunities for social-emotional support for when they are done with therapy and to help in the management of their current health condition.

Mood Chart: How are you Feeling Today?



REFERENCES

Cireddu, J., Dolansky, M., Shetler, D., Hughes, J., Gunstad, J., & Josephson, R. (2015). Unappreciated Cognitive Dysfunction is Common among Patients Hospitalized with Cardiovascular Disease. *British Journal of Medicine and Medical Research*, 9(12), 1–9. doi: 10.9734/bjmmr/2015/18618

Gabriel, M. G., Wakefield, C. E., Vetsch, J., Karpelowsky, J. S., Darlington, A.-S. E., Grant, D. M., & Signorelli, C. (2018). The Psychosocial Experiences and Needs of Children Undergoing Surgery and Their Parents: A Systematic Review. *Journal of Pediatric Health Care*, 32(2), 133–149. doi: 10.1016/j.pedhc.2017.08.003

Stein, M. L., Bruno, J. L., Konopacki, K. L., Kesler, S., Reinhartz, O., & Rosenthal, D. (2013). Cognitive outcomes in pediatric heart transplant recipients bridged to transplantation with ventricular assist devices. *The Journal of Heart and Lung Transplantation*, 32(2), 212–220. doi: 10.1016/j.healun.2012.11.006