The Impacts of Advocacy on Hospitalized Children

Children have been marginalized all throughout history. Their voices are often not heard above the busy bustle of the world of adults. When children are hospitalized, they often experience feelings of anxiety and fear. These feelings are unfortunately often overlooked, as practitioners and parents are often so busy focusing on their physical health that they forget to attend to their emotional and mental health. This large issue of systematically overlooking the needs of children in healthcare call for the need for advocacy for this population. Children do not have political power or a democratic voice, and generally have actions done to them, often without their consent (Devakumar, Spencer, & Waterston, 2016) . It is for that exact reason that the Child Life field was created, and it continues to change and grow in ways that help give children a voice. Advocacy in the context of paediatric medicine means speaking out on behalf of children and young people (Waterston & Haroon, 2008).

Parents are often unsure of what to tell their children regarding their upcoming medical procedures. They fear telling them, due to the fear that they will scare them. Too often, children are left out of the loop when medical decisions are being made. It has been found that the psychological preparation of pediatric patients undergoing surgery has significant benefits for the patient and the patient’s parents (Mahajan, et al., 1998). This goes to show that not only the parent needs help preparing but the children as well, and this is something that cannot often be done by solely the parent. Parents are often extremely emotional and lack the proper education to prepare their children for what is to come. Advocacy may relate to a clinical encounter with an individual child or family or to children's health within society as a whole (Waterston, 2009).

Tours, puppets; and medical play have been described as effective interactive methods of familiarizing the child with the experience of hospitalization (Jaaniste, Hayes, & Baeyer, 2007). Being able to connect with a child on their level and being able to make the process fun and interesting is essential when it comes to building a relationship with patients. Throughout this process they will open up with you, sharing more of their fears and/or concerns. Child Life Specialists then use this information not only to reassure the child, but also to advocate for them from the time their enter the hospital all the way until their post-op evaluation. “In ill childcare, the application of individual advocacy is the focus, while in healthy childcare, collective advocacy, policy advocacy, and social advocacy is effective.” (Cho & Chul, 2013).

Interview with Advocate

Krystian M Hudson is a licensed Child Life Specials at the Children’s Hospital of the Kings Daughter’s in Norfolk, Virginia. She works in the day surgery division. The Children’s Hospital of the Kings Daughter’s is a public, non-for-profit organization that provides comprehensive, pediatric medical care to patients from birth to twenty-one years old. Her passion is helping children be better cared for in hospitalization procedures, eliminating fear, and instilling a level of understanding. Her particular population that she enjoys advocating for are patients who are undergoing the Nuss procedure to repair pectus excavatum. This is a chest wall deformity in which the patient’s sternum is sunken in, making the chest appear concave. The Nuss procedure was created by Dr. Nuss, a surgeon at CHKD, in the 1980’s. Because the surgery originated from CHKD, they are a world-class center for the procedure , meaning that patients travel from across the globe to have their repair at CHKD. To help these patients and families better cope with such a big surgery in a new place and with new doctors, the hospital wanted to revamp preop teaching. In this endeavor, their goal is that through the Child Life department patients and families will learn more about what to expect while admitted to CHKD after their surgery.

When Krystian was asked how she determined who could be utilized for support she explained that although patients initially come through Day Surgery, once they are admitted, patients are under the care of a different CLS, so it critical that they work together to ensure patients are supported from the time they arrived for preop teaching (usually the day before surgery) until discharge. Along those same lines, they also needed to involve staff from the Nuss Center, which is the clinic through which patients with chest wall deformities are monitored. The nurses, surgeons, and care coordinators had the condition-specific knowledge they needed to properly prepare patients for the procedure, and therefore played a crucial role in implementing this new preop teaching.

In regard to the area of the creation of an implementation plan, Krystian and the impatient CLS began meeting with the Nuss Center coordinator to learn the ins and outs of the procedure. There they discussed everything from pain management, physical therapy recommendations, goals for discharge, length of stay, mobility restrictions, and postop follow-ups. In these discussions, they also collaborated to determine what child life could contribute to the experience. Once they had a better understanding of the sequence of events, Krystian and the inpatient CLS shadowed a few preop teaching sessions to see what the current flow of information was like. It was there that they noticed that there were many new faces patients and their families were meeting along the way, and it was a little unclear to these patients who they would be meeting. They also noticed that there was little structure in the sequence of events, so families were unsure where they were supposed to go and who they would meet with. They decided it would be best to streamline the process, creating a standard flow of events that was clearly laid out in a handout that would be given to families once they arrived at the hospital. Child life would then serve as a guide/navigator through the process, meeting with families in the

Nuss Center, walking them downstairs to Day Surgery to meet with an anesthesiologist and complete preop check-in, and then completing a tour of the hospital, which would then end at the outpatient lab to complete preop blood draws.

In regard to the specifics of Krystian's advocacy efforts, this advocacy effort would benefit families traveling to CHKD for a Nuss procedure. These patients typically are between the ages of 12 and 20, with some outliers. Many of these families travel from around the world for surgery. Krystian informed me that she had met patients who traveled from Ohio, California, Pennsylvania, and even Israel for surgery. To help patients learn more during preop teaching, she found it was most beneficial to streamline the process and clearly present it to patients, Additionally, Krystian found it was helpful to have one person act as navigator, the "point person" so to speak, who could answer questions along the way and help families get from point A to point B throughout the hospital. Krystian and the impatient CLS coordinated to share this responsibility, meaning that they coordinated with one another to always have one of them act as the navigator for each family. When Krystian was the navigator, she met the family in the Nuss Center to introduce herself before they met with the surgeon, providing a copy of the roadmap, walking families to different areas of the hospital to meet with each team, and then conducting a tour of the hospital.

When it came to executing an assessment plan for efficacy, Krystian's assessments typically relied on mini-interviews. Her biggest questions were "Was the information you received during your preop visit helpful?" and "Do you feel prepared for your procedure?". She also asked, "On a scale of 1-10, where would you rate your anxiety regarding surgery?" This last question was assessed both before and after the preop visit, to see if any change existed. Krystian says that overall she believes that the project was successful. This is due to the fact that it was well-received by patients, families, and staff. She does, however, say that she thinks it could have been improved by incorporating more staff members as navigators. She explained that sometimes, it was difficult to manage other patient care duties and support Nuss patients, since the preop appointment tended to be lengthy. She also believes that they could have completed more standardized measures to assess outcomes more concretely.

Towards the end of my interview I asked Krystian, “What advice would you give to me as a new professional interested in advocacy work?”. She replied, “Don’t be afraid to ask for help or ask for clarification”. “ It’s okay to not have all the information, but there’s almost always someone else on your team who has information that may help you. It’s also important to recognize that while advocating for a group of children is important, you will also have to advocate for individual children each and every day”. She also reminded me how important it is to advocate for organizational change, and that this is just as important as advocating for the needs of your individual patients.

Reflection

My experience with interviewing Krystian was extremely interesting. As a result of this interview, I was able to learn more about advocacy work and to understand the important it has, especially with marginalized populations. I have always felt a special type of dedication in my heart for children, so being able to see how this career helps make an impact on children’s life was very enjoyable and a fulfilling experience. Although this is not my future career path, I was excited to see that there are so many careers dedicated to helping this population. Krystian seemed to be very passionate and stated multiple times how much she enjoys her job and values the work she does.

The research I conducted highlighted how children have been marginalized and the importance of advocacy especially when it is concerning the hospitalization experience. This research provided me a bit of background knowledge surrounding the issues facing this specific population and helped increase my desire to learn more about advocacy efforts for this population. I was not aware of the importance communication plays in eliminating psychological distress. Being able to sit and listen to Krystian talk about how she contributed to the implementation of the current system was something I greatly enjoyed because you could just see the pride and joy she felt when discussing it. I learned a great deal about hospital proceedings and was also able to see how every single person who works in the hospital interacts some way or another. I was given information about CHKD that I was never exposed to growing up. CHKD is such an influential part of this areas culture and I just now was able to be exposed to the innerworkings of the hospital itself, I am extremely grateful that Krystian was able to make time for me in her busy schedule. I am interested in possibility becoming a volunteer with this department as I feel that it is something I would enjoy and that would give me a sense of purpose, just like it gives Krystian.

Overall, I found this experience to be fulfilling and extremely informational. I received a great deal of information both about the field and Krystian’s advocacy efforts. I feel that the questions that were provided for the interview really helped provide structure and allowed me to achieve in depth and educational responses. Being able to see how happy Krystian was with her work was a huge plus. I can only hope to love my future career as much as she loves hers. I plan on becoming a Speech-Language Pathologist, who advocates for children with disabilities. Being able to interview Krystian gave me a deeper understanding of what advocacy really is. Before this interview I never really understood what this meant, and I feel that I now leaving this experience a better person. I plan on becoming an advocate in my future field, because I now see the importance of advocacy efforts and understand that change starts with one person.

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