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M.S. IN CHILD LIFE AND FAMILY CENTERED CARE

2.5 YEARS EXPERIENCE

"YOUR VOCATION IN LIFE COMES FROM WHERE YOUR GREATEST JOY MEETS THE WORLD'S GREATEST NEED"
-FREDERICK BUECHNER

Can you tell me a little bit about your hospital and the units you cover?

I work for a pediatric palliative and hospice program where I visit patients and siblings in their home. The county I work in serves approximately 150 families. I work with patients with many varying diagnoses, such as various cancers and blood disorders, genetic diagnoses, congenital heart defects, traumatic brain injuries, and various types of muscular dystrophy. We have a team of three child life specialists and other psychosocial professionals such as social workers, music therapists, and spiritual care providers. In my role as a child life specialist, I support patients in their homes to prepare for upcoming medical procedures, as well as provide developmental play opportunities as children cope with living with a life-limiting illness. I also provide opportunities for siblings to discuss their feelings about having a brother or sister with a life-limiting illness.

What's your typical unit census and about how many patients do you see per day?

I have a caseload of between 30-35 patients, and I see all of them within the month. Depending on the acuity of the patient or sibling, I may see the child once a week or once a month. I drive throughout my assigned county to do these home visits, so I am able to see lots of beautiful parts of my state!

What does your average day look like?

Our team meets once per week to discuss the acuity of our patients and any medical updates that have happened. It is a great way for us all to collaborate and best serve the needs of the families. I spend a lot of time planning activities and researching resources of ways I can continue to interact with the families I visit! A lot of the children I visit enjoy engaging in medical play, whether it be making bandaid art or role playing with medical materials. I also have a lot of stories about the hospital that we read, and often discuss children's feelings about medical experiences. One of my favorite things to do is prepare children for an upcoming hospitalization through creating a prep book together and an "About Me" poster that they can hang on their door in the hospital.

What is your favorite distraction item and how do you use it?

Although I am not present with children while they are in a procedure, an important thing we do together is discuss what will help them to cope during a procedure. Children will find their favorite comfort item from home and often rehearse through play how they will cope during a procedure, such as hugging a stuffed animal or using guided imagery.

What's the best part about your job?

The ongoing therapeutic relationships I get to build with families. I see the families very frequently and have gotten to see their children grow over the past few years. Something very beneficial I have learned is the importance of being present with families during both the stable times and the challenging times. Our role may not seem as beneficial when things are going "well" for families, but that is often when a strong rapport is built. Families will then know that they can trust you, and your therapeutic relationship will be even more beneficial during the challenging times.

What's the hardest part in doing your job?

Learning boundaries of what my role entails. It is important to be flexible in meeting families' needs, but I am often put in a position that is more appropriate for another professional to address. I have learned the importance of making connections with interdisciplinary professionals to clarify the roles that each of us has, as well as find ways to work together to accomplish families' goals.

What's a facet of your job that people wouldn't expect?

Many of the children I work with do not physically look like they have a life-limiting illness. This is often one of the hardest things that families struggle with, as others do not understand the challenges they live with on a daily basis, such as the medical bills that pile up and how fatigued a child's illness may make him/her. I have done a lot of pretend surgery with kids on their stuffed animals so that they have a tool to explain to their peers about what it's like to live with things such as a scar or a feeding tube, since these are things that their peers may not physically see.

What's something you wish you knew when you started on this unit?

The importance of educating on the scope of child life! While it is important to recognize that play is a huge part of our role, there are times when people think that is all that I do. I have learned how to validate the importance of play in my role while also educating other staff as well as families that there are other things we can do to offer support. This includes things such as education on how children cope with hospitalization at different stages of development, or giving insight on ways to support siblings when they are struggling being apart while in the hospital.

Do you have anything else you'd like to share about your job, tips for students, or thoughts?

Be open to the journey that child life brings you on! As a senior in college, I had never heard of palliative care, let alone hospice for children. I have learned so many valuable skills from working in a non-traditional setting that I know will be useful wherever I go in life. There are so many ways to be creative in your role, so be open to the various settings that child life works in!

