Supporting Families Experiencing Chronic Illness

by Darbi J. Haynes-Lawrence

Cella is a bright, energetic four-year-old little girl with wise, brown eyes. Her dark brown hair is always piled high upon her head, and bounces about like little bunny ears when she moves. Her mother, Dr. Sarah Laurent, is a college professor, and her father, Dr. Mason Laurent, is a chiropractor. They are both worried about news they recently shared with her. Sarah has been sick off and on for the past year. Cella's parents — due to little family with whom to leave Cella — have had no choice but to take her with them to doctors' appointments. Sarah and Mason have been doing their best to inform Cella, using age-appropriate language, sharing just enough information to calm her yet answer her questions, and not overwhelm her. Before Sarah had an MRI, Sarah told her that the doctor was going to "Look at Mommy's brain with this machine to see what color it is." Sarah had Cella guess what color Sarah's brain would be. Cella was emphatic that it be pink, "'Cuz pink is our favorite color, Mommy!" This calmed Cella. Afterwards, the radiologist showed Cella pictures of Sarah's scan, and Cella was disappointed to see a gray brain on the scan.

Sarah and Mason felt that including Cella in the diagnostic journey has been beneficial for her, and have discovered that Cella is handling the information quite well. While the Laurents have done their best to remain positive throughout the diagnostic process, they learned that Sarah has Relapsing Remitting Multiple Sclerosis. Sarah recently started her treatment, which includes giving herself shots at home to try and slow the disease progression.

At school this morning, Cella has been playing doctor, and is currently in the kitchen pretending to 'cook up a cure' for her mom. There is a row of dolls and stuffed bears on the floor, each awaiting their treatment. The phone in her kitchen 'rings' and she answers it, "Laurent Chi-practic" and carries on a conversation with a 'patient,' telling them they can come in to her office and she will cure their cancer. (She mistakenly refers to her mother's MS as cancer.) One bear is lying on the kitchen table with a box over its head. Earlier Cella told the bear, 'Gotta check your brain color. Bet it has pink or purple polka dots!' Next, she moves on to the row of patients, sitting quietly on the floor.

Mason laughs, as he sees Cella mimicking him and his patients. Sarah is saddened. The last thing Sarah wants is for Cella to worry about her and her 'cancer.' Sarah wants everything to be normal. She wants the fatigue to go away so she can volunteer in Cella's preschool on days she isn't at work. She wants to play with Cella instead of sitting in a chair with pain, fatigue, and worry.

Every family is faced with hurdles at some point in their journey through life. For some, it will be a financial hurdle. For others, it will be an illness. The children of these families are each going to be impacted differently, and may need support from an early childhood educator. The role an educator plays with families facing a major life hurdle varies from emotional caregiver, to community resource provider. Here we will explore how chronic illness impacts families and the challenges it presents, with special attention on the ways in which educators can support the children in their classroom who are members of these families.

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Chronic Illness

Chronic illnesses that affect families in the United States include Rheumatoid Arthritis (RA), Systemic Lupus Erythematosus (SLE), and Multiple Sclerosis (MS). These chronic illnesses can be a challenge to anyone, but especially those who have a family with young children.

Systemic Lupus Erythematosus

Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease (Poole, Rymek-Gmytrasiewicz, Mendelson, Sanders, & Skipper, 2012). This disease attacks many organs in the body, often at the same time (Cauldwell & Nelson-Piercy, 2012). Systemic Lupus Erythematosus affects approximately 1.5 million people in the United States (*What is Lupus?*, 2014). This disease affects women more than men (Kiriakidou, 2013) and typically affects women during their childbearing and childrearing years (Poole, et al., 2013). The cause of SLE is unknown and to date, there is no cure. However, it can be managed with medication (Kiriakidou, 2013). Like many chronic illnesses, SLE has a relapsing/remitting component (Garris, Oglesby, Sulcs, & Lee, 2013).

Rheumatoid Arthritis

Rheumatoid Arthritis is a debilitating, chronic, inflammatory autoimmune disease that attacks joints, and then progresses to cartilage and bone, and can attack other systems in the body (Gibofsky, 2012). An estimated 1.3 million in the United States have RA (*Who gets Rheumatoid Arthritis?*, 2014). The disease is three times more likely to be found in women than men, and can impact the reproductive years, as well as the parenting years (Meade, Sharpe, Hallab, Aspanell, & Manolios, 2013). The cause of RA, like many chronic illnesses, is unknown. According to Van Nies, De Jong, Van der Helm-van Mil, Knevel, Le Cessie, and Huizinga (2010), treatment options have improved over the past decade, decreasing inflammation and joint damage.

Multiple Sclerosis

Multiple Sclerosis is a chronic illness that attacks the central nervous system (CNS) (Mollaoğlu & Űstűn, 2009). This disease affects over 400,000 people in the United States (Agashivala, et al., 2013). The cause of the disease is not known. Women are more likely to have the disease than men (Cross, Cross & Piccio, 2012) and the disease strikes during the reproductive years (Pakenham, Tilling & Cretchley, 2012). Treatments slow the progression of the disease, but the side effects of the treatments can be uncomfortable.

Commonalities of Chronic Illness to Other Stressors

SLE, RA, and MS all have things in common. They are chronic (lifelong), debilitating, and incurable. Treatments can have negative side effects. The illnesses present challenges to everyday tasks, including parenting tasks. The pain and fatigue that accompanies each of these illnesses impacts the daily lives of parents and their children. Things as simple as picking up toys, playing with children, and fixing a snack all may be impossible tasks, especially during a flare (exacerbation of symptoms of chronic illness). Fatigue is a common thread with these three illnesses that occurs whether in a flare or not. Given what we know now about the challenges these chronic illnesses present to families, what role can educators play as supports and resources?

Tips for the Early Childhood Educator

Parent-teacher meetings, home visits, and play can serve as important outlets for families faced with chronic stress and opportunities for family empowerment.

Parent-Teacher Meetings. It is common for people who are diagnosed with chronic illnesses to try and hide their disease. In order to build trust with parents and families who may be suffering from a chronic illness, it is imperative that the families feel the teacher can keep the information confidential. The parent-teacher meeting is an excellent way to meet with parents and discuss their child's progress through all things academic, social-emotional, and so on. What may be of interest to parents and teachers, specifically with a family that has a chronic illness, is that increased meetings occur outside of the typical number held each year. For example, if your classroom meets with parents in the spring only, it may be a benefit to a family with a chronic illness if you meet with them twice a year. Obviously, if you are an educator who takes the time to communicate well with parents, this may not be necessary as the increased communication may be enough.

Home visits. Many early childhood programs conduct home visits. During these home visits, you want to take the time to discuss the child's classroom experience in general, as well as how the family is doing with the diagnosis and treatment. As a parent with MS myself, I would have appreciated another home visit during a relapse. Relapses attack each person with MS differently, and the result is the entire family system is taxed. During a home visit a plan can be made that might include alternatives for transporting the child to and from school, after-school care, and so on. Another person who can offer resources to the family during such a difficult time can be a great benefit.

If the family of a preschooler in your program has younger children, a traditional home visiting program may be of benefit to the family as well. A more traditional home visiting program, for example, Healthy Families America (HFA), may be of benefit as they can help engage children at home in play activities. HFA is an excellent source of information for families as well, as they have access to community resources that the family may be unaware of, ranging from transportation, to housing, to parent-focused resources such as Mommy-and-Me programs.

Play as an outlet. According to McCue (1994), a great way to talk to a child about a parent's illness is to focus on one facet of the illness. Discussions about the entire disease and all of its challenges and implications can be too overwhelming for the child. It is overwhelming for most adults! For example, fatigue is a shared effect of the disease and one that impacts the mothers most often (Meade, et al., 2013; Mollaoğlu & Űstűn, 2009; Poole, et al., 2012). Thus, sharing the journey towards a diagnosis of any chronic illness really needs to be shared with educators as they may 'see' this information in the child's play.

Play is a wonderful way for children to come to terms with their life experiences. Reflect on the case study presented at the beginning of the article. Cella was playing doctor to her stuffed animals and recreating a scenario that she had experienced when her mother was going through the diagnostic process, including having an MRI. She incorporated her father's work, "Laurent Chiropractic." Daddy fixed people. Mommy was sick. Cella was pretending to be the doctor at Laurent Chiropractic, giving stuffed bears MRIs and 'cooking up a cure' to fix them. Cella was making sense of what was happening in her life through what is known as medical play (McCue, 1994). What role could an educator play in this scenario? Although not play therapists, Cella's teachers can enter the play process and help her work through issues that might be frightening her. Her teachers can also build Cella's understanding of the situation by providing age-appropriate resources, such as children's books, or through role play in the classroom's learning centers. Lastly, her teacher can be a comfort to Cella by clarifying any inaccuracies the child has about her parent's illness (McCue, 1994).

As discussed previously, fatigue is a primary symptom of RA, SLE, and MS so there are times when Mom or Dad cannot play. Recent data collected by Haynes-Lawrence and West (2014) discovered that mothers who have MS have a desire to play with their children, but fatigue often prevents them from doing so. One mother, Janet, said:

"It makes life hard because I can't keep up with him. . . . I can't run with him. I have to do activities that limit us to inside stuff or if we are outdoors it's not for long because I can't take too much heat. . . . I try to incorporate house stuff with him. I let him do small stuff in cooking with me. I let him vacuum after I do; just anything I can to incorporate stuff with him."

It is upsetting for parents with young children to not be able to play with their children. It is equally confusing for the child, who likely does not understand why one day Mom can play, but on another day Mom looks the same but cannot play. Brooke said, "I play with [my children] as much as I can and let the housework go for when they are in school. . . . I want them to remember me as a fun mom." And Sandy says, "I would like to be more physically involved in different aspects of their lives. They are only young once and I wish I could do more with them, like take them to the park."

Reflecting on other scenarios that challenge families, for example job loss and the subsequent job search, balancing a budget on dwindling funds, and the interruption to typical family activities, like play, presents stress. Much like the mother who would love nothing more than to play with her children but cannot due to chronic illness, a parent who recently lost her job and is preoccupied with the financial crisis this presents may not be able to engage with her children like she once did. Similarly, parents who work multiple jobs often suffer from extreme fatigue, limiting their interactions with their children. Fatigue from a chronic illness and fatigue from overwork are two very different things; however, the effect on parent-child interactions can be the same.

Empowerment

Empowerment is important for parents who are facing challenges. Most parents doubt themselves at some time or another and the efforts they are making when it comes to their children. We can be our own worst enemies! Parents living with a chronic illness may worry about their ability to parent well, and whether they are 'giving their all' to their children. One of the key ways an educator can assist parents is to empower them. For example, when Dr. Laurent was diagnosed with MS, one of her concerns was the loss of self. She was concerned that her daughter would never know the person she used to be: a physically active, athletic, energetic person who loved to run and take long hikes, among other things. The MS had affected Dr. Laurent to the point that she could no longer run, and trying to take a long hike would be too much for her body to handle. It also affected Dr. Laurent's ability to actively participate in Cella's classroom. What role could Cella's teachers play in this situation?

The grief Dr. Laurent was feeling about this 'loss of self' might lead her to question her ability as a parent. Cella's teachers could help empower Dr. Laurent by sending notes home that:

- applaud her parenting skills and practices.

- highlight Cella's positive behavior throughout the day (that may reflect on parenting skills).

- offer ways for Dr. Laurent to be involved in the classroom that don't require her presence in the classroom: designing a monthly parent newsletter and working on craft projects at home.

When Dr. Laurent felt able to participate in the classroom, she could volunteer her time, if only to be available in centers to engage with the children.

Conclusion

Life's challenges, both big and small, will never cease, and the support systems to assist families through these challenges may fluctuate. However, one constant for young children is the early childhood educator. Children's teachers are fabulous resources for parents. They understand child development, guide children's behavior, and promote social-emotional development, just to name a few of their many talents. As a result, many parents with chronic illness will view their children's teachers as resources that can benefit both the children and their families.

It's important that educators understand the profound impact they can have on families who are struggling with chronic illnesses like SLE, RA, and MS. If we take a step back and replace the phrase 'chronic illness' with 'families facing challenges,' then we see how working with families living with chronic illness is not that much different than working with families who are facing any number of stressful situations.

If we reflect on the economic issues that have negatively affected families throughout the United States over the past few years, we can see that the role of the early childhood educator for families who are struggling financially would include connecting families with community services such as health care, housing, food banks, and maybe even the unemployment office. In other words, early childhood educators can play an important role in the lives of every family in their care. In this way, educators are invaluable to every family and child as members of their support system.

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