

Hear My Voice: An African American Mother's Experience Raising a Child with a Chronic Illness

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Abstract

African American children are at greater risk of developing asthma and are more likely to die from asthma-related complications than European American children (Centers for Disease Control; Mannino et al. 1-13; U.S. Department of Health and Human Services). In addition, African Americans have poorer access to quality healthcare (U.S. Department of Health and Human Services). Scant research has been conducted regarding the experiences of African American mothers raising children with asthma and navigating the healthcare system. This qualitative study provides rich descriptions of a well-educated African American woman's experience raising a child with asthma, allergies, and eczema.

The case illustrates the stressors that may be experienced by many women who have children with chronic illnesses, and voices perhaps unique issues experienced by African-American mothers. Themes that emerged from the data included role strain, marital strain, insurance issues, barriers to quality medical care, impact on career, time management, childcare issues, family support, and the importance of spirituality. The authors describe each theme and provide specific examples to support conclusions derived from the data.

Introduction

African American children with asthma exhibit earlier disease onset and have higher morbidity and mortality rates than European American children (Centers for Disease Control webpage; Mannino et al. 1-13; U.S. Department of Health and Human Services webpage). Increased morbidity rates cited in the empirical literature suggest that morbidity is influenced by factors that include: 1) lack of medical continuity in asthma care and management; 2) medication regimens that do not follow current National Heart, Blood, and Lung Institute (NHBLI) guidelines for asthma management; 3) exposure to indoor allergens; and 4) lack of follow-through with prescribed treatment plans (Kattan et al. 253-262). Children from African American and Latino families are disproportionately affected by chronic illness (Centers for Disease Control webpage; Mannino et al. 1-13; National Center for Health Statistics webpage; Stein 119-124). The higher numbers of African American children with chronic illness coupled with lack of access to quality healthcare create incredible healthcare disparities for the treatment of asthma (U.S. Department of Health and Human Services webpage).

Perceptions of health care are culturally based (Ngo-Metzger; Telfair and Sorkin). When medical diagnoses or prescribed management plans conflict with one's cultural beliefs, the likelihood of barriers to care or health care services increases. Factors such as communication anxiety may be present during the social interactions and conversations between individuals in underrepresented cultural groups and individuals holding "expert" roles, such as physicians. The medical professional's awareness of this imbalance may help to minimize communication difficulties and encourage trust between medical professionals and families (Betancourt; Ngo-Metzger; Telfair and Sorkin).

Changing demographics suggest that by the year 2010, individuals from underrepresented racial and ethnic groups will constitute one half of the population in the United States (Sue, Arredondo and McDavis 477-486). Census data indicate that African Americans and Hispanics make up approximately 25% of the population while European Americans make up approximately 70% of the population (U.S. Census Bureau). Despite this imbalance, populations from underrepresented groups continue to grow at rates faster than European Americans.

Thus, the United States is experiencing the "diversification of America" (Sue, Arredondo and McDavis 477-486) where counselors (and other professionals) can no longer fail to serve clients from underrepresented populations (Ponterotto and Casas 430-434). Recent efforts have called for the health care profession to take a more responsible and ethical role in the training of culturally effective healthcare providers (Betancourt March 27, 2007; Ngo-Metzger, Telfair and Sorkin).

Even with the high incidence of asthma in African American children and an increased likelihood of dying from asthma compared to other racial groups (Centers for Disease Control; Mannino et al. 1-13; U.S. Department of Health and Human Services), there have been few studies documenting the experiences of mothers of children with asthma. Because research indicates that there are cultural differences related to perceptions of healthcare, quality of healthcare, and access to healthcare (Betancourt March 27, 2007; Ngo-Metzger, Telfair and Sorkin), a deep and rich understanding of familial experiences is necessary. Gathering data on maternal perceptions of healthcare, the barriers mothers encounter, and maternal evaluations of healthcare services is important when attempting to understand the differences and difficulties experienced by African American mothers who have children with asthma.

Case studies provide rich, descriptive accounts of individual experience. In the current study, the authors selected one mother from a larger qualitative study involving six mothers whose children were diagnosed with asthma. The mother in this study was selected because she provided vivid descriptions of her experiences as an African American mother interacting with the medical system. We continue the piece by describing the methodology employed, the purpose of selecting this particular case, themes found in the larger qualitative study, and specific examples to support the themes derived from the data. We conclude with assertions for maternal care and African American maternal care for children with a chronic illness. This study may contribute to discourse on the racial, gender, class, and educational attainment of persons attempting to navigate the medical system and adjust to the demands of raising a child with a chronic illness.

Methodology

The case study presented here was part of a larger qualitative study on the life experiences of mothers of children with asthma. We chose a unique case from the larger pool of cases because this particular case was filled with rich descriptions of the experiences of a well-educated African-American mother whose child was diagnosed with a chronic illness. The data from this case was first analyzed as a part of the larger study. We extrapolated the data from that larger study to situate this specific case.

Participants

Participants in the larger study were recruited by posting flyers in physician's offices, accepting referrals from persons who knew about the study, and through contacts one researcher had with women who had children with chronic illnesses. A purposive sampling methodology was used, as each mother in the larger study had to meet the specific criteria for inclusion. The criteria for inclusion were to be: 1) the mother of a child who had been diagnosed with a chronic illness and 2) the mother of a child who was under 10 years of age. The researchers also specifically recruited mothers from different socioeconomic and racial backgrounds. In sum, six mothers were selected for the study, including one Latina, three European American, and two African American mothers. One of the African American mothers was selected as a unique case to present. This specific mother owned her own business and had a daughter diagnosed with allergies, eczema, and asthma.

Data Collection

Each mother completed a permission form, a demographic information form, and an Honoraria form to receive reimbursement for participating in the study. Mothers also completed a number of psychological rating scales that assessed parental involvement, parenting skills, family routines, family resources, and stressors and uplifts. Each mother was interviewed on two separate occasions at her convenience and in a place selected by the participant. The second interview took place four to five years after the initial interview. Member checks were conducted during the second interviews to ensure that the data collected and conclusions drawn reflected the mothers' experiences.

Analyses

Grounded theory principles were used to analyze the data (Strauss and Corbin 312). Each session was taped and ultimately transcribed. Three researchers independently read the transcripts and coded the data utilizing an open coding strategy (Strauss and Corbin 312). The first interview for each mother was analyzed and this information was used to structure the second interview to fill in gaps or gather more detail. Each researcher independently coded the data where themes emerged. Next each researcher independently assigned the data to categories. After each researcher had independently coded the data, the researchers met to discuss the themes and generated a final coding scheme for the data. While the data from all six participants is not included here, basic themes from the first interviews have been used to organize the data presented in the current case study. In addition, the second interview for Candice, the African American mother of the child diagnosed with chronic conditions, was analyzed using the same procedures as the first interviews and is included in this report

Triangulation

To improve the rigor of the study, the researchers employed triangulation techniques to investigate “different operational measures of the ‘same’ concept” (Patton 532). Triangulation of data sources was also accomplished by interviewing the mothers at two separate points in time and checking the consistency of what each mother reported (Patton 532). Mothers were asked many of the same questions during the first and second interviews. Questions about past events, diagnoses, and experiences were consistent, thus suggesting the trustworthiness of the data.

In addition, the researchers used multiple analysts. Triangulating analysts is a strategy that involves multiple persons independently analyzing the same data and then comparing their findings (Patton 532). Three analysts independently analyzed the data using open and axial coding. The primary researcher then met independently with each of the two analysts to compare findings. Themes were solidified during these meetings and subcategories were connected to the larger themes.

Case Description

Candice, an African American mother in her mid-30s, was interviewed. She was married and had two children. Her four-year-old daughter, Tinesha, had a history of eczema, allergies, and asthma. Candice earned a bachelor’s degree in business and was self-employed in a successful business with an annual household income of \$200,000 per year. She was interviewed on two occasions. The initial interview took place when her daughter was four years old and the second interview took place when her daughter was nine years of age. There was almost a five-year span between the first and second interviews. Tinesha’s health had improved between the first and second interview and Candice’s family income had increased to \$250,000 per year.

Health Insurance

One of the primary themes that emerged from Candice’s interviews was concerns about health insurance. For Candice, insurance issues had been a substantial stressor as she worked on behalf of her child to broker medical intervention. In the beginning, she found it difficult to obtain a referral for Tinesha to see a specialist. As a result, she found herself advocating for her daughter because she believed her daughter was not being diagnosed properly. She also indicated that the insurance company was a substantial obstacle. Candice described what she experienced when she attempted to obtain a referral for her daughter to see a specialist.

...But to see a specialist it took an act of Congress...I remember going through it with Tinesha trying to get her to see a specialist...we're no longer with [insurance company], and her doctor now is just a pediatric doctor...She probably needs to see a specialist. I don't know; it's like an act of Congress to get that done... I was told that when I would call one on my own; "Do you have a referral from your doctor?" [I said] "No." [They said] "You need a referral from your doctor." Of course, your child has got to be near dead for you to get a referral.

Even though Candice had what would be considered good insurance, was well-educated, and advocated for her daughter, she had a great deal of difficulty navigating the medical system. The insurance company required a referral and her child's physician seemed reluctant to provide a referral to a specialist. Candice even changed insurance companies and continued to have difficulty obtaining a referral to a specialist. Her perception seemed to be that doctors do not grant referrals unless the child is in a critical situation. Candice expressed that her daughter probably needed to see a specialist, but she had experienced such difficulty with the first insurance company and physician that she appeared not to possess the energy to pursue obtaining a referral when she switched insurance companies. When Candice described her efforts and struggles with getting a referral, her voice tone changed. She talked louder and there was an edge that indicated she harbored anger about the entire process.

I don't know if it is a money issue or what, but they [doctors] will not give a referral to a specialist. So then I said, "I am paying out of pocket." They said, "You can't do that." [They asked]" Well, do you have insurance?" [I said] "Yeah, I do." [They replied] "Well, you can't pay out of pocket. Your insurance has to pay it." So I would call another one [specialist] and tell them I didn't have any insurance...I was put on hold for about fifteen minutes. They came back [and said] "Well, we can't see you without any insurance." But I'm paying out of pocket. And, you know, if you need me to pay by cash, credit card, whatever your payment method, if that is your concern that I'm not going to pay, I'm telling you it's not an issue. I'm going to pay with cash." They put me on hold for another fifteen minutes. I'm serious. When I say fifteen minutes, I mean fifteen minutes... [They said]..."Well, we have never had anyone to do that before and we can't do that. You have got to have insurance in order for us to see you." So, she hasn't seen a specialist yet.

From Candice's testimony, it became evident that she tried several different methods to enable her daughter to see a specialist, but ran into obstacles each time. Candice described how frustrating it was to pay for insurance, but not be able to see a specialist because she had been unable to obtain a referral from her child's primary physician.

Difficulty Accessing Quality Medical Care

Candice described how difficult it was for her to receive the quality of care she felt her daughter needed. Ironically, when Candice and Tinesha were finally able to see a dermatologist, Candice perceived that the quality of care her daughter received was due in part to the dermatologist's interest in Tinesha's case, as Tinesha's symptoms were much like the symptoms presented by the dermatologist's own child. Candice noted

... My saving grace now is that her doctor, her son has a similar condition to Tinesha. It's not as bad and she seems to be a little more understanding so at least when I take her [Tinesha], she doesn't write her a prescription and send her on her way. She will actually do some tests and she will actually sit down and ask me what is going on. And when she does give me a prescription, it works!

Candice seemed to think that the doctor's own personal experience was the reason she was able to find medication that helped Tinesha's eczema. Tinesha believed that the doctor was willing to listen and actually took the time to find medication that worked.

Role Strain Contributed to Maternal Stress

Candice described how difficult it was to juggle her different roles: mother, wife, caregiver, sister, daughter, career woman, etc. Candice described how stressful it was for her to leave town for work-related business.

Going out of town still is stressful...not so much now for her asthma, but for her eczema...he [her husband] doesn't pay attention to her outbreaks...he will let her go a day or two without putting any cream or any lotion or anything...So when I am gone past two days, I am frantic...it would take me two to three weeks to clear her skin up when I would go out of town...

Clearly, the caretaking role created strain in the family. Candice was frustrated and angry because her husband did not diligently stick to the medication routine when she would go out of town. As a result, Candice would spend extra time for two to three weeks to clear up Tinesha's eczema. Although this had become less stressful as Tinesha got older, it was still a problem because Tinesha would break out in the areas she could not apply medication to very well. The breakouts caused marital stress and impacted Candice's time, as well as her work and home life.

In addition, as a mother, Candice had to deal with the emotional strain that occurred when Tinesha questioned her about the medication or why she had asthma and eczema. "When am I not going to have to put this stuff on me...?" Candice said she knew that Tinesha got tired of doing the medication routine and sometimes she became so frustrated that she just told Tinesha she could take a break from the medicine for one night. Although Candice knew this might create problems, she was emotionally drained and did not have the energy to deal with Tinesha and her medication. Candice felt like everyone needed a break sometimes.

When Candice was asked about stressors that impacted her daily experiences, her reply was filled with emotion that demonstrated the extreme amount of stress she felt.

Oh, God, where do I start? I can remember when I was pregnant with Tinesha, a friend of mine said... "My son has diabetes." And she said out of all [her] sisters, ...if any one of us were to have a sick child that ...she would probably be the best one to handle it. And sure enough, she had a son with diabetes and she says she always remembers that conversation with her sisters...I remember the conversation with her, because I said, "Well, you know, in my family I would probably be the one that would handle it better." And then I have Tinesha. But when they told me she had asthma, I was like, "Alright, you hear people saying asthma and you think what is the big deal? You just give them a little pump and they run on their way." I wanted four kids. After I had Tinesha, I said I cannot, because I don't know whether I am coming or going. I mean, trying to work and take Tinesha through all of her daily routines, it is a lot. It is very stressful, I mean to the point that I also told my husband that if I wasn't self-employed that I would have quit my job...I could not have kept a job down and done for her what I'm doing because you just don't have any time left. I mean, I don't cook, not because I don't want to. I don't have time. I have got to get home and work on Tinesha...

Candice stated that maybe her comments were a slight exaggeration. It was possible to ascertain the amount of stress she felt as she continued her explanation. Taking care of Tinesha took a lot of her time and that time was not available to do other things at home. There seemed to be feelings of guilt surrounding her mothering role and her inability to do everything. Candice further commented that having a child with a chronic illness impacted work, home, and time. She also felt that she would not have been able to work if she was not self-employed.

Marital Strain

Candice also discussed the strain Tinesha's illness had on her marriage. Candice expressed that she felt like she did everything in the home. It was not that her husband could not do some of these things; he simply wasn't available because he was working.

I do all the cooking. I do all the laundry. The kids are kind of old enough now where they can help fold the clothes. But as far as everything in the house, I do all of that. All of the kids' doctor appointments...most of their school appointments.

As overwhelmed as she sounded, Candice also added that this was primarily due to her husband's job. He left home early and arrived back home late; therefore, he was not available to help out at home or with the doctor's appointments. However, Candice also explained that she felt Tinesha's illnesses had a huge impact on their marriage when Tinesha was younger. Candice stated that it was hard for her to get her husband to understand how serious Tinesha's condition was and did not seem to want to take the time to learn about her health conditions. She also described one instance where she became so upset that she said:

If something happens, are you ever going to forgive yourself because every time I tell you Tinesha...is asthmatic or her eczema is out of control, you will go nothing is wrong with her. Do you not have eyes in your head?

Candice said that marital conflict was worse when Tinesha was younger. Her husband did not act as if Tinesha's asthma was serious. He also did not follow through with treatments or medication schedules. Candice said that if she had it to do over again, she would involve her husband more in the medical routine and seeing doctors. She was not sure if her husband just did not understand the seriousness of her condition or if he was in denial.

However, she was adamant that their differences in regard to understanding Tinesha's health issues had created substantial conflict in their marriage. Candice added that as her daughter got older and could take more responsibility for her own illnesses and medication, the marital conflicts had been less frequent. She no longer relied on her husband to be totally responsible for her daughter's care as Tinesha was developing these skills on her own. However, there was still concern because Tinesha would break out in areas that were difficult for Tinesha to reach on her own to apply the medication sufficiently and effectively. Candice noted that she often reminded Tinesha or sometimes Tinesha told her that she was having problems and her husband then assisted her with the medication.

Juggling Mothering and Work

Candice described a number of difficulties associated with being a working mother and having a child with asthma and allergies. Candice said she had thought about working in "Corporate America" but she knew that it would probably not work out because she would not be able to be dependable in her attendance due to Tinesha's health. Candice emphasized that being self-employed permitted her to be flexible.

...I know that because I am self-employed I am able to do this for Tinesha...I can work at home on my regular job...I would often tease people and I would say I know that my boss would have fired me by now. Because [an employer] needs somebody there that can do a job and I can't. I mean, if the school called me, I'd have to go regardless of what I was doing.

Candice recognized that if she worked in corporate America, her ability to drop things at a moment's notice would be limited or have severe consequences for advancing in her career. Although being self-employed created a degree of stress, Candice seemed to feel that self-employment was her only option. When she was asked about her three top stressors, Candice replied:

Being a mother working, working and being a mom. Juggling that is stressful...what I notice is that my life goes a lot smoother at home when everything is in order at work...to work a 40 hour week and then take care of the house, it is very difficult for me to do that...when I am short staffed, I end up working those 40 to 60 hours...so my work life kind of determines my home life...so that would be one of the top ones [stressors], everything going well at work. And if everything is going well at work, I don't have stress at home, because I have the time.

Even though Candice indicated that when things were going well at work she did not experience stress at home, it became apparent that Tinesha's medical issues often impacted her work and that there were consequences when she took time off work to care for Tinesha. Candice described how taking off work impacted her schedule and why she took off work rather than her husband.

...I may have an appointment scheduled that I have to cancel because my husband does not have that flexibility on his job. And he would lose his job...so I try to do most of the emergency, last-minute things with Tinesha and sometimes I do have scheduled appointments...that is added stress...I have lost some clients over it.

Candice conveyed that although taking off work was detrimental to her career, she did not feel that she had a choice. Her husband's work was not flexible and therefore he was unable to take off. Candice did not have family members who could take care of Tinesha, take her to the medical appointments, or care for her at home. When Tinesha's child care center called, Candice felt she must leave work regardless of what she was doing.

... so you just go on and hope that one day they will understand that it is not something I am doing intentionally and I that I cannot control it. I don't have a choice.

Candice, like many mothers of children with chronic illness, felt like she did not have a choice about missing work. If there is not a partner who can step in or other family members who can provide assistance, mothers often feel that they have no other options. The lack of resources often increases stress because mothers often must leave work or call in to say they must miss work because their child is ill.

Child Care Issues

Candice was advised by the pediatrician not to put Tinesha in daycare until she was four. Unfortunately, when Tinesha was three, the person who provided childcare needed to find a job with insurance and was unable to continue to keep her. Candice found a daycare, but soon realized that they were not able to care for Tinesha.

The first week she [Tinesha] was there, the school was closed about a half week because it was icy and we were having bad weather. The second week, I took Tinesha on Monday. They called me on Monday...just called me to say she wasn't doing well. Tuesday, they called me to come pick Tinesha up. Now, I live an hour away from my job. So, of course, to pick her up, that day is, you know, gone. Tuesday, they called me and I went and picked Tinesha up. Wednesday, they called me and I went and picked Tinesha up. Thursday, they called and I went and picked Tinesha up. So, the next week I just decided to keep her. I brought her to work with me. So then, the fourth week, I said, "Let's try this again because," I said, "okay, maybe she was doing different activities." So I kind of started giving her extra asthma treatments and so the same thing happened, but it started on Monday. They called on Monday and I remember this specifically because by the end of the week I was in tears. They called me Monday. I said, "Are you sure I have to come?" They said, "Yeah, you have to come pick her up." I picked her up Monday. Now, they had a nurse on staff and I had her nebulizer and everything there and I said, "You know, when you notice the symptoms, are you giving her the treatments?" They said "Well, her nose is running real bad and it's green and that means she has got an infection." I said, "No, her doctor said that she has— I think it is rhinitis...and that the green doesn't necessarily mean that it is an infection, where it is contagious."

Even after this explanation, Candice was told she must provide a doctor's note stating that Tinesha was not contagious before she could bring her back to child care. Candice took Tinesha to her doctor and obtained the required doctor's note.

...After the doctor, we took her to school. When I picked her up Tuesday, [I was told you] can't bring her back tomorrow unless you have a note with him [the doctor] saying that the green is not contagious—now, this was the nurse at the facility—that the green mucous...is not contagious...

Candice explained that it was not sufficient for her to produce a doctor's note stating that Tinesha could return to school. The child care wanted a note that specifically stated the green mucous was not contagious. She then described her interaction with the doctor when she went back to him.

So he writes out this long letter...Rhinitis. It's not contagious, da, da, da... I had to ask him specifically, "Can you state that the green mucous is not contagious?" He kind of looked at me. I said, "I'm serious. That's what the lady said I needed. That you needed to say the green is not contagious." So he wrote that in there and I gave it to her. And that was Wednesday. But even Wednesday, I talked to her later; they still called me. Because when they called me, they said she wasn't feeling well again. So I picked her up.

It was evident from Candice's description that she was both angry and frustrated regarding the child care nurse's request. When she described her interaction with the doctor, there were many pauses. It seemed as if Candice felt the doctor was thinking that surely she was not serious about needing a statement specifically about the mucous. In addition, Candice explained how frustrating and stressful it was to just try and keep Tinesha in child care. She was called nearly every day to pick her up even after she had given the child care center a doctor's note, instructions on what medication to give to Tinesha, and multiple explanations about what to do when Tinesha was not feeling well. Perhaps the most telling incident was when the daycare called for the fourth day in a row requesting that Candice pick up Tinesha.

So Thursday when they called...[I told my employee] "That's not funny. You know, I have been to that school about five times now...Don't tease me like that. "No," Candice [the employee] said, "Tinesha's school is on the phone." I just put my head down and started bawling because I had been to that school more picking her up and when I picked her that particular day, she was sitting on the curb and she was just looking so pitiful. When I saw her like that, I said, "You know, I just need to take her out. Y'all aren't even trying to deal with her. I mean, you have her nebulizer..." I found this lady where she is now and I won't leave that woman for nothing...I'm like, "Oh, God, I hope she never retires..." I feel comfortable...I keep her there because I know [child care provider]...knows that Tinesha is asthmatic...she is very cautious and keeps an eye on her.

What became evident was that finding a child care professional that could handle Tinesha's medical issues made a tremendous difference in the amount of stress Candice encountered. Candice emphasized how important it was to find someone she could both trust and depend upon.

The Impact of Chronic Illness on a Mother's Time

Much of what Candice shared regarding what it was like for a mother raising a child with a chronic illness centered on time. There did not seem to be enough time to work, maintain the household, spend time with the children, and get adequate rest. Candice, like many moms, felt stressed about doing it all.

*It becomes stressful at home...you have to plan an extra 15 to 20 minutes in the morning to rub her completely down...in the evening you have to do the same thing...It may seem small, but when you have to do it **every** day, it takes a toll on you...it takes a lot of time to make sure she has been medicated properly...*

Candice implied that although it might not sound like much, the medication schedule demanded time that was then unavailable for other things. She also made clear that the time she was describing was the time medication procedures took every day when Tinesha was well. When Tinesha was ill, more time was spent on her medical care.

Financial Difficulties

Even though Candice's family income was quite high, she could not seem to escape the financial pressures that often accompany a child who has a chronic illness. Candice explained that it was not necessarily the cost of insurance or the cost of seeing the doctors. The primary costs were pharmaceutical. She discovered that her new doctor was more sensitive in regard to the cost of medication and worked with her to find medications that would work but that did not require a higher co-payment.

In addition, we discovered an interesting financial impact. Because Candice worked full time and her husband's job was so demanding, she had little time to cook. Candice admitted that they ate out a lot and their food bill contributed to their financial difficulty and to Candice's surprise it impacted other areas as well.

Oh, my God. We have no spare money. This is pretty sad, but on our refrigerator Harrison has his little paper about Mother's Day...Thank you for all the things you do. I like it when you sleep with me at night. I like it when you read and play with me. I like it when you cook dinner for us, Mom...

Candice asked Harrison what he meant by that; was it just that she was a good cook? Harrison replied, “No, you just don’t cook that much so when you cook, I really like it,” Candice realized that not having the time to cook impacted her son and her family in ways she had not anticipated. She also realized that eating out or bringing precooked meals home was expensive and left little money for other things.

Family Support

When Candice was asked about her biggest source of support, she quickly responded that it was her family. Candice explained that when Tinesha was younger, they did not live near any family and she found that extremely stressful. However, several years ago, they moved closer to her family and she found that living closer to family was a great source of support; “*because they are so close or [they can be], if something is going on, I can leave the kids with them... pick Tinesha up...*” Having resources to help with child care and other needs seemed to reduce stress.

Spirituality

Candice, like many African American mothers, spoke about her faith. Candice would often make statements indicating her strong faith, saying that she was blessed or “I just pray a little.” These statements indicated that her faith was central. In addition, Candice stated, “She’s such a blessing otherwise.” Candice was saying that other than her medical condition, her child was a blessing, though she also stated that, “I think that God did allow it to happen to her because she is so strong.” She specifically talked about the role God and religion played.

My belief in God just lets me know that everything happens for a reason. I'm not seeing it now and it's not clear now. One day it will be...you know, maybe her being ill brought out all those strong characteristics...I think my belief in God allows me to accept this as a blessing more than...a punishment...God doesn't put any more on you than you can bear...it definitely helps me to go on.

Candice’s faith seemed to help her make sense of Tinesha’s illnesses. She also utilized her faith to help her understand and cope with the many difficulties she faced.

Conclusion

Candice's case supports the conclusions other researchers have drawn on the impact of childhood illness and its relationship to maternal experiences. Candice reported that almost every aspect of her life was affected by Tinesha's illness; her career had been impacted, along with the family's finances. In addition, Candice expressed that she felt a lot of pressure and anxiety in her multiple roles as a mother, sister, wife, caretaker, and career woman. She also discussed the impact that Tinesha's illness had on her marriage. Child care issues, time management, and role strain appear to be the primary stressors for Candice, while her spirituality and her family appeared to serve as buffers to stress.

Further Discussion

Upon reflecting on the interviews with Candice, it is apparent that even when one is financially sound, well-established in a career, and well-educated, the difficulty mothers encounter in navigating the healthcare system remains the same. From this case, we can see that the medical profession has not seemed to embrace or respond to the changing demographics of the 21st century. In our diverse society, there needs to be greater recognition of the needs of diverse clients, the importance of ethical treatment, and caring with competence. In meeting families where they are, and working to understand the world views of families, medical practitioners will be able to modify their practice to meet the needs of a more diverse population. In addition, mothers of children with chronic illness need to make changes to more effectively navigate the healthcare system. Candice's case illustrates a need for change and suggests changes to the health care system that would be helpful. First, mothers need to ask questions and suppress their fear of being seen as incompetent or overprotective when asking questions about their child's health. Second, it is important for mothers to feel empowered to find another medical practitioner if the treatment is not a good match, if communication difficulties continue, or they do not feel comfortable.

Candice's case suggests that mothers need to provide support to one another. Support may include attending health care visits together to minimize or negate the power differential that sometimes exists in medical settings. Mothers also need to share their experiences with one another so they can better understand how to navigate the medical profession from a layperson's perspective. Finally, Candice suggested that mothers seek support from life partners in understanding and navigating the health field. Bringing and encouraging partners, spouses, and loved ones to attend appointments may assist family members in obtaining a better understanding of the medical conditions and treatment options.

As educators, we are in a vital position to assist mothers in need of medical treatment. By sharing our knowledge and showing concern, educators are able to build bridges with the medical profession to allow for positive treatment outcomes. Connecting families facilitates support for one another and can also steer mothers to liaisons that may provide them with empathetic supporters who can also help them navigate the medical labyrinth. Professional school counselors, social workers, and child life specialists can all aid mothers by improving their access to community resources. Professionals and experienced mothers can also serve as advocates by offering support and by working from a place of understanding.

Medical practitioners need to understand that mothers are experts on their children, as well as what practices mesh with or enhance families' cultural and religious beliefs. Mothers need to have a voice and this voice needs to be heard. Doctors can improve their effectiveness and possibly improve outcomes if they are empathetic, practice patience, employ a good sense of humor, and hear a mother's experience while acknowledging strengths these mothers bring to developing the necessary medical treatment plans for their children.

To be truly effective, medical professionals need to identify and communicate effectively across cultural barriers. Yes, this means educators, counselors, and medical personnel must acknowledge that differences do exist between clients and doctors. These differences include class, race, ethnicity, sexual orientation, gender, and disability, but one should not get caught in the boundaries. Rather, one should recognize that some families may have cultural mistrust regarding the medical profession. When mistrust is present, professionals need to find a way to bridge gaps based on similarities and respect. Medical professionals must strive to become culturally competent when working with all clients. Cultural competence requires proper training in cultural aspects of healthcare. Cultural education should focus on self awareness, knowledge of the various cultural groups changing our demographic populations today, and developing the necessary skills needed to work with all clients who may walk into a medical facility in need of treatment.

After reviewing Candice's case, it is evident that mothers are under a great deal of stress and may be tired from the experience of navigating the medical system. Children often miss a substantial number of school days and many mothers may not naturally trust the medical profession. If one couples a mother who comes from a culturally diverse background with one who may also be unfamiliar with the medical system, a gap occurs. This gap is the place where educators, counselors, and practitioners need to work to ensure that all clients in need of treatment are being seen as a "whole" and that their culture and worldview is taken into consideration. The medical profession is beginning to recognize the need for culturally competent health care professionals who are able to assist all clients not in spite of their background, but rather *because* of their diverse backgrounds and experiences.

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