

## CHAPTER FOUR: RESULTS

### Introduction

This research study was undertaken to investigate how African American fathers participate, cope with, and manage the chronic illnesses of their children, to explore how they believe they are perceived in their work on behalf of their families, to discover how they experience paternal involvement in light of their family's circumstance, and to learn how their descriptions and advice to professionals can inform clinical practice. The five men recruited into the study were perceived as involved, resilient parents who cope well with chronic illness in their families.

The five stories of paternal resilience are five stories from which many themes and concepts emerge. Each father's experience of life with stressors associated with parenting a chronically ill child is unique. Yet common themes emerge from the advent of illness in their lives. Through the process of analysis and interpretation of data, I was able to identify similarities and differences, themes and concepts and to present them in the pages that follow.

First, case studies of each participant are presented. The names and identities of participants were changed to protect confidentiality. Details of their lives that might compromise privacy were also altered slightly. Each case study begins with a quote from the participant. The quotes introduce the voice of each man and the uniqueness of his parenting experience. A brief synopsis in the form of case studies follows. The synopsis highlights my perception of each father and provides a backdrop from which each parenting story unfolds. Next, the major themes that emerged from five transcribed interviews will be described. Then, the major themes and categories that emerged will frame the parenting stories and will capture the compelling convictions and complex processes participants manage in their efforts to parent effectively. In order to provide clarity and to verify themes and categories, verbatim quotes are presented throughout this section that is organized thematically. Finally, fathers were asked for their advice to professionals in fields that serve families with children who have chronic illnesses. Their views of ways African American fathers of children with chronic illness might be better served are summarized at the end of this section.

## David's Story

### To Re-dream for Them

*We had all these dreams. When he came through – it's a boy. We elected not to find out until he was born. So he comes through: it's a boy. Great. Okay, he's the next famous football player . . . he's going to be the next Thurgood Marshall, or the next Sidney Poitier.. You just think those dreams. Well then, all of a sudden when you realize that those dreams are not going to come out that way. I think the challenge is that you are going to have to re-dream for them. Our dream for him is for him to be as self-sufficient as he possibly can. I made a pact with him when he was medevaced [medically evacuated] out of Germany in a coma, in a medically induced coma, because they couldn't control the seizures. So, the only thing they could do is to put him in a coma. I made a pact with him then. I said, "I'm not giving up until you give up. And even then, I'm not givin' up." **David: age 38; married; father of two.***

David, along with his wife, Doris, parent two sons. They live in a metropolitan area chosen by the couple for its proximity to health-care and educational facilities that meet the needs of their youngest son. Chronic illness became a part of this family's life while David was out of the United States in service to his country. He serves as an officer in a branch of the United States Military. During an overseas tour of duty, Doris recognized early developmental delays in their infant child and sought medical intervention. Their son, Jim, has been diagnosed with autism and a seizure disorder. Jerry (10) and Jim (8) are the sons of a man who considers himself "an eternal optimist," and "an aggressive type person." His view is that obstacles are "just another hurdle to jump over." Throughout his experience with chronic childhood illness, David's approach to participation has contributed to his development as a man, a husband and a father. He remembers that very early on he had ideas of just what kind of parent he would be.

### Always Being There

David described that his view of parenting included memories of examples set by his father and perceptions he collected over time through that father-son relationship. He recalled that his father was a "good role model," and a "hard disciplinarian" who kept his children straight despite working a job that prohibited him from being around a lot. Part of David's

parenting approach, then, has been to discard some and to keep other aspects of what he learned from his dad:

I think when you grow up, you know, that there are always things . . . I know I said this . . . “when I get on my own, there are certain things that I’m going to do.” And that’s true. There are some things that I do differently from my dad. My idea of fatherhood was always being there. Taking care of your responsibility. Not being there, you know, working has its drawbacks. It has its benefits, but it has its drawbacks. So one of the things that I saw growing up that I wanted to change when I became a father was to spend more time with my boys.

### John’s Story

#### Just Another Brick

*As an African American father there are a lot of components to be that person and you never stop being a father. As well, you never stop being a husband. I’m proud of being an African American father. I’m committed to being one. I don’t take anything from any other races, but being an African American person, I guess it’s hereditary that you learn to deal with different crises and struggles. Because if I didn’t go through some hardships, I don’t think I’d have been able to improve myself. If everything was given to me on a silver platter, I think I’d be another statistic or suicide. So, watching my grandfather and my father strugglin’, makin’ it easier for me. I’m just another brick making it easier for my family. Let them know that it’s not always easy. The set backs that you get, you deal with them. But you have to be respectful. You think about it. Pray about it and apply yourself. Don’t just think about today. Think about tomorrow. **John: age 47; married; father of four.***

John describes himself as an introvert, a bit overprotective, and a man committed to his family. John’s daughter, Faith, has managed type-one diabetes for 17 years. She was first diagnosed at age 5. John and his wife, Karen, are currently launching their eldest daughter and second child, Faith. She is 21 years old and lives with her parents along with Teresa (16) and Phillip (14). John is employed as a mid-level manager. He has attended college and recalled that since the age of 16 he “always wanted to be responsible and there” for his children. His

commitment continued once his child was diagnosed with diabetes. He says, “I just had to pull up my boot straps and say that this is just another obstacle that I have to overcome. And so, I made up my mind that whatever it took, whatever it takes, that I was going to be there for her.”

### The Bottom Line – Love

Prior to his child’s diagnosis, John was familiar with diabetes although he had no direct experience with the disease. Adult members of his extended family lived with the illness. Nonetheless, he recalls the news that Faith was diabetic came as a “surprise and a shock,” something he didn’t want to face:

**Researcher:** Did your thoughts on what it meant to be a father change once you realized that your daughter was ill and had diabetes? Did it take on a different kind of meaning?

**John:** Oh, yes, greatly. You know, as a father, you don’t think of the negative standpoint. You are always thinking about what you can do to provide for your family. You know, shelter over their heads - they have a roof . . . the picket fence and the roses. You know everything is going well as long as you work. But even though I was pre-warned . . . that she had diabetes, it still came as a surprise and a shock. I didn’t want to face it.

Despite difficulties, John managed the illness related demands and stressors that became a part of his parenting process. He pointed out that involvement required modifying his work schedule, juggling economic resources, learning to prioritize, and discovering how to accept change.

“It gets frustrating at times because you have to change your schedule – cause you’re so use to doing your own thing. And now you have to do what her schedule says. But if you are dedicated, committed, the bottom line, love that individual, you will change. And that’s what happened. Love. (He chuckles). That was my child.”

### Isaiah’s Story

#### I’m the Full-time Dad and Mom

*“Whenever I tell someone that I take care of my son, it’s like, “What do you mean? You take care of your son? He isn’t with his mother?” I’m like no. I wanted him to be with*

*me. It's . . . like people's perceptions. I think that they all think fathers . . . play the weekend dad. Where, I'm the full-time dad. I'm the full-time dad. I'm the full-time mom. So, people say, "You take care of your son?" They're surprised that I'm taking care of my child. And then even when they find out that he has a disability, it's like, "So, you take care of your child WITH a disability?"* **Isaiah: age 30; separated; father of one.**

Isaiah is a single parent. His position in the military did not afford him the ability to be involved in his son's life at the level he desired. Therefore, he left the military in order to gain greater flexibility on the job. He sought a position that would meet his need to be involved and also meet his family's need for adequate health-care coverage.

Isaiah describes that his love for his son motivates him, and his faith in God compels him to be actively involved in Daniel's life. Daniel is 6 years old. At birth, a cranial bleed resulted in brain damage, a seizure disorder, and mild mental retardation. A number of physicians speculated to his parents that he would not be able to crawl, to walk, to talk. Daniel's has mastered all those milestones and continues to make great progress.

**Isaiah:** I think, the first 2 days I tried to be strong for my wife. I was like, "Everything will be fine. Everything will be fine." Until that day that they came in and said he wasn't going to be able to do this, he wasn't going to be able to do that, I BROKE DOWN (emphasis). I was like, "Now wait a minute. This is what you're telling me. God can oversee and change all of that." And that's what I say to this day. I mean to this day he does things that according to his doctors he wasn't going to be able to do.

Despite progress made, life with a seizure disorder has meant a regimen of eight different anticonvulsive medications taken concomitantly. Eight medications were not enough to stop the seizures. Daniel would go into status once a month and would require emergency medical treatment. The doctors recommended three alternatives: (1) one, add a ninth anti-convulsive medication to his regimen; (2) conduct a brain surgery to remove part of Daniel's brain; (3) try the Ketogenic diet. Daniel's parents choose the diet.

### Choices – The Right Medicine

**Isaiah:** We had three choices to control Daniel's seizures: it was to keep him on eight different medication, we were adding a ninth one – which was I was like "No, we are not going to do that"; the second option was to go in and remove the part of the brain that is

damaged - “Well, that’s good but brain surgery . . . can do more damage than good”; and the third option was the Ketogenic diet. And they (*the doctors*) said, look, if you get on this diet you cannot deviate. You can’t feel sorry for him and give him a french-fry or a hamburger or let him drink some Coke. You have to stick to the diet.

For 2 years Daniel has been on the Ketogenic diet to help control seizures. This very regimented diet requires that all meals are weighed and no meal deviations are allowed. Isaiah describes it as high in saturated fat, with no sugar and very limited carbohydrates. He also describes it as highly successful. Today, his son is prescribed one anticonvulsive medication and the seizures have lessened dramatically.

### Lincoln’s Story

#### Every Year Past Fifty – A Bonus

*Certainly by our prayers and stuff for Carter and I guess getting older, too. . . I’m not sweating the details, ‘cause guess what, I’m probably never gonna be rich in my life. I’m not gonna worry about that anymore. And in terms of my success, like I said, I’m already successful knowing my kids are going to be fine. And my personal success? Yeeeh. I’m not really worried about it. I think that/I feel/ I don’t know: a bolt of lightning came out and hit me right now, I’d say, “Okay.”*

*I have a strong family history of having heart problems. So, those heart problems usually coincide with our 50<sup>th</sup> birthday. Four, five, pretty much every male relative this generation other than one, has checked out at 50. So, with that in the history books, you kinda say, “Well, hey don’t worry about buying a lot of green bananas and don’t get too stressed out about anything.” ‘Cause I’m looking at every year past 50 as a bonus. My father died at 60. All my male relatives died at 50, so I’m like hey, you know. I ain’t trying to stress myself out of here. **Lincoln: age 47; married; father of three.***

Lincoln is the father of two daughters, Catherine (21), Jessie (16) and one son, Carter (10). He and his wife, Jacqueline, live in an area not far from the community in which he was raised by his mother and father. Lincoln is a physician and Jacqueline also works as a health care professional.

Lincoln reported that he and his family have traveled a remarkable journey: beyond coaching Bidy Basketball and practicing Aikido moves on the ladies of the house; beyond making school lunches and chauffeuring his children to and from school; beyond participation in a father/son book club and the race to complete assigned readings; beyond the bantering back and forth and efforts to break tensions with humor; beyond discussions about current news items, important life decisions, school performance, sex education, and being “Black in America.” Their son was 3 years old when Lincoln, Jacqueline and their family experienced an unexpected turn of events and life change. That is when their only son, Carter, was diagnosed with a rare organ disorder. They were told a transplant would eventually be needed.

### It’s Really Not That

**Researcher:** Describe a little bit about the diagnosis and how that’s progressed over the years. You said he was diagnosed when he was three?

**Lincoln:** Sometimes we’d get ticked off at one doctor and then we’d get ticked off at somebody and then we’d be like, “Oh, God. Tell us what to do.” It was the whole gamut. And when he was going to get procedures done, the big debate was whether we were going to tell the other children or not . . . It was classic . . . anger, denial . . . “well, it’s not really that.”

Lincoln said that at first he put the evidence before him in “cerebral terms” and tried to figure out alternative explanations. He recalled researching for days on the Internet and in the library. His family traveled far and wide to specialists for answers. After second, third, fourth opinions and more, Carter’s diagnosis was confirmed. Lincoln also discovered that “there was only one article written about this disease in children – in the entire world literature.”

### Dr. Edward’s Story

#### Not a Burden

**Researcher:** *So you’ve described what a typical day was with Lillian, having to give her insulin.*

**Dr. Edward:** *And that record, that very carefully kept day by day-record over five years you see. Eventually, she asked me for it. She said she wanted it to go to a doctor who*

*treats her today, every now and then. He probably has that record today. Day by day for 5 years. But that was not a burden on me. After all, I've been keeping records all of my life. I had to keep them. You see even then in my position at the college you had to know what to keep. You never know: I had to testify, all together 16 times—8 before the Senate and eight before the House—to get my money for the college. And so keeping a record was not a problem and keeping her record was no more difficult, time consuming, pressing than any other record that I'd kept over the years. So, I'm trying to say it wasn't that much of a burden to keep a daily record of the food, the sugar and the insulin, and any reaction and so forth. In other words, whatever it looks like in terms of quantity or time you have to throw in other factors like no problem here, experience here, all help to make this not a big problem. Dr. Edward: age 81; married; father of four.*

Dr. Edward reflected back more than 40 years to describe his experience parenting his daughter Lillian diagnosed at age 5 with diabetes. Lillian was one of four children raised by Dr. Edward and his wife, Ida. Among four children, Anthony (50), Roslyn (52), Lillian (48), and Susan (43), six academic degrees have been conferred. Dr. Edward is a retired top-level college administrator, educator, and historian. He described his experience as an African American father during three points in time: (1) the late fifties when Lillian was first diagnosed; (2) the sixties when illness related demands were less consuming and social unrest throughout the country increased his job related demands; and, (3) today as he reflects back on his contributions to his family's well-being and development and his perception of how his children see him. Until Lillian got old enough to do so, Dr. Edward administered insulin, kept a daily record of her food intake, analyzed sugar levels, and managed care needs when blood levels required urgent treatment. He also took her to doctor appointments. Although he was directly involved with his daughter's health care, Dr. Edward described his wife as the primary caretaker, the parent that did "most of the caring." He explained that his strategy was, "Doing for the children what needed to be done for children as they grow up. They needed clothes. . . . Essentially the same thing that man all over the world needs: food, clothing and shelter."

## Major Themes and Categories

Three major themes emerged from case analysis of participant interviews that described fathers' experiences parenting children with chronic illness: Appreciation of the Priceless, Commitment and Clarity of Priorities, and Anchoring in Race, Gender, and Legacy Building.

### Appreciation for the Priceless

The men I interviewed held several aspects of parenting in high regard. They described an appreciation for what it meant to be a father; for strength gleaned from their wives; for courage gathered from their offspring; for sustenance provided through faith and spirituality; and, for support of friends, extended family and community. Fathers described that each aspect of interaction enhanced their involvement in many ways. Benefits they reported included garnering strength, hope, and renewal as well as stability, clarity of focus, and the ability to navigate difficult times. In addition, a sense of the greater good of the child emerged as a regular thread that linked fathers, their families, and these aspects of participation.

Definition Developed of Self as Parent. All of the fathers in this study recalled that prior to the birth of their first child they had perceptions of what it meant to be a father. The five participants reflected on memories of their fathers' approaches to parenting. Some also recalled the involvement and participation of other significant men as well as the parent contributions of mothers.

Three fathers described that throughout their lives they made mental notes of refinements they thought might be of value to their families one day. The desires to spend more time, to demonstrate affection more openly, to be more available, or to follow positive examples were reported. The four contemporary fathers recounted the impact of chronic illness in the family and shifts that occurred in their perception of parenting. Isaiah described a shift that occurred shortly after his son was born and a diagnosis was made:

**Researcher:** Did your thoughts of what it was like to be a father change once you found out that your son was ill?

**Isaiah:** Yes. . . . I think it really didn't hit me that my son was ill 'til I think it was like after the third . . . the second day. The first day he was born, it was, "I'm a father" (he laughs). I have a little life I'm in charge of. But when I realized, when it really hit me that . . . he's gonna have some developmental problems, some medical problems . . . okay, being a father isn't all fun and games. It's a lot to it. . . I'm a single father now. I have to

. . . play the mom role and the dad role (laughs). So, it's interesting. It's definitely interesting.

David described that he expected his sons would enjoy similar interests and pursuits. He experienced redefining the meaning of time spent with his sons and learning to attend to the individual needs of each child:

**David:** So one of the things that I do now is I take time out to do something special with both of them, independent of the other one. Where I might not have done that necessarily, if Jim wasn't disabled. But I'll do something and say okay, "Jerry let's go out." And it's just me and him, and even if it's just for 1 hour or 2 hours, it's just me and Jerry. He gets my full, undivided attention. He realizes that everyone kind of pays attention to Jim, because of the fact that Jim is disabled, and we have to do more. Jerry understands why we do it, but then there's the child portion, the maturity, that doesn't quite understand – accept it yet. And so I had to make that change. I don't think I would have done that if Jim was not disabled because I would have done more of the group activity like my dad did.

David also described that he noticed his children's propensity to gravitate toward their mother for their wants and needs. In order to satisfy his desire to participate and to contribute to their care, he arranged weekend time in order to "provide his wife a break and to enjoy his sons:"

**David:** During the week, I don't get back home; it's usually six or seven sometimes. So, she (*David's wife, Doris*) carries the load. So, on the weekends she needs a break. I'll tell her to take as much time as she wants. And then too I actually enjoy keeping the boys when she is not here. And it's a selfish reason. But when she's here they gravitate to her. But when she's not, they kind of like, okay, "well it's Dad so I guess we have to use him." And so from a selfish standpoint, just for the short weekend . . . I get to do a lot.

Strength Gleaned from Wife. All five fathers described that they placed a high value on their wives' contributions to the family. Each participant reported that their effort to parent was in part due to the contributions of the mothers of their children. Isaiah, the only single parent in this study, described that Daniel's mother chose to avoid custody battles and to instead support an arrangement that kept Isaiah most involved:

When it was time for us to go our separate ways, she realized that Daniel does better with me than he would with her. And instead of hampering him and being selfish and saying,

“Okay, he’s coming with me,” ... instead its, “Okay he’s in school. He’s doing good in school. I’m not going to try to fight you for custody or anything like that. I know you love him. He loves you. I’ll still see him.” And she stills sees him, but , I take care of him on a day-to-day basis. So that was one way of her helping me out. ‘Cause it could have been a very hard battle over who gets Daniel.

Dr. Edward reflected back on more than 40 years of parenting and recalled his wife’s impact and how her contributions and work made it possible for him to be involved with Lillian’s health care regimen:

**Dr. Edward:** I think we worked together. It made it possible for her to do her job and for me to do mine . . . It works both ways. What I did would help her job to be easier. What she did, helps me to be more effective with Lillian.

John said the he found a “teamwork” effort was a helpful approach with his wife.

Similarly, David discussed how he valued his wife and recognized an appreciation for her point of view:

**David:** As my wife described it, it’s like her children are her soul. That’s how she views it. And I think other women probably view it the same way. At least I would hope they would view it that way. I think when you see something affecting your soul, I think it’s hard, I think it’s a little bit harder. But fortunately for me, I have a wife who is very tenacious, who doesn’t give up, just like me. So that’s good because . . . I might want to go 25 miles per hour; she may say enough on this one, we need to go 30. Then there may be another time that she may only want to go 25 miles per hour, and I say nope we got to go 30 on this one.” I think that’s the crux, hopefully, one of things that you look at in the study that you’re doing. I think that African American men need spousal support. I just think that women look at it just a little bit differently. And I think the way that they look at it differently is not better or worse, I just think it’s different and I think you need that perspective.

Courage Gathered from Child. Participants described that involvement was more than being active in daily illness regimens, monitoring symptoms and regular medical visits. Participants described that parenting exceeded their contributions to their child and included their experience of ways they experienced gain from their child’s interaction with them.

None of the participants described their involvement as insurmountable or excessively draining. Instead, four participants referred to their child as a source of encouragement, empowerment and renewal. After his son's organ transplant, Lincoln reported that he was personally inspired by a declaration of resolve and strength Carter expressed: "I'm goin' on with the rest of my life."

Isaiah described that his son empowered him despite the fatigue that results from illness demands and arduous meal planning and preparation:

**Researcher:** So, how do you get re-charged?

**Isaiah:** Seeing a smile on his face. . . .If I see that smile on his face, I'm happy. Just to see him smile is a good thing. I love to see him smile. 'CAUSE HE'S BEEN THROUGH SO MUCH. (He said this with emphasis.) He's 6 years old. He's had over eight, nine surgeries: seven surgeries on his head alone.

**Researcher:** Has he really?

**Isaiah:** Yeah. He's been through a lot. So, to see that smile on his face, or to pick him up from day care and he comes "Daddy! Daddy!" or when he wakes up in the morning, "Daddy." That charges me up. I GET TIRED (He emphasized as he laughed), but I get re-charged by that. It is tiring.

John recognized that illness demands encouraged him to grow and to learn a great deal from the courage of his daughter, Faith, and her siblings:

**Researcher:** What inside you helps you be her father?

**John:** Love. I know there is more to this answer, but I can't think of it right now. Bonding. Her strength, her lack of murmuring, and dealing with certain situations. In other words, I guess I'm proud of being her father. I guess between her and the oldest they have taught me and showed me myself through them. The oldest was the initiator. Faith was the tag team. I'm waiting for the other two to hit me with something now (laughs).

**Researcher:** So, through your daughter's illness you were able to –

**John:** Reach out. Be more objective –I mean more to other people's needs – that I'm not in this alone and somebody needs help. So, I wish there was another lesson. But, I don't regret it, 'cause I grew from that.

Sustenance Provided Through Faith and Spirituality. For each father in this study, faith and spirituality was an important component of their parenting experience. Each expressed that unique aspects of their beliefs and spiritual foundations sustained them as fathers. Lincoln, for example, found that he was more curious about the Bible. During commutes home from work he said that he would often decompress while listening to Christian radio. Dr. Edward described that his children's regular involvement with their religious institution contributed to the family environment and the atmosphere of the home. Isaiah's main source of help was faith based. He described that although he sometimes turned to his parents and has reached a point where he wants to seek out community resources, he draws primarily from a spiritual source:

**Isaiah:** Where do I go for help? Good question. I pray a lot. I go to my mother and father now and then. I've actually told the school that I'm interested in . . . talking to other parents . . . basically dealing with the same thing. I haven't really talked to a lot of people to be honest with you. I'm not a member of any support groups or anything like that. . . . I guess I just look at life like "God will never put too much on me" (He laughs). So, if I ever need help, I just go to the Lord in prayer. That's my help line there.

David described that life with autism and epilepsy was very complex and demanding. His son's illness demands required close monitoring and skilled care taking. Formal religious institutional settings were not a primary resource for him. In his experience, religious organizations like family, friends, employers, and others were empathic. He found that although they tried to be helpful, most could not fully understand the challenges his family faced. He explained that prayer and faith under girded his family. David described that he enjoyed the spiritual sustenance that came in part from a spirituality shared with his wife:

**Researcher:** What do religious organizations do to help you re-charge?

**David:** As far as that's concerned, we pray a lot. The thing about churches is that churches are made up of people and unless someone has experienced it, they can't – it's hard for them to be able to get you going. I mean unless you walk through their shoes. They can say they have. Like my boss at work is spiritual. The other day he brought me a really nice, a really nice book. You can read something spiritual and it'll get you going. So, from a spiritual standpoint, we get re-charged by praying. And saying, "Give us the strength not to give up." Sometimes you want to say let's give up. Then all of a sudden

Jim will look at us or he'll do something or we'll get a sense of no, no, no. I'm going to tell you when it's time to give up.

You know, times get tough and I'm not going to say that they don't. There are days when we say, "Well Lord, you said you're not going to put more on us than we can handle, but can you shift some things until tomorrow?" I mean, we've been down that road. But He's provided us with the strength and courage that we needed. And we're not going to give up in spite of all the obstacles that are being placed in our way.

Support of Family, Friends, and Community. All participants described forms of external support that were helpful to them as parents. David, for example, described that for now his son's illness demands required he and his wife be more hands on. As a result, time spent with extended family or at social events was limited. Instead of relying a great deal on family and friends for help, they sought help from Internet sources, organizations geared to address his son's illness needs, and a trusted team of medical professionals.

John, Lincoln, and Isaiah, on the other hand, described more direct extended family involvement. For instance, several members of John's extended family lived with diabetes. They understood how they could be helpful, and John learned that he could ask for their help. One relative donated supplies. John's mother, a nurse by profession, shared medical information and pamphlets. Both grandparents served as sources of encouragement for their granddaughter and for the family.

Lincoln recalled a very supportive extended family and that their involvement in hospital rituals, especially during the transplant process, helped him parent. Also during the progression of the rare organ disorder, Lincoln's siblings and some family friends made important contributions to the needs of his other children. Furthermore, Lincoln in his response to where do you get help, described a community of elders he considered a resource. He reported that they provided insight and a point of view that differed from his peer group:

**Lincoln:** Sometimes my buddies. You know, I sit down and talk to them . . . I kinda of like talking to them about different things. Most of my friends are older than me. One guy is two years younger than my mother. Another guy is three years younger than my mother. And this other guy is ten years older than me. And so, I try to find people that can give something back to me. I think because of the fact that my job is one of those where I'm

suppose to be the authority . . . I'm supposed to be the last word. Sometimes you don't feel like being the last word. Sometimes you feel that somebody should give you some words.

**Researcher:** So, you go to elders.

**Lincoln:** Yeah. I think they're very important. So, that's what I look for, for support. 'Cause guys my age, if they're married, they're struggling just like I am: with their wife, with their kids, whatever. But if they're single or married, when they are older they just have . . . a perspective to give me that maybe I don't have.

Dr. Edward recalled a community that was able to support his parenting efforts in ways that differed from the four contemporary fathers. Three contemporary fathers, for example, described that they sought out communities with access to educational or medical resources. Each moved family in order to accommodate the needs of their child with chronic illness. David described lengthy commutes to pharmacies and to treatment facilities. Lincoln's family traveled significant distances to transplant centers hundreds of miles from home. Dr. Edward and his family, on the other hand, lived within walking distance of schools, work, a hospital, the treating physician's home, and grocery stores. He described a community that contained "all the essentials of life" and a community that served as a natural buffer between the illness stressors and parenting. He recalled a close-knit community and recalled that resources were readily available. Economic, health care, spousal, and community resources were "no problem" and exceeded his perception of illness-related stressors.

**Researcher:** Can we talk a little bit about the resources that were available and the kind of resources that you tapped into?

**Dr. Edward:** Plenty of food right up here on 14th Street. The Mega Food Chain had just been established when I was a child. The first Mega Food Chain was located not far from here. I see now that they have sold out to a Dutch company . . . . But anyway, food was no problem. Shelter was no problem. Clothing was no problem. So the essential of life were very easily acquired. Hospitals near by for help, that's number four.

...Now where I work was very close to here. I could always walk to work. I never had to drive. So that would, by the way, eliminated one more problem. There was never any of that out here on the highway and beltway, and all that sort of stuff. So, I never faced any of that.

**Researcher:** So you were in very close all the time?

**Dr. Edward:** Yes, all the time.

For Dr. Edward, part of his parenting experience included watching the community he valued go up in smoke after the assassination of Dr. Martin Luther King, Jr. He described that tensions during that era were particularly challenging. He recalled that Lillian's ability to manage her health regimen was well established by then. Community unrest in 1968 and student unrest in 1972, he reported, posed pressures that were "much weightier than Lillian and her diabetes, because she was handling it very well by that time." He remembered his concern for his family when riots occurred and that Lillian had to make her way home from school:

**Dr. Edward:** She had to make her way home by herself, I think, with maybe one or two other fellow-students at the academy. She had to get home that day.

**Researcher:** What was that like? Do you remember?

**Dr. Edward:** Well many stores, buildings, and houses were burned down on 14<sup>th</sup> Street, one of the main corridors here. Another one was H Street, N.E. from about the 400 block east and 7<sup>th</sup> Street. That's where the three main corridors of conflagrational fire took place. And Lillian had to make her way home that day when it already had started.

**Researcher:** Was that kind of scary for you as a dad?

**Dr. Edward:** Well in a way yes. Because standing here looking west to 14<sup>th</sup> Street . . . well one block further west is 14<sup>th</sup> , you could see the smoke and the fire. From this house you could see the smoke and the fire on 14<sup>th</sup> Street. So each child . . . now this is 1968 . . . each child had his or her bag packed, plus my wife's bag and mine. All the bags were right here, on that walkway to the street that you came in, ready to go if a fire came all the way down here. What it meant then to each of those four children, I don't know. That's nineteen sixty- eight. What's that? Thirty-three years ago.

**Researcher:** But then you were obviously concerned about everybody's safety.

**Dr. Edward:** Yea. That's why I got all of them to pack their bags. And incidentally I got a phone call from a man who said, "Look I know you got a problem there." I said, "You know I got four children?" He said, "I don't care how many. Bring them all out to my house." He was Jewish by the way. He was in the Anti-defamation League of B'nai Brit. But I called him back and said, "No, fire has slowed down. I don't think we're going to have to leave." So everybody trooped back into the house with his or her bag.

**Researcher:** It must have been a relief once everybody got home from school and everything was safe.

**Dr. Edward:** That was that bad evening of '68. Then we did walk up and down 14<sup>th</sup> Street. the next day. Bobby Kennedy came up, too. That was when he was . . . Attorney General of the Department of Justice. He came up. And I can remember a picture of him in the *Star* or the *Post* at 14<sup>th</sup> & Park Road looking at the debris.

### Commitment and Clarity of Priorities

The theme “Commitment and Clarity of Priorities” emerged from the five interviews and can be further divided into three categories. The three categories illustrate a resolve and purposefulness participants described. One category within this theme, “Sorting Employment and Illness Demands,” refers to the demands and stressors of employment, finances and chronic illness and participant strategies developed to manage them. A second category, “Assuring Quality Care,” emerged from descriptions of persistent efforts fathers made to be involved in obtaining care; monitoring the delivery of health-care services; and following up on health, education; and child development needs. The third category, “Setting Aside Self,” refers to decisions made by participants to make personal sacrifices and to focus priorities in order to respond to chronic illness stressors.

Sorting Employment and Illness Demands. Dr. Edward did not recall times when employment demands or stressors made it difficult for him to parent. His career in education and position as a college administrator, he explained, afforded him a level of job security and income adequate to meet his family’s needs. Similarly, John described a level of employment security that resulted from seniority earned, an established history of high on-the-job performance, and an accumulation of substantial sick leave. Therefore, he could assume responsibility for scheduling and attending doctor appointments with his daughter. He said he chose to communicate to superiors that his child’s health care needs were a priority. His employer responded favorably to his paternal needs.

David and Isaiah, on the other hand, described less on-the-job flexibility. Because both wanted to be involved fathers, they reported a willingness to risk job loss, promotions, and the consequences of workplace misunderstandings regarding their level of commitment to their careers:

**David:** So yes it does affect your career. I don't cast any dispersion on anyone who didn't, but most people are not going to understand. I put that (career) on hold. I didn't have to put it on hold for any other reason than I wanted to be involved in my child's life. If I have extra work to do, I would have to do that at night. There are certain jobs that . . . if you have an exceptional family member, you just can't do.

Isaiah described the choice he had to make regarding a different career path. He experienced a lack of flexibility and inconsistency regarding the granting of leave to attend to his child's medical needs. In addition, he experienced misinterpretations of his intent when doctors assumed his absence at medical appointments meant he lacked concern for his child:

**Isaiah:** His last doctor in the military was the director of the neurology department. Well, the reason we were seeing him is because we had a fallout with the doctor that was seeing Daniel prior to that. The doctor we were seeing, wanted Daniel to come in and this is at the time I was working in the military and my boss wouldn't let me go to appointments. My wife was working. I was in the military. We weren't making a lot of money . . .if we take off work, then we are not going to get paid. And the doctor . . . told my wife . . . that if you care about your son you'll bring him to the hospital . . . When she told me this, I called him up. . . . He out ranked me. . . . But I didn't care about rank at that time. I was like, "You don't talk to my wife like that." So, I explained this to the chief neurologist who said, "Well, I'll follow Daniel." Now, on the outside the only experience I ever had was with the current clinic we attend and they are wonderful individuals. I haven't had any problems at all.

Isaiah said that experience taught him that his ability to participate in the care of his son was influenced in part by the supervisor he reported to. He found that rigid job expectations and gender bias did not support his involvement efforts. He chose to leave the armed services and to risk the high cost of medical coverage for family members with pre-existing conditions:

**Isaiah:** And again that's depending on in the military who you work for – your supervisor. If your supervisor is like, "well, you have a wife." And actually that's one of the reasons I got out. My last supervisor didn't understand or wouldn't –didn't have kids. And it's kind of hard if you don't have any kids to understand what you have to do

as a parent. So, if I'm telling you that I need to take my kid to an appointment and you don't have any kids, it like okay, "why can't your wife take your kid?"

**Researcher:** And what was your response?

Isaiah: Yeah. So, it was like, you know what? I don't think I really need to be in the military any more. (He smiles and laughs.)

Assuring Quality Care. All fathers were involved in daily health care regimens and symptom monitoring. Dr. Edward, for example, administered the insulin, kept a detailed record of food intake, reactions and blood levels and attended doctor appointments. Isaiah, similarly, managed a very detailed and regimented diet in which all meals require that ingredients are carefully measured and each meal is meticulously prepared. He coordinated and attended health-care and educational consultations to assure Daniel's needs were met. For John, assuring quality care meant monitoring symptoms as well as attending medical appointments. He described that although his daughter is now 21 years old, he stills sleeps lightly and listens throughout the night for indications that she might be experiencing nocturnal distress.

Isaiah, Lincoln, and David described stressors associated with assuring quality care. They experienced difficult and complex medical choices. These three participants were involved in efforts to understand and to stay abreast of medical situations. Involvement included searches for effective treatments, for state-of-the art protocols and for appropriate service delivery. In addition to stressors associated with their efforts to assure quality care, David, Isaiah, and Lincoln described times they experienced being discounted and times when unilateral decisions were made on behalf of their sons without considering them or their wives in the decision making process:

**David:** We've seen that if you're Afro-American, the assumption is made that you're not knowledgeable of this. And, until you prove otherwise, you'll . . . be taught and treated like you're not knowledgeable. We've seen a change in behavior from when we first started in the processes. Like okay, here's what you're going to do for your child, go do it. As soon as we asserted our authority and our rights as his parents, and then articulated that we know about his condition, maybe not as much as you do, because you went to school for this, and been doing this for 20 years. But once you start interacting with them and they see that you're researching and that you're keeping up with the latest trends and

you're debating them and you're challenging them on their diagnosis, then all of a sudden they stop treating you as someone who doesn't know.

David described an incident that demonstrated his experience of exclusion from the decision-making process. He described his response and that inclusion meant acknowledging and welcoming his need to be well informed and consulted about medical interventions:

**David:** Afro-American men, what they face on the outside, they don't have as much control. That's probably a whole new/different subject, but they don't have a lot of control. And so most doctors, and everyone else have to realize that and help them to empower themselves by making them a part of their child's decision.

For instance if something's not working, "Here's why I believe it's not working. And we're going to go to this because this will do this."

A doctor just said okay and he just put in a new order for a new antiseizure medicine. It took us three weeks to track him down. He said, "Did you give it to him?" I said, "No."

He said, "Why didn't you give it to him?"

I said, "Because, one, you didn't consult us about changing his medicine. You just put it in the computer system. When we showed up to pick up the medicine and they said oh you got to pick this up." I said, "What effect is this going to have on his mood? What affect will this have on his liver?" . . . Then he had an appreciation for us. And so he learned from that point on when he dealt with us, he went from A through Z with us to make sure that we felt comfortable.

At the clinic that sees my son, the difference is that they have maturity and expertise. They're more into, "Here's why we want to go this way. Here's what it's going to do for him. Here's some possible side affects, and do you feel comfortable with this advice we're giving you? Because if you don't, we can help you get a second opinion, or we can back off of this." That's why we feel very comfortable with them because they share that with us.

All participants described a tenacity and determination to do what was best for their children despite obstacles encountered. Lincoln referred to life with chronic illness as "parenthood taken to a new level." He had an extensive medical background. In some ways his

insider prospective contributed to his efforts to advocate for the most helpful treatment available and to “cover all bases.” In other ways his knowledge of the frailties of the health care system created its own set of stressors. Whenever their son, Carter, was hospitalized, Lincoln and his wife agreed that a fundamental component of assuring quality care was to never leave Carter alone. Someone in the family was always by his side:

**Researcher:** So, you guys have had to be very vigilant.

**Lincoln:** Yeah, it’s taken parenthood to a new level.

**Researcher:** What do you mean by that?

**Lincoln:** You just can’t miss a stroke. You can’t go to sleep. You can’t go to sleep at all on your kid’s health care. Well, the thing is on the health care side, I know the system is straining and coming apart at the seams. I know that doctors are pressed. I know that hospitals are pressed. I know that people are just running people through left and right, because they are pressed . . . Knowing the medical care system from the inside out, you know that you can’t sleep anything, EVEN if you know the person means the best by you, they can screw up ‘cause they are under . . . the gun to process, process, process. There is no time to think. . . . Again, from the inside out, I can see it very clearly. Patients don’t see it. And till somebody does a study to show how many people are coming up dead, nobody will see it.

Lincoln reported that the hospital vigil the family developed helped to relieve stressors and kept the family close. He described that it proved to be vital to Carter’s overall well being and helped in one instance to avert potential crises:

**Lincoln:** Whenever he was in the hospital, my wife and I made a point – one of us stayed with him. . . . We never left him by himself. And that turned out to be the best thing . . . they had in him . . . a central line into your blood stream. And the . . . the God-forsaken nurse that was taking blood from him to check his blood gases – he was on oxygen of course . . . she forgot to put the cap back on. And he bled out in the hospital bed. Luckily, I was sleeping right there.

And he said, “Daddy, there is water over here.”

I said, “It’s not suppose to be water over there, son. Are you sure?”

He said, “Yeah.”

So, I get up. I turn on the light. And I said, “Oh, God!”

So, I clipped it. And then I called the nurse and said, “What the Hell?” You know. So, if you want your kid. If you EVER spend time, that’s the time to spend with ‘em. You cannot leave your kid in the hospital. You know if my wife and I couldn’t do it or if our kids were available, they would do it. But somebody was always with him. We never left him by himself.

Setting Aside Self. With the exception of Dr. Edward who is now 82 years old, the men I interviewed described that part of the parenting and involvement process included participant’s decision to set aside personal needs in order to meet the demands that chronic illness created in their lives. Participants also had clear perspectives regarding their approach to the unpredictability and unending challenges their family faced.

Lincoln and John, for example, described that they prioritized and chose to make personal sacrifices. They expressed that their priorities shifted to meet the needs of family and the demands of chronic illness:

**Researcher:** How else might you describe your experiences facing the demands of fathering a child with a chronic illness?

**Lincoln:** Well, it makes you put yourself in a secondary capacity as opposed to primary. If your career was that important to you, it becomes less important. If . . . like I hang out with my buddies sometimes . . . the bantering that you have back and forth . . . you know, got less important.

A guy asked me about that the other day, “Hey, I don’t see you hanging out anymore.” Well I don’t have time. Because I’m not gonna leave my wife alone to deal with this issue. And she needs support. She needs help. He needs support. He needs help. And even if it’s just being there and going to sleep upstairs, it’s important. The other stuff just don’t mean as much to me. Maybe it never should have meant that much (he laughs).  
But it did. What the hell.

Similarly, John took a stance on behalf of his family that required self-sacrifice and prioritizing needs in order to address illness demands. He made sacrifices based on his love for his family and faith in God.

**Researcher:** How would you describe or characterize your experience having to face your demands as a father?

**John:** Struggling – Hardships and stuff. It’s difficult. You know when you look at the prices of what you have to pay out of pocket to be reimbursed, you know, I wasn’t born Howard Hughes (laughs). So, it was some sacrifices. It seemed like she needed the supplies right when I was low (laughs) on cash. But, I mean, God was a big part of that. A major part of that. You know I don’t know how I got through without Him. It was difficult at times. But when I put aside my wants and needs and I think I took away from other things in the family so that she could have what she needed. Sacrifice and prioritize things so that she could have what she needed, because to me that was more important than things that I could go without really using. Rob Peter to pay Paul so to speak. (laughs.)

**Researcher:** So, it was very, very difficult?

**John:** Yeah, in the early years it was. I had never dealt with diabetes before. So, yeah, difficult.

Several participants referred to “swallowing their pride,” “not letting their ego get in the way”, “realizing that their time was not their own.” Participants described that setbacks and obstacles were offset by the ability to prioritize and to remain focused on the immediate needs of children and family in order to assure the optimal level of care:

**Researcher:** Can you describe how you came to the decision to reach out to community organizations and resources?

**David:** It’s what I said earlier. I look at it as success or failure, life, or death. So, anything that’s available, that’s going to help me help my son, I’m not going to leave any stone unturned. I’m not arrogant and I have the right amount of pride, but I can swallow my pride to go out and ask for help. And I’m smart enough to know where I need help. I mean, I know that I can’t cure him. We firmly believe that the only way that he’ll be cured is if Jesus and God wants it for him.

When Carter developed “a rare complication to a rare disorder,” and it became clear that a transplant had to be performed, for example, Lincoln remembered setting aside pride and personal frustration:

... one thing that my wife said and I whole heartedly agree with . . . “Anybody that takes care of my child, I’ve gotta be nice to them.” I don’t care what you say to me. I’m gonna

look right in your face. I'll do what ever the hell it takes, 'cause you're gonna help my child.

And I found out when this transplant was gonna go. When we got ticked off at our transplant center. Which we shouldn't have gotten ticked off at our transplant center. Should have got ticked off at the guys here that didn't correctly diagnose the case. We got ticked off at them and we were gonna go someplace else. We were gonna go, actually, to another metropolitan area. They kicked the case. They wouldn't even touch Carter. They wouldn't DO the surgery.

Now you talk about somebody in tears. I cried all the way home from the hospital. Tears were streaming down my face. I said I gotta get home to find somebody that's gonna do this thing. I got on the Internet. I got on the phone. I talked to five different transplant centers and they wouldn't do it, because of his high surgical risk.

Then I talked to the guy we'd been referred to originally. He writes the papers on the high surgical risks. He has a 96 percent success rate. Man, I went back and asked him will you please do the surgery? My ego meant nothing to me. And I understood that. I don't know how others don't understand that. When it's your kid you just have to swallow whatever the hell you've gotta swallow.

### Anchoring in Race, Gender, and Legacy Building

This emergent theme refers to descriptions in which race, gender, or legacy building (future planning) was described as part of participants' experience parenting children with chronic illness. Two categories: "Putting on the Uniform" and "Preparing for Tomorrow" describe strategies that assisted involvement despite the potential road blocks incurred due to racial, gender, and chronic illness occurrences.

Putting on the Uniform. "Putting on the Uniform" refers to descriptions fathers provided of the impact of race or gender on their families and ways they responded to the immediate and long-term needs they perceived. With the exception of the two fathers whose children lived with diabetes, the participants described that they faced racial barriers and employed strategies to address them. When asked whether being an African American had been a barrier David answered affirmatively:

**David:** I think in the big scheme of society, yes. Because my son is autistic doesn't change the fact that I'm African American. It doesn't change biases that people are going to have. People might show compassion for you to a degree, but that doesn't necessarily change some of the ways that they may perceive things.

David described his experience with stereotypical responses he encountered and an effective strategy he employs in response to constraints that create barriers to his efforts to achieve desired paternal results:

**David:** For instance, when I show up in civilian clothes. When I first started through this, I got a certain reaction. One time I showed up in my full uniform. Full "class A" uniform with all my medals. All my stuff. Threw 'em for a loop.

"Wow! What are all these medals?"

**Researcher:** So what did you notice specifically? What was the difference...

**David:** You gain more respect. They treat you with more respect. They treat you with the fact that you know what you are talking about. Just in appearance wise.

**Researcher:** So in civilian clothes compared to being in full dress?

**David:** Right because the assumption is that if you say . . . I'm in the Army, even if you're African American, the assumption is that you're enlisted. Okay, you're enlisted. And I don't say well I'm an officer in the service. I just say, "I'm in the Army." The natural thing is that they figure that you're enlisted. Until they find out later . . . Cause someone will say, "What do you do?"

"Well, I'm a transportation person. I happen to be an officer."

"Oh! You're an officer."

Immediately, their whole train of thought goes away. Being an officer means you went to college, you got a degree. You start talking and things.

Then, "What's your rank?"

All of sudden, they're like, "Uh oh!"

One time I went to one of my son's meetings and I was in full uniform. Quite frankly I did it purposely. Because, I knew the reaction that I was getting before, and I needed to send a signal to them that they're not dealing with uneducated people. And that I will get the respect that I earned and that I deserve one way or another.

And so, I can be a confrontational person. I have that personality if needed be. But I usually don't. I prefer not to. I prefer to try to finesse people. But when I have to be confrontational, I can be pretty efficient at it.

So I said okay. So I put the uniform on.

Isaiah described the reaction of people when they discover that he doesn't conform to typical gender roles and is parenting his son as a single father. He experienced that he is often called upon to explain that he parents his child. As described in the introduction to "David's Story," people often questioned that he is both a single parent and a single parent managing life with a child with a chronic illness:

**Isaiah:** When I talk to people and tell 'em I have my son, it's like, "So, what do you mean you have your son?" (He laughs) Well, he stays with me. His mom lives in another state. And I live here and I take care of him.

Lincoln described that part of participation involve teaching his son about race and gender issues. He recalled discussions about appropriate male boundaries and conduct. He also recalled discussions with Carter regarding the impact of race on his future:

**Lincoln:** And then you've gotta realize that when it's all over and done, you're a Black male kid. And ain't nobody gonna give you NOTHIN.' So, if you don't get it together, there ain't gonna be no sympathy out there for you in the larger White world. So, don't even think that. So we do talk a lot about, not a lot, but I will have some discussions about race relations and, you know, things like that.

Preparing for Tomorrow. This category refers to participant descriptions of future plans and legacy building. Part of parenting for each father involved thinking about, planning for, and preparing to engineer each family's tomorrow. Dr. Edward's children were all over 40 years of age. He reflected on his children's current interpretations of their family experience, the foundation he laid, and his experience of contributions made in their lives. The other four participants were currently involved in establishing a foundation and preparing for the family's future. Lincoln discussed his belief that parents should consider future generations as they plan for and are involved with their children:

**Lincoln:** As we move through the generations, and move forward, we're suppose to give our kids the benefits of things that we've learned and give the benefits of what our parents

taught us. We can't afford to go through life and I learned something from my father but I happen to not teach my kids that.

John, who described himself as “just another brick,” reported that he participated directly in his daughter's education about gender relations and personal development, and preparation for the future:

**Researcher:** So, in what ways are you involved in her life right now?

**John:** I guess, teaching her what life is about – what to expect. Mainly giving her the insight about men, because I think it's important that she knows how men act around young ladies. What things they expect to hear / why they are going to hear it. Land mines, you know, so to speak. Don't step on something that looks pretty and then explodes in your face. So, I try to tell her how men think. Because coming from a father, I've been there. I've done that. And I know what some of the games are. So, I try to keep her aware of that. Also, to be independent. Not to totally rely on man, so to speak. Just on her own abilities. A good education, so she'll have something to fall back on. . . . I guess the facts of life. And how to be a good person – an example for her siblings and other women out there. No gender, I mean, no color; just women in general.”

David described this type of involvement as “re-dreaming.” Isaiah spoke of his thoughts about his son's future and goals he has a parent to assure that Daniel is self-sufficient and taken care of:

**Isaiah:** I would love to be there, but I'm not going to be there forever. I know this. So, I need to do whatever I need to do now, so he'll be fine later on.

#### Stress & Coping, and Advise to Professionals

Illness-related struggles, demands and adjustments led the fathers in this study along an unexpected path. Each described that chronic illness entered their lives unexpectedly. Each chose to become acquainted with unfamiliar terrain and to adjust to the illness stressors their family faced. The parenting experiences described by the fathers in this study are in part summarized within their definitions of coping. The parenting experiences are also summarized in part within the nuggets of advice fathers were willing to share with other curious about life with chronic childhood illness. These two summaries follow.

## Summary of Stress and Coping

All participants were recommended to this study because they were perceived as involved parents and parents coping well with chronic childhood illness. Each participant, though, defined coping with chronic illness in various ways. Lincoln, the only participant to experience stressors related to the transplant process, found that the word “coping” accurately described his parenting experience:

**Researcher:** Would you use the word “coping” to describe your experience?

**Lincoln:** Oh yeah. It is. It’s just one of those things where you just take a deep breath and you say, “Okay, I’ve gotta get past this hurdle.” And you get past it. But, you know you gotta get past it. You can’t just sit there and dwell on it. So, coping is probably the best word to use.

Dr. Edward, John, Isaiah, and David did not describe that they coped with illness-related demands. Dr. Edward, for example, expressed that once he learned what was required, he simply did what needed to be done:

**Dr. Edward:** No. I wouldn’t say, I wouldn’t use coping: because, it wasn’t that big of a problem. It seems to me you use the word “coping” when you got a problem that’s substantially weighty. Almost formidable and so you cope with it. I wouldn’t use that word. I would have to look it up in the dictionary to see exactly what coping means. No I wouldn’t use that term.

**Researcher:** How might you describe your strategy?

**Dr. Edward:** Doing for the children what needed to be done for children as they grow up. They needed clothes. All. . . essentially the same thing that man all over the world needs: food, clothing and shelter.

John, similarly, found that the word “coping” did not accurately define his experiences:

**Researcher:** Would you use the word “coping” to describe your experience, or what word would you use?

**John:** Manage. Use the word “dealing” or “sacrificing.” Coping is a little thing that I am hung up on. I don’t want to sound like I was doing it because I have to. I manage to do it. And I’d do it over again. Yes, I’d do it again if I have to. But, uhh, coping seems like you are taking it lightly. Manage. Manage to do it.”

Isaiah, for example, described that he “dealt with” demands:

**Isaiah:** Coping is like a bad thing. It's like okay, how do you deal with this, how do you cope with this problem. Well, I don't cope with it. I deal with it.

### Summary of Advice to Professionals

I asked participants how they would advise professionals who work with African American fathers parenting children with chronic illness. Several participants recommended that professionals involved in work with African American families living with chronic illness carefully consider the impact of economics, employment demands, race, and culture on paternal participation and that professionals “understand the challenges that an African American father or family may face.” Challenges described included a variety of personal constraints participants described in the data collection process and constraints they observe among other fathers: the economic constraints that may impact a father's ability to take time away from work, the part culture plays in how families make sense of and respond to illness, and the degree of information and education a parent needs to clearly understand the disease process and to prepare themselves and their families for the illness demands. Advice regarding how professionals might be more responsive ranged from suggestions to implement the practice of basic human courtesies to suggestions of effective multi-system collaboration of services and resources. I have highlighted the advice in three categories: advice of fathers as individuals; advice of fathers as parents managing chronic illness; and, advice of fathers within a community of multi-systems.

### Advice of Fathers as Individuals

**Researcher:** What advice would you give professionals regarding how they work with fathers or what do you think they need to know?

**Isaiah:** Treat the fathers the same way you would most likely treat the mother. In this day and age you find that a lot of fathers are raising their children. And they are capable of it. So don't, if anything, don't think that this person can't handle it just because they are a father. And, just work with them as you would work with anybody else. If you're patient with the mother, be patient with the father. I always think back to this and I always say this, treat others as you want to be treated. If you talk down to somebody, would you like it if somebody talked down to you? No. Treat others as you want to be treated. Plain and simple.

### Advice of Fathers as Parents

**David:** Don't respond to me because I'm a man. Respond to me because I'm a concerned parent. Bend over backwards for a concerned parent, because that's what you want – parents to be involved.

Part of that process means they're going to challenge you. Don't take it personally. Take it as: that's good. African Americans, we believe in the stereotypes ourselves. Empower that person. Encourage people to get involved.

You'd be surprised at what a few words on a piece of paper can do signed by a doctor. If a father comes in and makes a comment, "Yeah boy, I tell you I hope I got a job when I get back."

And if that doctor believes that it's important for that father to be involved in that child-care, then write a note. Or even a quick little 5 minute phone call to the person's business, because on all medical charts you have to put your work phone. And say, "Hey, I'm doctor so and so and I really thank you for allowing Mr. Concerned Parent to have the day off today."

In a conversation like that from the doctor will let the employer know that the guy is not goofing off. Afro-American men, what they face on the outside, they don't have as much control. That's probably a whole new/different subject, but they don't have a lot of control. And so most doctors and everyone else, has to realize that and help them to empower themselves by making them a part of their child's decision.

For instance if something's not working, "Here's why I believe it's not working. And we're going to go to this because this will do this."

### Advice of Fathers Within a Greater Community

**Researcher:** What advice would you offer professionals working with African American dads with chronically ill kids?

**Lincoln:** Well, think there's a difference working with African American fathers and with Caucasian fathers. It may be cultural. More than likely it's going to be geared around the economic situation. People like me that can afford to take off from their job and still have a job when they go back are few and far between, I would say in the African American male population. I just don't think that a lot of us can do that. This lady told me, she said, "God, you took off 3 months from your practice and you still got a

house?” But it didn’t dawn on me that that was a major accomplishment. Most people would go into bankruptcy or something. So, I think that we are very fortunate in that. So, I think that’s one of the major things.

I think the other thing is to modulate your requests from them according to what they can do given their job situation. And it’s a hard thing for a physician to take that type of a role. It’s better for the social worker to sort of debrief the family about what’s going on – know what the situation is that’s going to happen – and then be able to talk about the time commitments and stuff like that and what they can do. And then to work with the family to arrange time off, so that the family can be there for the child and can do what they can do. If I had my druthers, I say, look to have volunteers that can help stay with your kid and do things for you. You’ve got family that can help you out. So, I think you should encourage the family to use all of their resources and coordinate them so that they can provide the support for the child, that’s important. And for the rest of the family, that’s important.

**David:** Because a lot of things are culturally based. Even in today’s affluent society. A lot of things are culturally based. This is not just Afro-Americans, this is across the whole spectrum. You still have fathers who they don’t have boys, they’re upset. You still have families if they have a disabled child they think that God’s cursed them or something, and they don’t want to have anything to do with that. They are still a lot of people who believe those archaic things.

Education has a lot to do with it. Not everyone goes off to college and beyond. A lot of people finish up at high school. So I think if they would encourage them . . . help provide resources to them. Provide support to them by saying, “Here, here’s a recommendation. Your son has autism. Here’s a good autism support group that’s in your neighborhood.” Those kind of things to help them cope with that. I think they will get a better product. If they have parents who are much more involved and have an understanding.

## Conclusion

Central to descriptions of paternal participation and definitions of coping was a core commitment to parenting and positive involvement. Within each emergent theme – “Appreciation of the Priceless,” “Commitment and Clarity of Priorities,” and “Anchoring in Race, Gender and Legacy Building” – participants described an approach to parenting that prepared them for the unexpected. That preparedness consisted of devotion, loyalty, awareness and love. Devotion demonstrated by doing what was required. Loyalty expressed through participating without regret and reservation. Awareness discovered when acknowledging personal limits, when availing personal and family resources where required and while assigning priority to the greater good of family and child. And lastly, participation consisted of acts of love evidenced in their commitment and courage to parent despite all odds.

## CHAPTER FIVE: DISCUSSION

### Introduction

The purpose of this study was to investigate paternal involvement of African American fathers in families with chronic childhood illness. In addition, this study was aimed specifically at fathers who were perceived as coping well and actively involved in their family's care. Data collection was achieved through five descriptive accounts that explored several aspects of paternal participation while managing illness-related stressors.

In the previous chapter, I presented the voices and unique parenting experiences of each father. From the personal realities fathers described, three broad themes emerged: "Appreciation of the Priceless," "Commitment and Clarity of Priorities," and "Anchoring in Race, Gender and Legacy Building." The 3 themes referred to fathers' perceptions of daily parenting demands, tasks, responsibilities, expectations, constraints to involvement, and strategies for coping. Within these themes, 10 categories emerged to further describe paternal participation. The 10 categories described factors that influenced or enhanced involvement and were incorporated into fathers' overall approaches to parenting. They included clear paternal definition; strong parenting alliance; gains experienced through father/child relationship; strong spiritual foundation; responsive social support system; effective strategies for managing employment demands with illness demands; confidence in ability to navigate health care structure; attitude of self- sacrifice and flexibility; strategies for managing perceived disparities; and maintenance of future focus. In addition, fathers' define coping and advise professionals involved with families who have children diagnosed with chronic illness. In doing so, they reveal challenges to participation, potential constraints to involvement, and suggestions for productive encounters with systems of care and collaborative exchanges on behalf of children engaged in treatment.

In this chapter, those findings are examined with respect to studies I found that explore this research area. In addition, the implications for clinical interventions as well as the strengths and limitations of this investigation will be discussed.

### Findings

The personal interview process and extensive study of data revealed several core beliefs fathers found helpful as they navigated various chronic aspects of their family's illness experience. These beliefs were linked to strategies for active participation throughout their

illness and parenting experiences, to processes for coping with internal as well as external stressors, and to systems of support for the maintenance of balance of helpful family interactions.

#### Experiences of Paternal Commitment

Fathers in this study expressed a fundamental commitment to “always be there” and to “do what had to be done” on behalf of their family. Fathers recalled that prior to the diagnosis of illness they based their view of parenting on models provided by their fathers, some mothers, and other significant role models. They described the impact of “good role models.” The role models were not idealized or without flaws. Descriptions typically included efforts to incorporate adaptations to the previous generation’s parenting practices and beliefs.

In addition, some participants recalled that their child’s initial diagnosis precipitated a shift in thinking for them and involved a conscious decision to adjust their approach to parenting or to make lifestyle changes in order to meet the demands of tasks before them (working fewer hours, changing work schedule, balancing time spent with other offspring, socializing less, and being physically accessible to wives and children). Beyond the expressed commitment to “be there,” they sought ways to actively engage in relationships with wives and children with chronic illness and their siblings. In doing so, fathers adopted plans of action congruent with their core beliefs. For instance, one father recalled that he made several personal life style changes and that chronic childhood illness “took parenting to a new level.” Furthermore, all participants in this study expressed a belief that they could be flexible and could adapt to illness-related changes: “if you are dedicated, committed, the bottom line – love that individual you will change. And that’s what happened. Love.” This finding is consistent with an earlier study by Mattson and Gross (1966) that fathers, in their efforts to cope, did not withdraw emotionally or physically from their sons with hemophilia. Similarly, findings reflect those found in a study of coping patterns in fathers of children with cystic fibrosis (McCubbin, H., McCubbin, M., Patterson, Cauble, Wilson, & Warwick, 1983). Coping patterns used by fathers in that study were associated with family organization, cohesiveness, organization and control – system maintenance dimensions of family life.

#### Experiences of Wife’s Contributions

In addition to retaining a clear perspective of paternal commitment, each father described that their wives’ contributions to the family were vital to paternal involvement efforts. Other researchers have noted the role of egalitarian decision-making processes in resilient African

American families (Hill, 1999) and flexible role responsibilities and functions within families (Billingsley, 1992; Boyd-Franklin, 1989). Fathers in this study recognized mothers' positive impact on child development and each esteemed their wives contributions to the family's well-being.

Often fathers described that their wives approaches were different from their own and that they valued and depended on the unique perspectives their wives brought to parenting. Interdependence was described as efforts to balance each others "strengths and weakness." One father, for example, spoke of his recognitions of different approaches to parenting. He said, "I depend on her to point out important things that I tend to overlook or view differently." Another father firmly stated that he could not have done his job as a father without his wife "doing her part." This finding also applied to the only single father in this study. Although separated and divorcing at the time the interview took place, he spoke of the value of contributions his wife made to their child. This study did not explore the impact of marital quality on paternal involvement. Instead, fathers' descriptions of alliances with their wives were shared in the context of being an involved father. The results of a recent study of father involvement and parenting alliance (McBride & Rane, 1998) indicated that parent's assessments of parenting alliances were strong predictors of paternal involvement. Fathers were found more involved when they were in agreement with wives regarding parenting strategies and when they believed their wives had confidence in their ability to parent.

#### Experiences of Child as a Source of Personal Growth

Fathers in this study also described an alliance and interdependence with their children. Although my research was aimed at what fathers experience in their efforts to parent, this study revealed fathers experienced valued gains as result of interactions with their children. Father involvement research has recently begun to explore not only what impact the father has on the child and the child's development, but also what impact children have on fathers' personal development (Allen & Connor, 1997; Palkovitz, 1996). Several fathers referred to their children as sources of strength, courage, rejuvenation, renewal, hope, and wisdom. Fathers were often empowered by their child's tenacity when faced with tough medical procedures and regimens. One father spoke of being "re-charged" by his child's smile. Another described the two-edged nature of growing personally in response to parenting challenges and the impact of illness:

**Researcher:** So, through your daughter's illness you were able to –

**John:** Reach out. Be more objective – I mean more to other people’s needs – that I’m not in this alone and somebody needs help. So, I wish there was another lesson. But, I don’t regret it, ‘cause I grew from that.

### Experiences of Faith and Spirituality

It has been well documented in literature that faith and spirituality has been a source for coping in African American families (Bowman, 1993; Boyd-Franklin, 1989). All fathers in this study referred to aspects of their faith and spirituality that contributed to the wellness and balance of family. Prayer was identified as an aid to decision-making, for example, another father shared that he and his wife prayed together in order to gain strength and focus. For another father, listening to religious stations during drives home from work helped him unwind and transition. Some fathers found that participation in formal religious institutions were important and they enjoyed the encouragement and support of their faith community. Another father experienced that ceremonies and religious rites of passage served as important milestones and markers of child growth and development. For some fathers, formal religious institutions presented constraints such as the inability to accommodate the special needs of their children. For example one father described that religious institutions were comprised of individuals who often “meant well” but were unable to “really understand.” Nonetheless, a wide range of faith expression was important for coping well in families.

### Experiences of Work Demands and Health-care Demands

Fathers in this study experienced a variety of responses to their requests for time away from the job to attend to the medical and educational needs of their children. All fathers were actively involved in their child’s medical care, attended doctor visits and participated in hospital rituals. Some fathers in this study experienced their places of employment as sources of support, while others described challenges to work and to their desired levels of involvement. One father experienced that his request to attend his son’s doctor appointment was denied and his superior inquired regarding whether a wife was around to take care of medical demands. Another parent was aware that time away from the job to care for his child created a climate in which his job loyalty was questioned and promotion possibilities were jeopardized. In light of the related stressors due to inflexible work environments, for example, fathers reported changing places of employment; accumulating large amounts of leave in anticipation of emergency medical needs; working to establish solid performance records to buffer the impact of unplanned absences;

changing expectations regarding advancement opportunities; and creating a line of communication with employers to inform them of shifts in medical status and related needs. These coping strategies were aimed at relieving complex work constraints and were part of a system of beliefs and behaviors geared toward “being there” for their child.

### Experiences of Chronic Illnesses

This study found that fathers focused some of their involvement efforts on learning about their child’s illness, monitoring symptoms, communicating regularly with health care providers regarding treatment regimens and health-related needs. These efforts were consistent with other research findings (McCubbin, et al., 1983; Horn, Feldman, & Ploof, 1995). McCubbin et al., found fathers demonstrated two coping patterns that involved system-maintenance-dimensions of family life and were associated with family organization, cohesiveness, conflict, organization, and control. In a qualitative study, Horn, et.al, reported that the top coping strategies parents utilized included “gaining information, obtaining support from hospital staff, reprioritizing, normalizing, obtaining support from family and friends, obtaining support from families having a similar experience, relying on inner strengths and beliefs” (p. 118).

Also, each father held the view that the challenges they faced while living with chronic childhood illness were manageable stressors. The majority of fathers did not perceive that they “coped” with illness demands. They defined themselves as actively “managing,” and “dealing with” the challenges before them. In their view, coping did not adequately define their approach to parenting and life with chronic illness. The Double ABCX Model for stress and coping proposes that whether a crisis is experienced results from the definition of the stress event and the interaction of demands and adaptive resources. Stress, then, has been defined as “specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141) or “hardships of the situation or event itself” (Hill, 1949, p. 9).

Furthermore, all fathers described that it was important to them to be involved in decision-making processes, to know that their daily observations and concerns regarding their child’s care were part of a collaborative exchange. Some fathers described subtle barriers experienced in efforts to parent, and they perceived those subtleties stemmed from racial or gender biases as well as economic constraints and constraints of the particular culture of medicine. Encounters with negative stereotypes included presumptions of un-involvement,

exclusion from treatment decisions, questionable hospital admittance practices, and condescending dialogues with teachers and health-care providers. Those roadblocks were viewed as navigable parts of the landscape. Coping strategies focused on the greater good of the child and ranged from “knowing when to be confrontational” to “knowing how to swallow pride.” Fathers described incorporating strategies to speak directly to offending parties or to seek redress higher in the chain of command, to participate actively in schools and within advocacy agencies, and to create an appearance of confidence that commanded respect. Awareness of stereotypical responses did not deter them from the overall goal of involvement.

### Implications for Clinical Interventions

In response to chronic childhood illness, fathers in this study described a variety of ways they were involved as parents and a range of coping strategies helpful to their families. Clinicians are therefore challenged to explore with similar families what is important given their current illness status, and to work effectively with families to define needs and strategies congruent with family goals, expectations, and outcome desires. Based on this study, following are some implications for clinical interventions that may assist in such efforts.

The fathers in this study faced difficult decisions and daily challenges. “Coping” was a word that did not appropriately describe their experiences. The majority defined themselves as “managing” and “dealing with” illness related stressors. Therefore, it is important that clinicians listen to the language of African American fathers and inquire about their definitions and preferred terminology.

“Being there” was a priority for fathers in this study. They worked to achieve effective outcomes despite life and illness stressors. Fathers and their families who appear to cope well may tend to minimize the degree of stress they encounter or choose to focus away from areas of difficulty in order to attend to more immediate needs. It is important that clinicians consider the effect of multiple stressor pile up and collaborate with clients to create a climate conducive to explorations of a range of stressors including insidious encounters with covert and sometimes overt expressions of gender bias as well as racial and ethnic disparities they may encounter. It may also be useful to consider that over-functioning in one role may indicate the need to balance other aspects of personal functioning (establishing self-care routines; monitoring personal health

needs, including maintaining routine physical examination schedules; and seeking help with matters that are not targeted toward illness demands).

Clinicians should also watch for opportunities to identify and to enhance competence. Fathers, for example, described that knowing that their wives worked in partnership with them helped their involvement efforts. The exploration of ways to strengthen the parental alliance would be valuable to clinicians in their work with African American families living with chronic illnesses. Opportunities for enhancement might arise in explorations of potential areas of conflict and may include the following: parental decision making processes regarding the coordination of illness related tasks and regimens; adaptation of parenting styles and strategies in response to illness experiences; couple communication of personal needs for intimacy and distance; couple negotiation of individual tolerance for outside help and information sharing; parental preparedness for the impact of financial stressors and employment related demands; and consideration of sibling needs and stressors.

Fathers in this study also described the importance of their involvement in health-care decisions which included the value of education and information regarding the illness process and the effects of drug therapies; the struggle to balance their desire for optimum health and development outcomes and information from professionals that falls short of their vision for their child; and the desire to plan for long-term educational, medical, and personal needs. Clinical interventions designed to assist African American fathers might consider ways fathers believe they can be actively involved. For example clinicians can direct interventions toward the following: assistance developing health advocacy skills, including navigating complex hospital systems, insurance systems, and communication processes with and among physicians and staff; developing systems of obtaining and maintaining health records, recording day-to-day observations, keeping track of questions about protocol, directives, and developmental issues for use when collaborating with medical personnel and for future reference; taking advantage of opportunities to cultivate a climate of cooperation and teamwork with care providers, which may require taking the role of team member versus team leader; establishing relationships with caring personnel within physicians practices who are willing and able to take time to review directives and to answer questions that may arise when a physician is not available; utilizing the Internet and educational centers at teaching hospitals to gather medical information and to network with

other families; and connecting families with lists of advocacy and support groups and services that may provide assistance during different stages of the illness process.

Furthermore, some fathers experienced that work environments with rigid expectations and gender bias did not support parenting an exceptional child. Clinicians should be alert to provider role strain, potential threats of joblessness, pressures of underemployment and related conflicts that may arise. Interventions aimed at short- and long-term strategies for coping with employment challenges should not be overlooked and should include strategies for the negotiation of time from work to attend to parenting demands. Real and honest evaluations of time demands and the unpredictability of illness demands may help fathers plan and prepare for employment and economic stressors.

#### Study Limitations and Strengths

This study examined a small and selective sample size of African American fathers. The results are not generalizable to any population. The sample of fathers was not randomly chosen. Each participant was recommended to the study because someone else believed they were coping well and involved parents. Studies that involve larger populations of resilient fathers from a range of socioeconomic strata, and racial and ethnic backgrounds would serve to inform research in a more comprehensive manner.

Additionally, this study was limited to the paternal point of view and did not include the accounts of mothers, children with chronic illnesses or their siblings. Including other family members helps to better inform research and triangulations of data. While focus on fathers is informative, greater insight into the family system would include mothers, children, and siblings living with chronic childhood illness.

The strengths of this study far out weigh limitations. First, the voices of five fathers in this study communicate remarkable realities and serve as models for others who share the experience of chronic childhood illness and inquire regarding its complexities and solutions. Second, this investigation is a departure from the acute focus in society and in literature on the shortcomings of African American men and instead explores coping well in the intimate role of a concerned, caring, competent, committed parent. Third, readers of this study are provided an opportunity to examine the assumptions and biases they bring to work with African American families in general and African American men in particular. Fourth, these descriptions by fathers

provide an alternative to mother-focused accounts of family interactions and are important contributions to the study of father involvement in family systems. Furthermore, this study provides an opportunity to learn about illness-related stressors and to examine assumptions regarding families living with chronic childhood illness.

Most importantly, this study has provided an opportunity to appreciate a complex set of life struggles and the experience of families willing to share intimate aspects of their lives. As several fathers aptly commented upon completion of the interview process, “I hope this helps someone else.”

#### Suggestions for Future Research

The complexities of the experiences presented in the study suggest many avenues of future exploration. Research of African American fathers and their families could, for example, involve larger samples sizes of men of similar and/or more economically diverse populations. The sample in this study was perceived as involved and coping well. Future research may endeavor to explore the experience of men involved in ways not readily observable by outsiders. Further research may also examine family dynamics, the experiences of mothers, children diagnosed with illness and their siblings, and the impact of those interactions on involvement.

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## Appendix A

### LETTER OF INFORMANT RECRUITMENT

Dear Mr.(s) Potential Referring Source:

Thank you for your interest in the research I am conducting that involves African American fathers of children with chronic illness. I am a graduate student at Virginia Tech investigating this very important topic area. The central focus of this project is to gather stories of African American fathers' involvement in the care of their chronically ill children. I ask that as you consider contributing to this project in one of two ways: considerer personally volunteering to be a potential study participant; or, consider recommending a father that you believe may be an interested in participant.

I have attached a synopsis that highlights the aim of the study. It includes a general description and can be passed on to potential candidates or other professionals involved with families living with chronic childhood illness. I will contact you in the next few days to answer questions that you might have about this project and to talk with you about candidates you would consider referring for this study.

If you would like to reach me before than, I can be reached at (222) 123-4567. Thank you for you time and consideration.

Sincerely,

Researcher  
Master's Candidate  
Virginia Tech at the Northern Virginia Center  
Falls Church, Virginia  
(222)123-4567

Dr. Advisor  
Thesis Advisor  
Department of Human Development  
Falls Church, Virginia  
(333) 987-6543

## Attachment to Letter of Recruitment

### **Title of Study**

Toward a Greater Understanding of Fathering: How African American Fathers Experience Parental Involvement and Participation in the Care of Their Children with Chronic Illnesses – A Qualitative Study

### **Investigator**

This study is being conducted by Researcher, candidate for the master's degree in Marriage and Family Therapy at the Virginia Polytechnic Institute and State University at the Northern Virginia Center and Dr. Advisor, faculty advisor.

### **About The Study**

- The central focus of this project is to gather stories of African American fathers' involvement in the care of their chronically ill children.
- Fathers participating in this project will share information about their contributions to the well-being and development of their chronically ill children and families.
- The chronic illnesses studied can be described as illnesses that are “prolonged, do not resolve spontaneously and rarely cure.”
- Fathers will be asked to participate in one or two, one-on-one interviews with the researcher regarding their parenting experience.
- The information provided can be valuable to therapists and others who work with fathers and their chronically ill children and desire to work from a perspective that is informed by African-American men.
- Identities of fathers and their families will be kept confidential.

### **Additional Information**

To inquire about participation in this study, to refer candidates for participation, or to talk further regarding this project contact Researcher at (222) 123-4567 or Advisor at (333) 123- 6789.

## APPENDIX B

### Telephone Screening Questionnaire

1. Have any of your children been diagnosed with a chronic illness? (*Chronic illness in this study is defined as an illness that is prolonged, does not resolve spontaneously, and has a rare history of being completely cured.*)
2. How long has it been since your child has been ill? When was the diagnosis made? What is your child's diagnosis?
3. How do you identify yourself: working class?, middle class?, upper-middle class?, Black?, African American?, Minority?, other ways of being identified?

## APPENDIX C PARTICIPANT INFORMED CONSENT

### **Title of Study**

Toward a Greater Understanding of Fathering: How African American Fathers Experience Parental Involvement and Participation in the Care of Their Children with Chronic Illnesses: A Qualitative Study

Investigator: This study is being conducted by Researcher, candidate for the master's degree in Marriage and Family Therapy at the Virginia Polytechnic Institute and State University at the Northern Virginia Center.

### **The Study and Its Benefits**

This study examines how African American fathers of chronically ill children experience their contributions to the development of their children and families.

The chronic illnesses studied can be described as illnesses that are “prolonged, do not resolve spontaneously and rarely cure.”

The information you provide can be valuable to therapists and others who work with fathers and their chronically ill children and desire to work from a perspective that is informed by African-American men.

A benefit to you may be an opportunity to reflect on what living with chronic illness means to you and to your family.

If you would like, a summary of the findings will be sent to you when the project is completed.

### **The Procedure**

Participate in one or two, 2-hour tape recorded interview(s) with the researcher.

Complete a one-page background information form regarding age, education, child's illness and other demographic data.

Answer open-ended questions and talk with researcher about how you experience the chronic illness of your child and the impact of the illness and stress on parenting.

Allow your interview to be audio taped and transcribed for research purposes.

### **The Risks**

Because of the sensitive nature of the subject matter shared and the potential vulnerability of fathers who are experiencing stress, you may experience discomfort with talking about a topic. You are free to choose not to respond to or discuss topics that make you anxious. A list of mental health and community resource list will be provided you.

### **Your Privacy**

All information you provide will be treated with complete confidentiality by the researcher, her advisor and the transcriptionist. Tapes will be stored under lock and key. Names will be replaced by pseudonyms for use during data analysis and in any oral or written presentation. In addition, every effort will be made to eliminate any identifying features from information

that you provide. Upon completion of the study, all tapes pertaining to the study will be destroyed.

**Will You Be Paid?**

Other than our sincere appreciation, no guarantee of benefits is being made to encourage you to participate in this study.

**Can You Quit?**

If at any time you change your mind about participating in this study, you can withdraw your consent and cancel participation.

**Research Approval**

This research project has been approved, as required, by the Institutional Review Board for projects involving human subjects at the Virginia Polytechnic Institute and State University and by the Department of Human Development.

**Participant's Responsibility and Permission**

I voluntarily agree to participate in this study. I have read and understand the informed consent and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent for participation in this study. I realize I have the right to withdraw at any time without penalty.

Should I have any questions about this project or its conduct, I can contact any of the following: investigator (222) 123-4567; faculty advisor, (333) 987- 6543; or Chair of the Virginia Tech IRB (111) 222- 3333.

\_\_\_\_\_  
Participant's Signature Date \_\_\_\_\_

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Witness Date \_\_\_\_\_

APPENDIX D

Participant Family Information Form

- 1. Age: \_\_\_\_\_
- 2. Marital Status: \_\_\_Single \_\_\_ Married \_\_\_ Divorced \_\_\_ Widowed \_\_\_Separated
- 3. Total Number of Children: \_\_\_\_\_  
Ages of Children Living With You: \_\_\_\_\_
- 4. Number of Chronically Ill Children: \_\_\_\_\_  
Ages of Chronically Ill Child(ren): \_\_\_\_\_
- 5. Your race or ethnicity: \_\_\_\_\_

To what extent do you identify with your race or ethnicity?

- |                        |                   |                     |                |
|------------------------|-------------------|---------------------|----------------|
| 1                      | 2                 | 3                   | 4              |
| Do not identify at all | Slightly identify | Moderately Identify | Identify a lot |

- 6. Your occupation: \_\_\_\_\_

Household Income Level:

- (circle one)
- Less than \$10,000 per year
  - Between \$10,000 - \$30,000
  - Between \$30,000 - \$50,000
  - Between \$50,000 - \$70,000
  - Between \$70,000 - \$90,000
  - Greater than \$90,000

- 7. Your highest level of education: Elementary Education; High School Graduate;  
(circle one) Vocational Training; College Graduate; Masters Degree;  
Doctoral Degree

- 8. Diagnosis of child with chronic illness:

\_\_\_\_\_

\_\_\_\_\_

## APPENDIX E

### Guiding Interview Questions

1. Before you became a parent, what were your perceptions of fatherhood? Did your thoughts on what it meant to be a father change once you realized your child was ill? If you also father non-chronically ill children, does your experience of what it means to parent them differ in comparison to your chronically ill child? Does your perception of fathering differ from the way others view you?
2. Describe the demands placed upon you as you father a chronically ill child. How are you involved in your child's life? Describe times where it has been difficult for you to maintain a relationship with your child, your spouse/significant other, your extended family because of the diagnosis? Describe ways in which your work in the home and on the job has been affected.
3. Describe your experience with others (the child's mother, the extended family, the health care system, other professionals) that support you in your efforts to be an involved father. Also describe your experience within these relationships that make it more difficult for you to be an involved father with a chronically ill child.
4. Describe external resources (extended family, community resources, religious organizations, schools, professionals, etc.) that support you, your chronically ill child and family. How have you used those resources? Can you describe how you came to the decision to reach out to or not reach out to external resources for support (friends, church, community services, extended family, schools, medical professionals, etc.)?
5. Can you describe internal resources you have employed in fathering a chronically ill child? How did you learn to utilize those resources?

6. Describe the tasks associated with your child's illness demands. Describe ways that you have learned to cope with your child's diagnosis and the associated demands. Would you use the word "coping" to describe your experience? How else might you describe or characterize your experience facing the demands of fathering a chronically ill child?
7. What advice would you offer professionals who work with African American fathers of chronically ill children?
8. What questions haven't I asked that you believe are important?

APPENDIX F

Research Transcriptionist's Confidentiality Statement

**Title of Study:**

Toward a Greater Understanding of Fathering: How African American Fathers Experience Parental Involvement and Participation in the Care of Their Children with Chronic Illnesses: A Qualitative Study

**Investigator:**

This study is being conducted by candidate for the master's degree in Marriage and Family Therapy at the Virginia Polytechnic Institute and State University at the Northern Virginia Center and faculty advisor.

**Confidentiality Pledge:**

I understand that the information being collected in this study is sensitive, personal and is strictly confidential. I hereby pledge that I will keep all such information confidential. I also pledge to withdraw immediately from further involvement with a particular interview if I discover that the participant whose interview I am transcribing is an acquaintance of mine or is known by me in any way.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness' Signature

\_\_\_\_\_  
Date

## Vita for Symone Colquitt

### EDUCATION

#### **Master of Science in Marriage and Family Therapy, 2002**

Virginia Polytechnic Institute and State University  
Falls Church, Virginia

#### **Bachelor of Arts, Journalism, 1980**

Indiana University  
Bloomington, Indiana

### CLINICAL EXPERIENCE

#### **Family Counselor**

Bowie Youth and Family Services

**July 2000 – Present**

Bowie, Maryland

Provide counseling and related services to youth ages 3 – 18 and their families: school and juvenile justice related problems; child behavioral difficulties; stress management; parent skills training; anger management; domestic violence; adjustment to separation, divorce, and re-marriage; chronic illness in families; grand parent and single parent matters; relationship enhancement skills training. Conduct group and individual filial play therapy trainings for parents. Facilitate family therapy intern training: supervision and didactic instruction in general systems theory. Conduct high school leadership training workshops.

#### **Family Therapist Intern**

Bowie Youth and Family Services

**September 1999- July 2000**

Bowie, Maryland

Therapist for families, individuals, and youth: family, school, and community related problems. Received training and direct supervision in Solution Focused Therapy. Applied theory to practice in work with single parenting children and adolescents; step-family conflict; anger management; mother/daughter relational difficulties; divorcing family adjustment; families managing depression and conduct disorder.

#### **Family Therapist Intern**

Center for Family Services

**September 1998 – December 2000**

Falls Church, Virginia

Provide family counseling for children, adolescents, and families: domestic violence, family relational conflict, anger management, infidelity, depression in adolescents, and other mental health issues.

### PROFESSIONAL MEMBERSHIP

American Association for Marriage and Family Therapy

Current

### PROFESSIONAL TRAINING

Relationship Enhancement: Brief Couples/Family Therapy

May 2002

Internal Family Systems Training

May 2001