

## Chapter 11

# **THE VOICES OF TEENS LIVING WITH HIV: HOW YOU CAN SUPPORT US**

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### **The Gift of Love**

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Love is a gift  
That enables us to care  
A feeling that we give to those we hold dear  
Without love there can be no peace of mind  
Love is a force that releases the bind  
Love is a feeling that captures the soul  
A special feeling that never lets go  
Love is an emotion that you should let grow  
And share with others  
Even those you don't know  
For giving love under any light  
Purely shows that your heart shines bright

The Burgess Clinic is an HIV/AIDS specialty clinic that operates within the Division of Adolescent Medicine at Children's National Medical Center in the District of Columbia. One of the oldest, largest, and most comprehensive care clinics in the United States of America, the Burgess Clinic is a model of integrated multidisciplinary care. The integrated HIV services include medical care and treatment, psychological evaluation and psychotherapy, case management, risk reduction education and counseling, nutritional assessment and care, and research opportunities. The Burgess Clinic is dedicated to educating and treating adolescents to prevent the spread of HIV/AIDS.

To give a human voice to our work, we invited a group of adolescents from the Burgess Clinic to share their personal and psychosocial experiences of living with HIV. Focus groups and semistructured interviews were conducted, which resulted in the following themes: social support, disclosure, HIV-related needs and challenges, and the role of spirituality and religion in coping. As a result, youth-specific suggestions for peers and others who have been recently diagnosed with HIV are offered along with advice for family, peers, teachers, health care providers, and clergy, with regard to how they can support teens living with HIV/AIDS. We review the youth's experiences with HIV-related research, and close the chapter with recommendations for advocacy, empowerment, and education.

## **SOCIAL SUPPORT**

HIV/AIDS is associated with social, psychological, and behavioral stressors that significantly affect coping patterns, psychosocial factors, and overall health status. Youth living with HIV identified the significance of social support in their survival, coping, and general livelihood. The presence of informed, nonjudgmental understanding and reliable support systems has resulted in positive outcomes for many HIV-infected youth. Conversely, the lack of understanding, acceptance, and positive social support has also been correlated to deleterious social and emotional effects.

### **Who Do You Look to in Your Life to Give You Support with Your HIV Status?**

"My mom, mainly because she is pretty much the only one that knows."

"I would say my mom because she is the only one in my family that is infected and she is the only one in my family who accepts me."

"My sister because she understands me and my best friend because I have known her 11 years."

"My mom, because she is the only one who knows and she has been there since the beginning, when I first found out."

"I haven't told my parents. The only person I told was my best friend, because he told me he was HIV-positive. We got into a conversation about that. I have a great support network, which includes the advocates here at Children's."

"I would really say myself because I don't have a lot of support systems in my family."

"My family."

"Myself. Since I have been told, I have basically been on my own. I can't depend on my family. I don't use drugs or drink a whole lot."

"Nobody, because I really don't have anyone. But, there is this one lady at church that I can talk to or ask questions because she is positive and works in the field now."

"Honestly, I might go to my mom or brother for some things, the church for other things. I might go to God for some things I really need, but not all the time the way I am supposed to—so I'm learning how to go to Him. But

there is no one person I go to for everything, support with financial, spiritual, emotional things.”

### **Since Receiving Your HIV Diagnosis, Who in Your Life Has Been *Most Supportive*?**

“My boyfriend, he’s very supportive. He listens. He asks me what do I think I should do. He doesn’t tell me what to do.”

“My Mom. I can’t explain it, because she always supported me in whatever I did. “Mainly she gave me the ‘your life is not over’ speech, ‘you can still live on,’ ‘you have a lot to look forward to.’ I knew a lot of that before, but she reinforced that.”

“My Mom. She has common sense. I’ve never been hospitalized. I’ve always been healthy. She says, “I’ve been blessed.” I’ve never missed school. I can get up in the morning and do what I want to do.”

“At one point in time it was my Mom, but me and her had a falling out. Now, it’s more my sister or my boyfriend. They bring sunshine into my life. They’ll be like, “You’re blessed you don’t get as sick as your other friends. If you are in the hospital, it’s just for normal things.’ I shouldn’t take it for granted.”

“The two most important people have been my best friend and [my care advocate]. He just came up to me and told me. ‘[I’m] there to listen. We can talk.’ And the care advocate here, he makes sure I do what I need to be doing and just taking care that I am a balanced person. They’ve been real supportive in that way. My best friend’s whole approach is not judgmental and not coming to you in a negative way. ‘You need to take care of yourself. This is what you need to do.’ I was real upset and he helped me keep a positive attitude. It crossed my mind to tell my family, but it crossed real quickly. I was having a hard time dealing with it myself so I wasn’t about to put a burden on them. So when my friend told me, I didn’t feel like I was putting a burden on him.”

“My best friend’s aunt was very supportive of me. Even though I didn’t tell my best friend, I told her aunt, because she was in the same situation as me. She was in a nursing home before she died [of AIDS]. She told me about her situation. She told me that she didn’t think that she could live with it. That’s why she let herself go and didn’t take her medicine. She told me that I could do better for myself. I was there when she passed.”

“I would really say the staff at Children’s. I am always in their face. I know I can come to anybody and they help me.”

“People who aren’t in the same situation can be helpful too.”

“Me—I just feel like I have to worry about being healthy and doing what I need to do to survive and stuff.”

“Myself. My first social worker was good, but I didn’t come here. I come a lot more now than I did because my advocate is always calling and nagging me. I don’t want to hear her mouth so I come in and take care of my business.”

“For me, I don’t think that there is one person. I meet people in life that are supportive along the way that have been encouraging. Some people might have been there for one year or two to three years that have said positive things that have been encouraging to me.”

## DISCLOSURE

Disclosure of one's HIV diagnosis may be one of the most challenging experiences for HIV-positive teens to negotiate. It is common for adolescents to experience feelings of shame and guilt regarding their infection, which may result in a downward spiral of isolation, fear, discrimination, and depression. The decision to disclose to family members, friends, and sexual partners is a complex issue that requires sensitivity, support, and understanding. The individuals, who help facilitate the disclosure of the youth's HIV status to important people in the youth's social and personal networks, must consider the benefits and potential detriments of such disclosure. Barriers to disclosure and social support strategies need to be identified in advance.

### What Was Your Best Experience When You Shared Your Diagnosis with a Family Member or Friend?

"I was just relieved. Before I told anyone I felt like I was in a box. I couldn't sleep. I was like, 'Who can I tell?' I wanted to tell my grandmother, but when I called her she wasn't home. I went to my mom's house. My mom just got back from work. My little brothers and sisters were out with their father. We went down and had dinner. We talked about it. I think my mother about passed out, once she heard the words coming out of my mouth. She got up and walked out of the room. She went to the basement. I thought she was going to get a bat. I had to go by the front door, so I could run you know (laughing). She came back. She hugged me for about two hours. She was hurting me. She was suffocating me. Her bosoms are big, you know."

"Well it was when I was talking to my best friend. It was definitely relieving. To me, it definitely made a difference that he could relate. It was a real big shock. We had known each other for 11 years. We had worked together. He would have been on my short list of people to tell. He just told me [he had HIV]. I thought there ain't no better time than now. It made me feel better about the whole situation myself, too. Other people are living with it and are normal and living their everyday life. They are not letting it run them. It can have a positive impact on your life."

"Mine was when I told my first love. It was because I really liked him. We both had the same feelings for each other. He really did care about me. Our relationship grew more. He had a damn good response."

"The best experience I had was telling the whole school. I came into it thinking it was going to be a negative experience. They were treating me well. And it was high school students and they were helpful and supportive at the same time. I am just saying that I am very surprised that high school students took it in a mature manner. It was more so [that the] teachers who were ignorant than students. There were a lot of teachers who said, 'What gave me the right to go on their morning announcements and tell the whole school?' They even complained to the principal and hounded the guidance counselors. It was still a positive thing, because a lot of people who were not educated about the subject became educated about it."

“I have not had any good experiences. My aunt tried to be there, but she was too nosy. She would always ask me about what I was doing and if this boy knew that I was positive.”

“For me, a lot of people were more accepting than rejecting. However, I do wonder to this day, I can hear my aunt say, ‘Y’all better stop hanging out there with those girls before you catch that stuff.’ I’ve had more good experiences than bad.”

## **HIV-RELATED NEEDS AND CHALLENGES**

With respect to treatment and care, HIV/AIDS-related needs for infected individuals are similar to those of other individuals living with chronic illnesses. An expressed need of young people living with HIV/AIDS is that of a supportive help system, for example family and peer acceptance, healthy emotional attachments, basic living necessities, spiritual and psychosocial outlets. Some challenges of living with HIV/AIDS can be directly connected to the disease itself, such as adherence to antiretroviral therapy, resistance to medical treatment, and the mental ability to deal with the illness itself. Challenges also include stigma, which can prevent adolescents from obtaining proper care. Once adolescents are diagnosed with HIV, education and treatment may encourage them to use programs.

### **What Are Some of the Issues That Teens with HIV Need Help With?**

“Keeping doctor’s appointments. There’s so many of them. Run these tests. Take this assessment. You really don’t have a clue what’s going on. It took me a long time to understand about my T cells. Instead of just saying it in doctors’ terms, say it in regular terms.”

“One, I say is that they need to know exactly what this disease does to your immune system . . . bones, muscles what organs are affected. They need a support group, some other peers that are experiencing it too, that can help them. They need help with taking medication and have a person that will help them understand the medication and what it does and just send them home with a bottle of pills to take. Also, they need reminders of doctor’s appointments and just encouragement.”

### **How Can Health Care Providers Help?**

“Make sure [the] family understands, too. It goes back to having a support network. I might forget about my doctor’s appointment. Or a care advocate [may say], ‘You know you have an appointment in a month? You know you have an appointment in three weeks? You know you have an appointment in two weeks? You know you have an appointment tomorrow?’ Call us and remind us about our appointments.”

“Just be there for them and don’t always try to give answers. Because you can’t always answer every question. Sometimes you just got to be there and listen.”

“Let me decide when I want to come in and make my own appointments.”

“Hire more peer support, more youth. Just because they are talking to their social worker or doctor don’t make the assumption that they feel comfortable or mentally related to the social workers. Bring more youth on to the team or HIV-positive youth, not to say that just because they are positive or youth that they will be able to relate but they may feel more open to communicate than adults. Will they do that? I don’t know. But that’s my suggestion.”

## **THE ROLE OF SPIRITUALITY AND RELIGION IN COPING WITH HIV-RELATED ISSUES**

It is characteristic for people faced with a life-threatening illness to search for meaning, understanding, and coping mechanisms to deal with their circumstances. The search for meaning often leads some to search for spiritual and religious answers. For some, their spirituality or religiosity serves as a protective factor and contributes to their ability to cope effectively with their HIV status. However, others have questioned, ‘Why me?’ with regard to their infection, which they associate with punishment. Individuals’ attributions and faith may have an impact on their mental health, disease progression, and long-term survival. Therefore we believe that it is imperative to comprehend and begin query into the youth’s spiritual and religious coping styles.

### **How Does Spirituality or Religion Impact Your Life and Coping?**

“[I] pray and read the Bible.”

“That’s my reason behind everything. I can’t explain everything. I just go to God and say, ‘You know the reason, the reason behind everything.’ Otherwise, I would be all stressed out so I just take it to God.”

“I believe in God. But I am not sure if this is right. I mean, how come I have to have a disease, you know?”

“Sometimes I throw spirituality up. I believe that I am going to live a long life, I believe I have a purpose and the purpose is to help youth do something . . . HIV can be a mind boggler, it can bring fear, low self-esteem and depression based on the things you hear. I know I’m not going anywhere and am going to be here for a long time so I just brush it off. I believe that God’s got something better for me.”

“Honestly, sometimes with me, I question whether I am going to be healed, ‘Okay God you are a healer and why can’t you heal me?’ Now I view healing differently. I see other people living with cancer and other things. God can heal the body at the same time there are different forms of healing, physical, mental or spiritual healing, and it is knowing what God has done for you. I know that God is a healer and I believe that I will be healed, that I have a purpose. I may have difficulty taking medication and wonder about whether I will be resistant or something. But, I am not leaving this world until God has finished the purpose that he put me here to do.”

## **ADVICE FOR FAMILY, PEERS, TEACHERS, HEALTH CARE PROVIDERS, AND CLERGY**

Adolescents living with HIV/AIDS express the need for their support systems to be more active in their lives. This need was most pronounced at the time of diagnosis. Youth are also concerned that their support systems try to understand the difficulties of managing a chronic illness. This includes finding a doctor with whom they are comfortable, someone to help them schedule medical appointments, and having a professional explain HIV/AIDS to them in terms that are practical and easily understood. It is important for support systems to inform young people of their options and invite them to collaborate in their treatment planning. For teens diagnosed with HIV/AIDS to maintain medical care, it is essential that adolescents have consistency, feel supported, and are given positive reinforcement and encouragement by those in their support system.

### **What Advice Would You Give to Parents When Attempting to Be There for Someone They Care about Who Was Recently Diagnosed with HIV?**

“First is definitely just listening and being more educated about it. While I haven’t shared it with my parents, part of it is [that] I don’t want to put an emotional burden on them. The other part is, I don’t want to tell them something and they are going to base their reaction on a lot of ignorant facts they just heard or assumptions. I would be damned if I would eat off of a paper plate or get treated a certain way because of a health condition, because they aren’t educated about it. The best thing is to get as much education about it as you can. Keep an open mind and don’t judge. How it happened is irrelevant. The important thing is that it did happen and how are you all going to work with it as a family and that the person gets the best care possible.”

“I think if a parent doesn’t understand what is going on with a child, they should research it on their own, before trying to deal with it with their child. They might come off bad or the child [may] be offended. Of course their reaction might be, huh! Or in denial. I think they should go to the doctor’s with them and get their questions answered.”

“I was going to say the best source of information is the doctors and case managers and also listening to their child, because most parents don’t know much about it.”

“I think parents should ask their child if it is alright if they disclose their status to someone else, even someone else in the family. I don’t think the parent should disclose about their sickness or any other sickness.”

“When I told my aunt she told me, ‘Don’t tell anybody.’ And then I found out that she told other people in the family. Why is she telling? Why can’t I be the one to tell them? She didn’t even check to see if I was ready for them to know.”

“I think they should have a conversation with their child and their doctor.”

“I think it needs to be a partnership. I think it is important that some family member or someone you are close to is involved. So someone can check in on you and encourage you. One of the most important things for a parent to do is to seek

professional help. It's just as traumatic for the parent as it is for the child. [They both may think], 'Why is it happening to me?' They should sit on the couch or talk to their clergyperson."

"You may have younger sibs who are sexually active. This is an opportunity to educate other family members."

"I love my mother to be involved. She stays on top of them, because doctors will get you to do studies or new medicine and the parent is there to say 'Wooo, what's going on?' If it wasn't for her I wouldn't be here today."

"If you don't have a support system, you have to reach inside yourself. I brought my late significant other with me. I had to be my own mother, my own father. To push myself to go down that road."

"The fact that I don't have someone to hold me accountable is a positive thing. To be honest, [my parents] are ignorant about HIV. That's why I don't want to tell them. Certain members of my family are insensitive. It's already a bad situation and they could make it worse. I don't want to burden my mother. It will hit her hard. If it gets to a point that I do need to tell them, I will. Right now I want to work on educating them, in little bits. So that if I do decide to discuss it, they won't say, 'Oh you been shooting up heroin.' Certain of my family members aren't going to be supportive. I think my parents will be supportive; it's a matter of preparing them for it and not just hitting them with it. Test the waters before I jump in."

"Don't judge; No type of judgment."

"Continue to care, support and give advice. Comfort them and listen. Just be there."

### **What Advice Would You Give to a Brother, Sister, or Friend Who Has Recently Been Diagnosed?**

"It depends on how close that friend is to you. Say you had a friend since third grade and you had HIV since you were born. You didn't really know what it was, because you were so young. I think if it is a long-term friend and you want to have that friend for a long time, you should disclose to them. I would research where she is coming from and what is going on with her. I would have a conversation like we are. So they won't get so emotional or depressed about it."

"Some of the same guidelines as with family as a friend. It's just like if you have a friend who is paralyzed, you can't run track with them, but the mentality of how you treat them doesn't change. I think the consistency is important. Treat them the same way as before. You may not ever go to the doctor with them. Just check on them, 'how are you feeling today?' If they know you have an appointment with your doctor on a Friday, after say 'how did it go?' Let them know that someone else cares. Don't make it the center of your friendship. Don't make it a big deal: 'Oh this is my friend Tony with AIDS.' (Laughter). Like you are only still their friend because you have HIV or with any kind of disease or whatever."

"It's really simple. Just be a friend. I still have school. Don't ask them everyday, 'How is your life with HIV today?' Like if they have a doctor's appointment and you think they should come, ask them to come."

"How would they feel about being friends with someone who is HIV-positive? I would like for a person to tell me. I don't want you being my friend just to give

me sympathy. That's why I don't have friends; I hang by myself and my significant other. I be chillin' in my room and partying."

"Tell them it's going to be okay."

"I don't have friends, but I would want them to treat me the same."

"Listen, be there and comfort them. Don't down them if they are homosexual or something. Just be there to support them with whatever like going to doctor's appointments. Love them no matter what decisions they have made and let them know that no matter what happened there is still life on the other side and that it doesn't have to kill you."

### **If There Is a Teacher That Finds Out a Student Is HIV-Positive, Is There Any Advice You Would Give That Teacher about Being Supportive?**

"Ask the student to be the teacher now. The teacher is now going to be the student."

"This is one I can talk about. I told the whole school on World AIDS Day. A lot of teachers wanted me to teach a class about it. It was really interesting to sit there and see them taking notes and asking questions. It was high school students. And there was no snickering or ignorance. Teach the teacher and the class, because that's real."

"Well I did notice one thing I didn't like is that some teachers wanted to be around me more. Trying to be extra nice and extra sympathetic. One teacher in chemistry passed me because she felt bad. I don't want to be treated differently. Don't give me no A."

"I went to school and no one wanted to learn anything. It was, 'She's got AIDS, don't touch her.' I would go to the pool with my mother and everyone would get out of the pool. My mother cried. I was the first student with HIV to be in a regular school. If a student was sick, they could call and say she shouldn't come to school. Sometimes you can't teach people."

"There is a saying, 'The road to hell is paved with good intentions.' With teachers you may mean the best for the student, they should definitely understand that confidentiality is the key. Don't go talking to others without the person's permission. Let the student guide how to deal with the issue. I may feel differently about my English teacher knowing and my chemistry teacher knowing. I don't want it to infringe on my relationship in class."

"First of all if the teacher don't know much about it I think she should research it and get the facts [about HIV/AIDS] before she approaches you so she won't be afraid and will know what's going on."

"Don't treat the student any differently. Don't give out sympathy grades. Keep it to yourself."

"Just know your place and when to keep things confidential and not to spread their business. Not to treat them different than the rest of the youth. Be sensitive to their needs and at the same time don't give them too many privileges because they are different."

### **What Have Front Desk Staff/Reception Done to Make Being HIV-Positive Easier?**

"One is always friendly and very real with me. We joke. It's not like I'm the patient, but like we are friends."

- “I think the health care staff are really good. They refer to you by name. How are you doing? Are you still working there? It’s a personal touch. You should take vitamins. Just small stuff. They not going to diagnose you or anything.”
- “I’ve been coming to Children’s since I was 3. I’m 19 now. They greet you. They even buy you lunch. They treat me like I am one of their children.”
- “I don’t know—they be nice, but I’m assuming being nice is a part of their job.”
- “Be nice and polite.”
- “They’re just friendly, that’s all. Kept a smile on their face.”

### **What Have Your Doctors Done to Make Being HIV-Positive Easier?**

- “My old doctor, he got to know me. He usually asked me what’s going on in my life. He would ask if there are any questions about my status or if I needed advice about anything. He made me feel like I was an equal. I don’t think he was just doing it because it was his job. My new doctor I don’t know yet.”
- “All of my doctors since I was a baby [lists all of her doctors] they are all wonderful. They treat you like they are your mother, ‘You know if you don’t do this, this is the consequence.’ Even while they are in there giving you an exam, they have a conversation with you like, ‘How is your day?’ Like you are a family member.”
- “It doesn’t seem like I’m a dying patient; doesn’t seem like I’m dying from anything. It’s just like come on in for your check up and do what I got to do.”
- “She asks personal questions. She is nice to me no matter what. She asks my opinions about treatments and gives me time to decide what I want.”
- “Just open. To me they seem caring to me, some of them.”

### **What Have Social Workers, Case Managers, and Care Advocates Done to Make Being HIV-Positive Easier?**

- “My old social worker, she’s no longer on the team. I miss her very much. They are like a buddy system. ‘Do you want to participate in this outing or do you want me to schedule your appointments?’ If there is something going on in the hospital that they think would be good for you, they let you know.”
- “The atmosphere is good. They actually do care about you. They want to guide you and support you in any way they can. They don’t always ask first about our HIV status. They ask about other things, like school and work and how you are feeling in general.”
- “The one thing I love about coming to the clinic is dealing with the case managers and care advocates. They make me feel like one big family. Even though I pick on them, I love them to death. We’re going to spend a lot of time with each other.”
- “My care advocate talks to me every time I come here. I can talk to her like the big sister I don’t have. She’s really nice to me.”
- “I think I have the best care advocate here. He didn’t just drag me in here. I about passed out when they told me I was HIV-positive. My care advocate took me home. He made sure I was all right. I was going to go to work, but he suggested taking the day off, which I did. It’s gone from a professional relationship to a kind

of like a brother relationship. I don't know how I would have handled it. He made sure I was okay, because I had a whole lot on my mind."

"They just give me type of resources that I can use to my advantage to help."

"Remind me of appointments. Sign me up for groups that I can make money for coming to. Buy cards for my birthday. Help me with stuff like finding apartments and jobs."

"Well, I can say one social worker for me, she showed me different avenues for doing things, that I have never seen, like getting us involved in activities. She opened my eyes to things that I was not used to doing, even at home with my own family."

### **What Have Mental Health Professionals, Like Psychologists or Therapists, Done to Make Being HIV-Positive Easier?**

"They can be supportive. I had a nice one. Sometimes they make you think you are crazy, but really you are not. They don't just sit there and say you got this diagnosis, like bipolar disorder or postpartum depression. They listen to you. They listen to your emotions. They ask you what you think is wrong with you and what do you think it's coming from and why. It was helpful. I don't have to see a psychiatrist no more."

"My psychologist helps me when I get a chance to see her. We put everything out on the table. When the session is over I think, 'Damn, I want to keep talking.' She makes me feel that everything is okay. She makes me feel motivated. She's very open. She's not quick to tell me what to do. I'm mostly controlling the whole conversation. To have someone actually listening, I don't get that where I am now. She helps me to see things clearly."

### **What Can the Church or Other Spiritual Organizations Do to Help Persons Living with HIV/AIDS?**

"I would tell them to put more information about it for their young people. Because in church they are like, 'young people are not supposed to have sex until married.' But not everybody waits; so they're not teaching them anything because they're assuming they're going to wait until marriage."

"Be more accepting of everyone."

"Don't be judgmental, like, 'they sinners.' Open some kind of ministry, do something with them. Help the people."

## **THE ROLE OF RESEARCH**

There is currently no known cure for HIV/AIDS, but clinical, community, and behavioral research agendas are focusing on prevention, treatment, health promotion medication adherence, and risk reduction among adolescents. Research targeted towards HIV-infected youth provides opportunities for the participants to: (1) learn information about HIV and how it works,

(2) increase adherence to therapy, (3) reduce transmission risk behaviors, (4) promote healthy lifestyles, and (5) explore end-of-life decision making, to name a few. Many youth stated that research gives them the opportunity to help other teenagers who have HIV/AIDS, as well as those who are not infected, whereas others discussed the burden research places on them and offered suggestions to balance the cost-benefit equation for both the researchers and participants.

### **What Has Research Done to Make Being HIV-Positive Easier?**

“During research studies they help you a lot and educate you about HIV. It’s not just like you are sitting around asking questions and they give you answers. It’s part of a gathering. It’s actually fun, like a party, a gathering. You learn and you have fun at the same time and you get to know more people that are very understanding.”

“I think that research definitely helps with the education part, and the monetary assistance they provide is really helpful for the financially strapped and broke patients like myself. (Laughter). But it’s definitely helpful in coming up for a cure for HIV. It may not work for you but it may change someone else’s life. Being a partner in change for someone else’s life too. I think that’s the great work that they are doing.”

“It really helped me to learn more about my diagnosis with HIV. The research projects, the research assistants, and nurses can also help me to help someone else also. It’s a two-way street.”

“It gives you information about it if you go to a research group and didn’t know about HIV—it gives you more information about it. They also bring the fact that you are not the only person going through this; you might be with other people going through this.”

“It pays me to come in and learn.”

“It just taught me different stuff that I didn’t know about HIV.”

### **ADVOCACY, EMPOWERMENT, AND EDUCATION**

Advocacy is an important part of prevention, care, and treatment for young people living with HIV/AIDS. Advocacy is what revolutionizes policies. Policies and practices can increase or reduce the availability of prevention education or access to effective treatment therapy. Adolescents believe that HIV/AIDS advocacy can be more effective through review processes that include those who are infected or affected combating this epidemic. Also, young people have identified that working with someone who has been diagnosed with HIV/AIDS is helpful. The basic needs of HIV/AIDS advocacy for youth are advocates who are open-minded, listen, make the young person feel comfortable, and most important, are informative.

Advocacy also works hand in hand with empowerment. Empowerment includes education and skills building. Youth infected with HIV/AIDS would

benefit from educational workshops that create awareness and prevention methods that can reduce the transmission and acquisition of HIV/AIDS. Education dispels myths and counters misinformation about HIV/AIDS. Youth would like HIV/AIDS education to be easily accessible to all populations to increase its effectiveness. Educational materials should also be straightforward, culturally relevant, inoffensive, and nonjudgmental. Advocacy, empowerment, and education can help sustain proper use of information regarding HIV/AIDS. These are powerful tools for adolescents who are infected and affected by this epidemic. These tools can help them make better choices.

### **What Can Health Care Providers, Advocates, or Social Workers Do to Help to Get Young People Who Have Just Been Diagnosed More Engaged in Care or Keep You Engaged in Care?**

“Phone calls, just like reminders. Letting you know ‘Okay come in.’ Sometimes the care advocate will just have you come in and just check in and that physical contact. See you in person and keep you informed about what’s going on and open you up to different experiences and other educational opportunities, like a trip that’s coming up or a research project.”

“I would say making it feel like it’s one big happy family, because it really helps me too. Helps me to be on time and keep my appointments. That’s what really makes it helpful. Interact, laid back. It’s relaxed, not so professional all of the time, not that you are not professional.”

“Try to talk them into coming without forcing them to come in. Let them deal with everything the way they want. Comfort and be nice to them.”

“They need to have more activities involving the youth and one thing that I know, for a person like me that wants to go into this field, they don’t have too many opportunities. Have more peer-to-peer or youth functions. Give them a little stipend or incentive to work somewhere or learn something. Give out some money for some youth jobs in HIV.”

### **What Should We Do to Help Teens Who Have Received Their Diagnosis, but Are not Coming Back in for Care? How Can We Get Them Engaged in Care? Should We Leave Them Alone? Become More Aggressive?**

“I think you should be very persistent and stay on top of the person, but not to the extent that you are badgering them, more like let’s go out and talk for lunch and talk. So it’s not so much surrounded around HIV status.”

“That’s the only way. I got dragged in here. I got tricked. (Laughter). By the time I realized I was coming in, I was here. Once you see someone else who doesn’t have to care [but] goes out on their own time [and] not because they are afraid you are going to die. It goes back to training. Certain language, manners, make it easier. They have a flow, if they do it right. General expectations can make it easier and comfortable, outgoing and aggressive approach, if you do it right, is the most beneficial approach. Use an aggressive direct approach. When I look

back I am definitely glad. The case manager thought about the situation. I could tell he planned it out. He only went at it one time. He put it out there. I did a Friday group. It blew my whole weekend, but by Monday I came in here. If I hadn't come in, in hindsight, I could have not cared and said it is not that serious and put others at risk, too. I think it was definitely a positive thing. He reached out to me."

"It may take some time for people, just call and talk to them about how it would be better to come in. Call to see how they are doing. Not something you need to do everyday and not something you have to talk with everybody. A person doesn't want to explain what's going on with themselves, because they think it is going to get out. They are afraid someone else is going to find out. That's why I didn't want to come in [after diagnosis]."

"Not totally leave them alone because you don't know what's going on in their head. I would check up with them. You got to let them make the decision to come back in for care. 'What they say in MI [motivational interviewing]?' Roll with the resistance."

"Find a way to make coming here fun. Don't be negative. Tell the truth no matter what."

"First they need to give more information up front when they are doing the counseling and testing. Organizations need to make sure they are giving information, getting information from people during the counseling and testing session, and have people willing to go out and find those that came to get tested, but did not get their results or are not following up with care."

## **What Can We Do to Encourage More Young People to Be Tested and Learn about Their HIV Status?**

"Show them that it's not as hard as it may seem and it's not the end of the world. It's a new beginning, by not making it look so scary and complicated. You're sick. It's a blood disorder, just like any other sickness. It's a sickness—more terminal, more severe than others. I don't think that people should look at it the way they look at it. I think they should look at it like cancer, just another way of getting it."

"A lot of times, the people providing the tests are doctors who make it more complicated and scary than it needs to be. Don't walk in and find out if you have AIDS. Just make it as simple and as less threatening as possible. You are going to have people staying away and not come in, if they feel threatened. People look at HIV/AIDS as a death sentence. If I go out and say something to somebody about getting tested for syphilis or gonorrhea or other STD, they may come in because there is a cure for those diseases. Because of the perceived death image and no cure and the stigma attached to HIV/AIDS, people don't come in. You need to let them know it is not a death sentence and also that nothing can be wrong with you. Also there is a stigma. You can learn something and then you can protect yourself and others, so that it won't happen to you."

"You could come in and nothing could be wrong with you. It's beneficial because it can protect you and others."

"Some people might see it as a death sentence or something, let them know it doesn't mean that they will die."

"Use nonoffensive ads. Be honest and ask for what you want. Slogans are annoying. Don't use one mode of transmission as focus for the whole commercial."

“Proper advertisement. You got to do something exciting that’s going to bring the youth out, like some kind of party with a go-go band. Entice them, and when they get out have people with flyers or something. Offer them an incentive to come in and get tested.”

### **Is There Anything You Feel Other People Can Do to Make Life Easier for Young People Who Are HIV-Positive?**

“Try to educate themselves more about the situation. Don’t criticize a person about what’s going on with them, without knowing what’s going on with them. When people think about HIV they think, ‘You got it from having sex.’ One way or the other it was your fault. That’s what my mother told me, but I also told her you really need to look into this disease before you blame me for the situation.”

“Give them unconditional love.”

“Just learn more about it!”

“Be supportive no matter what. Never betray that person. Never give up on them.”

“Just watch what they say out of their mouth, get educated because it may be someone in your family. Be a support system and just love them. Try to be there for them.” [For those who are HIV-positive] Try not to stress themselves out. Try to work on your thinking patterns. Because for me, I used to have negative thoughts, growing up so long in the street, trying to get over on people. But I can’t go into a job interview with that same mentality. So basically changing their outlook on life, not viewing the situation as a negative like they are going to die.”

In this chapter, we presented the vital voices of teens living with HIV and presented their suggestions for medical, mental health, and psychosocial support. The impact of social support has far-reaching implications for the development of culturally sensitive and contextually informed health promotion strategies, positive coping, and resilience among HIV-infected adolescents. Although the HIV/AIDS pandemic is having a disproportionate impact on adolescents, especially those of African American heritage, it is our hope that pathways to prevention, treatment, and care are moved from the margins of community, interpersonal, social, and political discourse to the center stage of our mental health and medical priorities.

### **NOTES**

We express gratitude to the youth who contributed to this chapter by sharing their personal information, feelings, and suggestions about how others can support teens living with HIV/AIDS. The entire Burgess Clinic and Adolescent Health Center staff at Children’s National Medical Center is essential to the care and treatment of the youth living with HIV. Mr. A. Keith Selden is gratefully acknowledged for his assistance in conducting the focus group.

This transcript has been edited to reduce repetition and to protect the privacy of the participants. Although the names used in this transcript have been removed, the integrity of their messages is maintained. The messages of our predominantly African American adolescents from the Burgess Clinic, like those of Jesus and the Dalai Lama, are simple yet powerful.