

Chronically Ill Adolescents as Health
Care Consumers

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In the past year we have conducted a series of pilot studies with older adolescents who have cancer or diabetes. The culmination of this work was the adolescent panel session, Adolescents Speak for Themselves, held during the Bush Conference: Chronic Childhood Illness: Policy and Practice, University of Michigan, September, 1984.

These intensive personal and group interviews have signaled some of the common issues chronically and seriously ill young people face as well as some of the unique disease-specific reverberations. For instance, it is clear they must deal with all the typical developmental tasks of late adolescence, such as separating from their families of origin, establishing intimate peer relationships, and solidifying a coherent sense of oneself and one's future, including school and career plans. Each of these tasks may take on a special character for chronically ill adolescents, however,

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as their medical or psychosocial reality alters the developmental process, or as others' reactions impede familial separation and intimate social relationships (Hamburg & Inoff, 1983; Hauser, et al, 1979; Kellerman & Katz, 1977; Zeltzer, 1978).

All older adolescents also must begin the task of becoming an independent health care consumer. This developmental task assumes critical and immediate import for those who have survived childhood with a chronic disease. They must undertake the independent negotiation of medical care. This task includes initiating and maintaining satisfactory relationships with health care providers and assuming personal responsibility for complying with a medical regimen and monitoring their own care.

The independence of this negotiation signals their transition from late childhood and from the situation in which parents arranged their access to, use of, and compliance with medical care. The negotiated character of their relationship with medical care, and the fact that they may conduct such negotiations in a manner (or even location) quite different from their parents, signals the beginning of an adult relationship with providers. And the medical care aspect of this independent negotiation signifies the continuing need for chronically ill adolescents to improve the functional outcomes of their illness, both in medical and psychosocial terms.

Background

Estimates of the prevalence of chronic childhood disease in this country range from 10% to 20%, depending on the definitions of chronic disease and the sampling techniques used (Haggerty, 1983). While incidence rates and prevalence rates at birth have remained relatively stable, the

early death rates for serious illnesses such as cancer and cystic fibrosis have significantly decreased and the survival of all chronically ill children into young adulthood has dramatically increased (Gortmaker and Sappenfield, 1984).

As recent advances in medical care have dramatically extended the survival of children with a variety of chronic diseases, ill adolescents, their family members, and health care providers must now address issues of improving function during the transition to young adulthood. While there is a critical need for interventions to assist older adolescents and medical caregivers with this transition (Gortmaker and Sappenfield, 1984), there currently is no careful documentation of this age group's development of independent relationships with medical care systems. Moreover, across all specialty pediatric clinics there is a lack of preparation for young adulthood and the independent negotiation of health care by older adolescent patients (Barbero, 1982).

Psychosocial research on chronic illness in adolescence has traditionally included a broad age range without regard for the distinct stages of adolescent development (Hamburg, 1974). Although there has been some anecdotal discussion of the impact of chronic disease in late adolescence (16-22 years), no empirical studies of this age group's need for health care services have been carried out (Gortmaker and Sappenfield, 1984). Moreover, relatively few studies have compared the experiences of youngsters with different chronic diseases. Those cross-disease reports that have appeared have relied primarily on pre-structured and standardized instruments to gauge adolescents' responses to issues researchers have selected and framed for them. Thus, they lack phenomenological validity

and fail to provide a rich sense of the issues adolescents themselves feel they encounter. Effective planning of medical and psychosocial interventions with this transitional age group must be grounded, at least in part, on adolescents' own experience and reality.

Haggerty (1983) has argued that research on improving the "disability" or dis-function often associated with chronic disease deserves the highest priority. "Containing the disability", or minimizing the negative psychosocial sequelae of chronic illness, may extend to medical care itself, as when interactions with health care providers and expectations for compliance with medical regimen become ongoing stressors affecting the mental and physical health of chronically-ill individuals (Stein and Jessop, 1984). Since continuity of care and compliance with treatment regimen are critical to "wellness" outcomes in chronic illness (Grave & Pless, 1976; Hamburg, 1983), it is imperative to understand how older, ill adolescents experience and manage these issues. With such understanding, we may be able to design and implement innovations in care.

Methods of Inquiry: Focus and Participants

In this paper, older adolescents and younger adults speak for themselves about coping with medical care. Data were gathered primarily using a semi-structured group interview format, in which two groups of from 2 to 4 youngsters each met for a 3-hour period. These discussions were taped and transcribed for an inductive and thematic analysis.

We have organized the conversations of these young people around six issues they emphasized relating to their interactions with medical care systems:

1. Reactions to diagnosis
2. Medical treatment regimen
3. Experiences in hospital and clinic and relationships with medical care providers
4. Financial concerns related to medical care
5. Advice for other youngsters
6. Negotiating an independent relationship with the medical care system

As we analyzed these issues in the data, we have placed them in relation to the context of reports of the experiences of adolescents with chronic and serious illnesses (Farquar, 1980; Hauser, et al, 1979; Kjosness & Rudolph, 1980; Orr, Hoffmans & Bennets, 1984; Pendleton, 1980;).

Dialogue and excerpts that follow were contributed with fully informed consent from six young persons; all names have been changed to protect the privacy of these research participants:

Gary is 15 years old and was diagnosed with acute lymphocytic leukemia at 9 years of age. He had been in remission for 2 years but has relapsed and is currently back on chemotherapy. Gary is in the 9th grade and comes from a rural family of 4 children, of which he is the youngest.

Rachel is 19 years old and at 16 years was diagnosed with cancer of the throat and stomach. She is now in the middle of a prescribed chemotherapy treatment regimen. Rachel is living in an apartment near the hospital, away from her family who reside in a distant part of the state. She is planning to marry in one year and currently takes several college courses.

Karey is 18 years old and was diagnosed with cancer of the pelvis at 15 years. She lives at home and is enrolled in her first year at a community college. Karey is also currently undergoing outpatient chemotherapy.

Bill is 24 years old and was diagnosed with insulin-dependent diabetes at 10 years of age. Bill is currently a second-year medical student and lives with roommates near the university.

Carla, 16 years old, is a high school senior who was diagnosed with diabetes at 2 years of age. Carla lives at home some distance from the hospital with her parents and brother.

Laura, 23 years old, was diagnosed with diabetes at 12 years of age. Laura works for a consumer diabetes organization in the state.

Ill Youth's Experiences and Perspectives

Reactions at Diagnosis: "What do you remember about first becoming aware that you had your illness"?

Reports from various studies confirm that the diagnosis of a chronic and serious illness is a shocking and stressful event for children and their families (Adams, 1979; McCollum & Schwartz, 1972; Ross, 1978; Meadows, 1968, Hamburg & Inhoff, 1983, Farquhar, 1984, Jacobs, 1982). At this point in time young people must affect a major transition, dealing with diagnostic information that mandates new definitions of self and family life. The strain of the diagnostic period, and of initial adaptations, is well-reflected in the following comments:

Karey

I had a really hard time going to the bathroom so I told my mom. I didn't know what the problem was. So I went to our pediatrician and he says, "We all get pimples on our fanny, now here's some cream" and he sent me home. The specialist said that tumor doubled in that three weeks that I waited before going to the emergency room. So, that really made me mad. Cancer was probably the last thing I thought I had.

Gary

I'd been having stomach cramps for quite a while and my parents had taken me to different doctors. They just couldn't find anything wrong. And they took me to a pediatrician, and the next day he called and said that I was real bad anemic and they wanted to see me at the University Hospital. Then two days later they found the leukemia and said that if they didn't find it when they

did, I'd a been dead within a week. They thought that I was just complaining to get out of school.

Laura

A week before I was diagnosed, I started drinking a lot, you know, the classical symptoms. And my brother who also has diabetes said at the dinner table, "this is how it starts". When he found out that I had diabetes, he thought he gave it to me. So he had the hardest time with it.

Carla

I had to stay in the hospital three weeks until I could give my own insulin shots. They just walked in with the needle and I rolled up my sleeve, and they said "No, now its your turn." I don't think it was ever laid out to me that if I didn't take my shot, I didn't leave.

Bill

I wasn't scared until I had to go home, I was fine in the hospital, taking my shots, showing off to relatives. I went home and I was in my bedroom and I had to take my shot alone for the first time. I couldn't do it, and I had been doing it for a week. Then I was scared.

Rachel

My diagnosis was hard to make because my doctor at home thought I had real trouble with strep throat. They ended up having to send stuff to the Mayo clinic and it came back saying to have surgery done as soon as possible. I KNEW it was cancer, I KNEW...because any kind of illness will go away like that if they put tubes and stuff in you and drain stuff out, it usually stays away. But, this stuff comes back all on it's own it grows back and gets bigger. My doctor said, "I apologize, you're not even a doctor and you knew what was wrong with you. We wouldn't even try, we were too busy trying to figure it was something else. That's because we don't find cancer in young kids up here."

For some of these youngsters, the recognition of their symptoms provided them with some preparation for the diagnosis; that appeared to happen for some youngsters with diabetes. For youngsters with cancer, however, no warning signs could be associated with such an unusual and shocking diagnosis.

In the early stages of treatment, moreover, youngsters with cancer

reported few self-care options; their care primarily is dictated by nationally standardized protocols that require little initiative of them aside from compliance with massive chemotherapeutic and radiologic treatments (and perhaps with surgery as well). Youngsters with diabetes, on the other hand, report their initial struggles with injections and self-care (adherence to diet, exercise and monitoring blood and urine). As Kellerman, et al (1980) point out in their study of several groups of ill adolescents, "(with diabetes and cystic fibrosis)...the patient is able to exert some degree of control over his illness and symptoms through manipulation of diet and self-administration of medication. This is not the case, however, in patients with cancer (p. 130)."

Medical Treatment Regimen: "What are the major issues you face with respect to your treatment regimen?"

The medical regimens for cancer and diabetes differ considerably. Moreover, since so much of the treatment of diabetes is conducted on an outpatient basis, by the young patient him/her self, a great deal of research has been conducted on the problems of regimen compliance (Litt & Cuskey, 1980). There are few such studies with youngsters with cancer, partly because survival rates have only recently begun to improve such that large numbers of youngsters are surviving long enough for compliance with a medical regimen to be relevant (Katz & Jay, 1984; Lansky, et al, 1983). Owing to recent advances, much of their extended care also takes place on an outpatient self-monitored basis. But for youngsters in remission, self-care primarily involves taking pills, a relatively non-intrusive treatment regimen. This is quite different from the self-administered

injections and dietary controls that generate the compliance problems reported in the literature on adolescents with diabetes. Some of these issues are identified and elaborated upon by ill adolescents as follows:

Rachel

...I have seven more treatments and if I get really sick from the treatments, then I'm going to go on until...probably March. When they switched my medicine one time my hair started really coming in a lot. It was almost like the guys who are in the army, then it all fell out. I was really depressed. But now everything seems to be going good for me, everything has gone so good...You have to have CAT scans every 6 months for 2 years and then you're doing really good and you have 5 years after that. And then, if by 5 years - that means you're cancer free. That's how I have it.

Gary

The pills make me tired. When they found out I went out of remission, I was just starting to get back to where I could eat like I did before and felt a lot better. After they started me back on the medicine, I started feeling bad again.

Bill

As I have been a diabetic longer and longer, it kind of becomes integrated into your thought process to think about your diabetes. You know you're going somewhere, just throw in those lifesavers or hard candies, whatever; it becomes a part of you, it becomes a part of your thought process all the time.

In the first couple years, everything's going right, and then all of a sudden you're told you're probably going to go blind, and your kidneys probably aren't going to work. You know that if you're not taking care of yourself, you're going to go blind if you don't. I fear the cumulative effects of diabetes. What's going to happen down the road.

Laura

There are times in your life and times even in your day that require more attention. You're almost on a clock of your own. When I started with the insulin pump, I went through a period where I had a lot of low blood sugar reactions. At that point in my life diabetes was a major, major concentration. But at other times in my life it becomes more secondary. I think the one point that really angers me is when I try real hard and I am doing the best I can fitting it into my life and making my life work with it and it still doesn't work well enough. That's

tough.

Carla

I remember getting pressures from home and sometimes from certain physicians I was seeing. Then I would start to "fix" my urine or blood sugar numbers because I knew they weren't what I knew they should be. Now, by understanding it more, and knowing how to control it more I'm finding how to fix them the right way rather than just erasing a certain number and writing in what I like. I think from so much pressure, I was trying to achieve perfection and cheating was the only way I felt I could do it.

As noted, one of the major differences in the medical regimen experienced by youngsters with cancer and with diabetes relates to the degree and timing of self-care. Most medical practitioners believe that diabetes can be controlled with proper diet and patient adherence to a medical regimen; thus youngsters are informed that they control their own functional outcomes of the disease. Few medical practitioners believe that youngsters with cancer can personally influence their functional outcomes, except by participating in standardized and high technology medical care. This major distinction in responsibility-for-outcome pervades many of the youngster's different reactions to treatment regimens.

A second major difference reflected in the above comments is that youngsters with cancer can expect a bright future, if they do not relapse. The longer they survive past diagnosis the better off are their chances for good health. Youngsters with diabetes often note their concern with the long-term consequences of their illness, consequences that are neither visible nor controllable in the present. The longer they survive past diagnosis the closer they come to experiencing major complications that further compromise their health and life chances.

Experiences in Hospitals and Clinics: "Are there some staff that you like more - or avoid more - than others Why?"

Adolescents are not passive and unfeeling medical consumers. Like adults, they constantly evaluate the medical care they are receiving and the behavior of staff providers. Farquhar (1984) notes that adolescents with diabetes object to medical staff members who are too busy to express care and who are judgemental with them. Orr, et al. (1984) report that youngsters with cancer desired the following behaviors from their physicians: openness and honesty, non-judgmental attitude, respect, inclusion in the formulation of treatment plans, and straightforward information. These reports are quite consistent with reports from parents of youngsters with cancer regarding their own problems and desires in relationships with medical staffs (Chesler & Barbarin, 1984).

Karey

Personalities in hospitals don't always click together, and there's some that you just don't match up with very good. I don't click with one social worker. She used to come in and say, "Now how do you feeeeel, how do you really feeeeel?" and I thought, how do you think I feel?... Me and my mom used to joke about it..."How do you feeeeel?"

Rachel

I guess to me, the ones that are special are the ones that seem to care the most--and there's just some you can tell, that do more than others. For one nurse, I had to tell them not to let her treat me anymore. I never got along with her. Sara is terrific: she will come right in, and she'll sit down for half an hour and just talk with us... When you're all alone that's nice. If I was really upset about something or if I needed to make a phone call, she made it easier. She tried to do more. I like Dr. Andrews too----she's a strict person and you know how far you can go with her.

When you have one an appointment for chemo they want you there early, and my mom has four other kids to get off to school, so that's a big whole morning thing. Then we get there and I'm not

getting my chemo til midnight. I waited the whole day and night. So the next time we came we said "When are the drugs going to be up from the pharmacy, when?" and they said "Well, two or three o'clock" And we said "good, we're going to the mall and we'll see you later", and we did. I'm not going to sit there and wait. You just sit there and worry. I really want those doctors and nurses to know at least I'm here for something and that something is really happening here.

Carla

I always wondered when I'd be sitting in the doctor's office, how does he know what I'm going through just this second? One doctor that I had said, "Well, I understand what it's like for you to be on a diet because I've been trying to lose all this weight." Well, it's a totally different thing, that was voluntary for him and for me, it is mandatory. I feel there does need to be somebody that understands what I am going through.

Bill

The more I get into it, the more I can see a real need for physicians who are diabetic. I think it automatically sets up a line of communication with your patients; there's that link. It's like, oh you're diabetic, so you must know how I feel a little bit. I take shots just like you do. I get tired of it like you do, too. That's a real big one. You just want someone to say sometimes - not like sympathy - but "it's rough." You don't want to hear, "Oh, I understand what you are going through."

Laura

My physician is really great. And the first time I went to him he says "Well, we have to run the diabetes around your life style instead of your life style around the diabetes." And no one has ever said that to me before. I felt really comfortable with him when he said that to me.

There is no question that the statement "I know just how you feel" is offensive to ill youngsters. While empathy is desirable, misplaced or false attempts at empathy are pretentious and usually rejected by insightful health care consumers. When youngsters experience insensitive staff behaviors, they often are discouraged and disappointed in their relations with the medical staff. They may keep their distance from or resist staff members' attempts to aid them.

Some youngsters understood that staff behavior itself often was constrained by rules and regulations of the medical institution, as well as by physicians' personal discomfort. They care about their health care providers, and are compassionate and perceptive with regard to the pressures under which they operate.

When asked whether they had any suggestions for improving hospital rules and practices, many young people discussed the need to shorten clinic waiting periods, educate young physicians in how to deal with people, etc. However, two young women with cancer raised an especially interesting issue:

Karey

I'm surprised that Rachel and I started chemotherapy at the same time and the first time we ever talked about it was two weeks ago in the group discussion. There were so many times I thought---"Gee, why am I feeling this way? Am I weird?" And then I talked with Rachel, and she feels the exact same way. I just think it is too bad they never get us in together. I wish they would get the patients together more. I think the cancer patient needs a lot of support and not only the first three months when it's the worst, through the whole of it.

Rachel

I think if they would put us in together we could talk and find out things. For instance, I had to drop out my junior year and when I went back to school, kids were even scared to ask me what was going on. And I thought, well, it must be me. I didn't know that Karey was having the same problems. If I'd have known that, we'd both have figured out that we'd have to do something to get our friends back.

These two adolescent cancer patients acknowledge quite clearly their delight in "discovering" one another and the benefits of sharing experiences. Their suggestion that the staff could have helped this happen earlier has been incorporated into a number of clinic programs, where discussion groups and social events have been planned for adolescent

patients with cancer, diabetes or other illnesses (Blum & Chang, 1981; Hamburg & Inoff, 1983; Lewis, 1984).

Financial Concerns: "In what ways is money a concern?"

Part of growing up involves understanding the value of money, and the impact of new financial needs and demands upon one's personal and familial lifestyle. Recent research indicates that the financial burdens of childhood cancer and diabetes often are significant (Hamburg & Inoff, 1983; Lansky, et al., 1979). Not only are medical supplies and treatments involved, but special diets, transportation to medical facilities and days off from work often represent non-insurable and non-reimbursable drains on a family's resources.

Rachel

My mom has really good insurance; it pays like 90 percent. And then my dad pays the rest but his ran out at \$40,000. We have over \$100,000 in bills so it's still quite a lot of money.

I was told that after I turned 18 my parent's medical benefits would be dropped and that I would have to pay for everything. And I said, "Oh, how could anybody do that. Even a doctor couldn't pay for half the medicine". So the social worker at the hospital said to me, "Well, I'll try to get you disability on your social security income. You should have gotten it a long time ago". That's one of those big things that should have been told to us. But I found out about this Supplemental Security Income you can get and we've been doing battle with them for over a year now trying to get it.

Karey

I originally found out about Supplemental Security Income when I was in the hospital and I shared a room with a diabetic girl. Their first response was, "You tell us you have cancer, you don't have cancer, you have (specific diagnosis)". That's what I got in the mail, no name, no phone number, no nothing. So, I applied again, "You had your tumor surgically removed, you can maintain nutrition, you are now recovered." Next time I got something similar to that. So, we finally got a lawyer and went in about 30 days ago. It only took five minutes. The judge knew,

obviously, someone made a mistake...I think maybe if they turn everybody down the first time, they save money because people go "Oh well" and they don't pursue it. So I'm sure you just have to keep going after it.

Once again, the benefits of peer discussion and exchange are obvious.

Advice for Other Youngsters: "If you were to give some advice to a young person who was just diagnosed with the same illness you have, what would you say?"

In some medical institutions, older youngsters with serious illnesses are being asked to "counsel" other youngsters with the same illness. The potent bonds of peer sharing and co-education can add to the wisdom of the medical staff. What wisdom do youngsters have to offer one another?

Karey

I'd like to tell little kids that funny feelings are normal, like wanting to kill yourself. It doesn't mean you're crazy. I went from that feeling to, "darn it, this isn't going to get me."

You gotta be super positive. I remember I had two posters in my room: one was "Super Chemo Woman" and another one was Pac Man eating up little cells.

You can't let the staff intimidate you with all their importance, you're a person.

I meet people who don't know I've got cancer, to me it's not a big part of my life; it's just something that's happening now, and something that will be over. My career and my music are my life. I'm not going to dwell on it; yeah, I have cancer, but it's not everything.

Carla

I can see how it would be so easy to blame your diabetes for everything. "Well, I wasn't feeling good and so I couldn't study for that test." Because I found myself doing that a little when things weren't going well: "my sugar's out of control, and I wish I wasn't a diabetic." It's so easy to get down on yourself for everything that goes wrong in your life and blame your disease. I always felt that I just want to be normal. I don't want to

have this affect me. I just want to be normal.

Bill

I think having people feel sorry for me is the thing that angers me the most. I can get along and I can deal with the diabetes itself. But when people feel sorry for me I kind of resent that. I think it goes back to a lack of education of the general public. You know, that's why they feel sorry for us, that's why they want to act like it's not there. They just don't understand.

Rachel

The way you're gonna make it is if you fight. If you fight it back, then it's gonna back up and slowly go away. How can you fight it? Take your chemo as it comes and realize that there's things you can do to stop you from getting sick.

You can wear a wig. There's thousands of wig stores that will do anything to sell you a good wig that fits you.

Most of the people are really nice. It's going to be hard to handle what happens to you, but that's when your mom and other people have to come in. Even though you say "well my parents are taking care of me," you're really taking care of yourself. Your own brain is telling you "God, you're going through all these depressing things" your parents aren't. I think the you have to learn to take care of yourself.

I think you really gotta speak up. There's this one girl here when you say, "How you doing Lisa?"...her mom will say, "Oh she's doing pretty good today" I don't know how she can get through to the doctors. You just gotta speak up. You can't sit back and let them run you over. You gotta stand up.

The central messages in the above advice include:

- Strange feelings are normal
- Watch out for pity...by yourself or others
- Be prepared to educate others
- Establish control over your feelings
- Don't give up...fight for your life

- Speak up when dealing with the staff

- Try to be yourself, be normal.

The themes of educating others (including sometimes the staff), and speaking up for what you need, lead us to a final issue, the ways in which ill youngsters reflect upon the unique task of late adolescent development, negotiating an independent relationship with the medical care system.

Negotiating an independent relationship with the medical care system:

"How do you attempt to gain control of what happens to you in the hospital?"

We indicated previously that this task is the unique important task for ill older adolescents, as compared with their physically healthy peers. They face all the typical developmental tasks of that period of life, although many of these tasks must be faced in a relatively unique manner as a result of chronic and serious illness. But in establishing an independent relationship with long-term medical care, ill youngsters face a particularly critical responsibility. Such a relationship requires youngsters to: care for themselves, including monitoring their symptoms and dosages; make their own appointments with the medical system, including selecting their physicians and care programs; and asserting their own needs and preferences in the physician-patient relationship. For many, it means affecting the transition from a pediatric clinic to an adult unit. In all, it involves youngsters asserting themselves and taking control of their medical needs. What did these youngsters experience that is relevant to this task?

Karey

I think one thing is that the parents can't speak for the kid if they're old enough to know. You have to ask the kid how they're doing, and not have the parents say "Well, he's not feeling good today..." Sometimes you can talk to the personnel there easier than you can talk to your parents.

Also, you need something separate. Cancer takes away a lot of your independence, because when I don't feel good I have to go to my mom to drive me to the hospital or something. Every time I feel like I'm trying to get more independent I feel I'm on kind of a leash to the hospital. Every time I get out so far they kind of pull me back in and say, "It's time for chemo, come back in". And then you start at the bottom of the hill again.

Carla

I've had diabetes since I was 2, and I've learned how to manipulate the doctors — the questions to ask, and what you want to get done. As soon as I learned how to get my own shots, my mother let me go into the nurses alone, and so she'd build up my confidence that I could do things myself. So I felt better about going with her and kind of doing my own thing. She'd just ask questions and if she didn't like the answers the doctors gave, she'd ask another question. And she'd always make sure I understood before we went on to the next point. And I just picked up those kinds of things from her. The last couple of visits I've been coming by myself. I look like I know what I'm doing and so the nurses just hand me papers and say "You know where to go, right?" And I say "Right!" and I've got it down to two and a half hours now...

Gary

In the hospital, they took my IV out so I could take a shower and just take a rest. I had it there for over a week. They were trying to decide who would put it back in so they asked one doctor who was an intern, and he goes "Well I've never put one in before...but I could try". I said "the hell you don't!"

Laura

I never really fought until I was feeling pretty miserable for too long. I was having more bad days than good days. So, I kind of pushed my doctor a little and he gave up on me in a way, and sent me off to some other doctors. I really plug for interviewing and talking to your doctors before you enter into therapy with them. I went on to realize that there were other things that I could do such as going to a third shot.

Rachel

As you develop...you want to talk to the doctors and staff yourself. I know that when I first went in, they wanted to talk to my mom and dad. I said "What's wrong? Why can't you talk to me? It must be pretty bad if you can't say anything to me..."

I asked a lot of questions. Nobody had told me anything about my surgery and all the lost time. I had this one doctor, she was a resident in surgery and she told me a bunch of stuff that she had to do when they cut my neck open. I was glad that some one was finally talking to me about it. Being told what was going on in that room when I'm just laying there was exciting.

You just try to make yourself look really good so maybe it'll help the doctors realize that they are making you feel better and really they are. I like to make myself look good, and talk good, and feel good so that the doctors know and think "hey this is working, we have something that's working and look how good she can do". It's not really an act all the time because for the three weeks on chemo that you don't feel good the day before you go in, you do feel really good. If you can make it work, then you know that you can talk someone else into making it work. And the doctors can see that the medical part of it works, and the mental part, my part, is starting to work. So maybe if you put both of them together----

The assertive nature of these youngsters' approach to medical care is quite clear from the above examples: "I've learned how to manipulate the doctors", "The hell you don't", "I'm not going to sit there and wait", "I asked a lot of questions", and "I kind of pushed my doctor" are indicators of a well-educated and assertive consumer approach. These comments also reflect considerable sophistication about the interpersonal relationships that occur between consenting adults. The youngster who commented on making herself look really good for the staff is well aware of the need to support the staff's morale. And the youngsters who advocate direct and mutual physician-patient communication speak to the same issues. In several examples, youngsters reflect their parents' critical role in preparing them to be assertive and sophisticated.

As assertiveness or control is exerted by young people, they know they cannot "push too much." Partly, they cannot push because they respect the

staff members who are trying to serve them. In addition, however, to be too pushy is to risk subtle retaliation. It may matter little whether or not such retaliation really occurs; whenever people with less power attempt to "push" people with greater power (students to teachers, minorities to majorities, workers to managers) they worry about the abuse of power that might harm them.

Successful attempts to negotiate an independent relationship with the health care system will have to build off these resources and overcome these barriers.

Critical Issues in the Transition to the Independent Negotiation
of Medical Care

Several themes can be identified in these excerpts, and they cut across several typical issues in medical care and medical care relationships. First, these chronically ill adolescents emphasize the necessity of information. They want honest information about their own health and treatments, and about their treatment options and staff options within the medical system. They also want up-to-date information on financial assistance and insurance. In addition, they discuss the need for information to be shared with the public at large, and for a public education program to help counter the ignorance or stigma with which peers and adults sometimes approached them.

A second major theme these adolescents identify is the crucial role of social and emotional support in terms of time availability and emotional sensitivity from the hospital staff and from other youngsters with similar illnesses. They also identify the supportive behaviors of their parents

who trusted them enough with decisions about their own care to enlarge their sense of self-esteem and to begin the establishment of an independent relationship with the care system. Obviously, some adolescents have a very different experience; some parents are not willing to "let them go" and increased dependency stalls their ability to establish an independent relationship with the medical system.

A third theme is the constant struggle to establish and maintain a normal life. Sometimes this is reflected in a personal desire to be treated like everyone else and to avoid being captive to their illness. They make it clear that living with a serious and chronic illness is indeed a struggle. Although they generally present an optimistic and assertive stance toward this struggle, coupled with attempts at normal behavior, it is obvious that this is not easy. There is pain, and confusion and worry and frustration all along the way.

Fourth, it is clear that the desired relationship between chronically ill youngsters and the medical staff is a mutual one. They are by no means the passive recipients of treatment in clinics and hospitals. Nor do they see the staff as a dehumanized and unnamed mass. They are willing to assert their medical and sometimes psychological needs, and they have figured out which staff members are generally receptive to them as human actors and which are not. They want to be treated as persons, not as bodies or illnesses or cases. And they are prepared to treat the staff as persons as well.

The relationships these young persons want to create with medical caregivers are independent of parents and negotiated by the adolescents themselves. They understand clearly that it is their disease, their pain,

their fight. These statements should convince us of the critical need for more research and systematic interventions that will aid their transition to adulthood as survivors of chronic childhood disease. On the basis of better data about this transition all persons involved - patients, family members, health care providers - may be able to make better decisions about appropriate service provision. To the extent that young people can identify the barriers to independent negotiation of medical care, we may be able together to test and implement intervention programs that guarantee better functional outcomes of care — health and quality of life — for young adults with chronic illnesses.

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