Hospital Experiences of Young Adults with Congenital Heart Disease: Divergence in Expectations and Dissonance in Care

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**Background** Despite increasing survival for adults with congenital heart disease, little is known about hospitalization for young adult patients with this disease and for their families. Because of the complexity of the disease and its management during the life span, young adults are often hospitalized on both pediatric and adult units during a stay in the hospital.

**Objectives** To explore the experience of hospitalization of young adults with congenital heart disease, the experience of their families, and the views of the nurses who cared for these patients and to generate substantive theory on interactions between patients, patients’ families, and nurses.

**Methods** Semistructured interviews and naturalistic observations were conducted with young adults with congenital heart disease (mean age, 28.6 years), their family members, and nurses who cared for the patients during hospitalization (N=34). Dimensional analysis was used to analyze interviews and field notes from observations.

**Results** A grounded theory was derived, explaining how the hospital context and relationships between patients, patients’ families, and nurses affect patients’ hospital experiences. Expectations differed among the groups, leading to dissonance in care, as exemplified by role confusion and power struggles over control of care. This dissonance resulted in interpersonal conflict, distrust, anxiety, and dissatisfaction with the care and caring experiences.

**Conclusions** Changes in hospital units, a better understanding of the healthcare needs of young adults with congenital heart disease, and acknowledgment of the expertise of patients and patients’ families are needed to improve nursing care for these patients and their families. (American Journal of Critical Care. 2002;11:115-127)

Through innovations in surgical treatment and medical management of congenital heart disease (CHD), 500,000 young adults in the United States are now surviving with a disease that once led to death in infancy or childhood. With the increasing age of this population, uncertainty has
developed about who should be responsible for their clinical management. Because of the complexity of the pathophysiology of the disease and its surgical interventions, adults with CHD often remain under the care of a pediatric cardiologist. In acute medical crises and after cardiac surgery, it is thought that pediatric intensive care nurses and advanced practice pediatric nurses (eg, pediatric cardiology clinical nurse specialists) have the necessary knowledge and clinical expertise to implement the required complex medical management. However, young adults with CHD may be hospitalized on a pediatric unit, an adult unit, or both during a hospital stay.2

In order to more comprehensively meet the special healthcare needs of these young people, CHD in adults should be considered a new cardiovascular subspecialty.1 However, this idea is new and is not widely implemented. Meanwhile, young patients are growing and developing as they live with this chronic condition. Patients with CHD generally face the same developmental tasks as do their non-CHD counterparts.3 Adolescents and young adults with CHD grapple with issues of identity such as developing a positive body image, envisioning adult roles and responsibilities, expanding peer relationships, developing a sexual identity and intimacy, and integrating a value system based on their own beliefs. Likewise, the development of increasing levels of independence occurs as these patients move toward more autonomous control over their lives.2

This development takes place in the context of social relationships, and management of illness has a parallel developmental trajectory. From infancy and early childhood, parents of a child with CHD take on the primary role of managing their child’s health and CHD. As the child moves through adolescence, parents must begin to relinquish control, allowing the growing adolescent to take on increasing levels of responsibility for self-care and management of the illness. Sparacino et al1 described the dilemmas that parents have in “letting go” of this control (eg, allowing self-management of activity restrictions) when health-damaging or life-threatening consequences are a possibility.

We are beginning to understand the developmental needs of adolescents and young adults with CHD and of the families of these patients. However, little is known of the experiences of these patients and their families during acute phases of illness that require hospitalization, when the self-management skills of both groups may be challenged. Likewise, little is known of the relationships and interactions between patients and their families or the issues that pediatric and adult medical-surgical nurses confront when trying to provide developmentally appropriate care for these young adult patients. In this exploratory study, we investigated the experiences of young adults with CHD during hospitalization for surgical or medical intervention, the experience of their families, and the views of the nurses who cared for these patients. These perspectives were used to generate theory on interactions between patients, patients’ families, and nurses in the postsurgical or medical hospital context.

Method
Sampling and Data Collection
Four groups were included in the study: young adults with CHD hospitalized for surgical or medical intervention, family members of these patients who attended the hospitalization, nurses on pediatric intensive care units (PICUs), and nurses on adult medical-surgical units. Because the typical hospitalization for adults with CHD at the study institution involves a stay on both the PICU and an adult cardiology medical-surgical unit, the perspectives of nurses from both units who cared for patients were considered relevant.

Purposive sampling was used to select study participants. Criteria for selection of patients included a diagnosed congenital cardiac defect, current hospitalization for surgical or medical management of the condition, a history of at least one previous surgical repair, age 21 to 40 years (this wide age range was used because the population of adults with CHD is still quite small), and an ability to comprehend spoken and written English. Access to participants was facilitated by their pediatric and adult cardiologists and surgeons. Letters describing the study and eliciting interest in participation were sent to potential participants in advance of admission for planned treatments. Patients who wished to participate in the study indicated so by returning a postcard. Upon admission, a research assistant met with each patient to provide additional details on the study, discuss potential risks, and obtain written informed consent. When admissions were unplanned, patients were approached for participation in the study during hospitalization.

For each patient who participated, 1 member of the patient’s family was asked to participate. Parents were the preferred participants because of their lifelong involvement with the patient’s social and health history; however, in some instances, a spouse or significant other was the family participant, and this selection was based on the patient’s preference and convenience. Written consent was obtained from family members. Finally, 1 PICU nurse and 1 nurse from the adult medical-surgical unit who had cared for each patient were asked to participate.
Data were collected through semistructured interviews and observations of the hospital environment and interactions between the groups of participants. Empirical literature and professional experience were used to derive the interview guide. The rationale for the use of these data-collection strategies was to give context and meaning to the phenomenon of hospitalization for these patients, their families, and their nurses. Patients and patients’ family members were interviewed independently approximately 24 to 48 hours after the surgery or medical procedure. A total of 2 parents and 1 patient were contacted for a second interview by telephone to gather additional understanding of conceptualizations being developed during data analysis. Nurses were interviewed within 1 week of caring for the patient to ensure recall of the nurse-patient relationship and the care provided. Interviews were conducted in a private space to promote confidentiality and candor and reduce distractions. Some nurses were interviewed by telephone when a suitable work time was unavailable. Interviews with patients were designed to last only 1 half hour to avoid causing fatigue; other interviews were approximately 1 hour long. All interviews were audiotaped.

Interviews focused on exploring the experiences of hospitalization of young adults with CHD from the perspectives of each of the groups in the study. Patients and patients’ family members were asked to describe the current hospital experience (eg, management of the illness, interactions with the nurses, and the care provided) and its impact on them. They were also asked to compare the current hospitalization with earlier hospital experiences and to describe any worries or concerns related to the current hospitalization. Finally, both groups were queried about what nurses could do to help patients and patients’ families in the hospital.

Nurses were asked to describe the course of hospitalization of the patients and the patients’ families and to indicate any particular issues in caring for adults with CHD on their units. PICU nurses were asked to compare their experiences in caring for adults with CHD with their experiences in caring for infants and children with CHD. Nurses on the adult unit were questioned about the similarities and differences between adults with CHD and other adult patients with cardiac problems.

Field notes were written by interviewers during the time spent on the units and shortly after all contacts with participants (eg, recruitment, interview). These notes included observations of the context for care; descriptions of participants, including affect, level of rapport, and nonverbal communication; and notable interactions between patients, patients’ family members, and nurses.

Analysis

Dimensional analysis, an approach to the generation of grounded theory, was used to guide data collection and analysis. The analysis was done concurrently with data collection as appropriate to the tenets of grounded theory methods. Interview tapes were transcribed verbatim, and the transcriptions were cross-checked with the audiotapes for accuracy. In the first phase of analysis, termed dimensionalization or data expansion, the data from the interview transcripts and field notes on observations were categorized according to the dimensions found in the interviews, without regard to the importance of the dimensions. Each dimension, defined as an abstract concept or as a component of a phenomenon, was given a designation or label. The purpose of dimensionalizing the data was to examine the breadth of conceptual possibilities in the interviews. In order to accomplish this purpose, all members of the research team independently coded the transcripts and field notes for initial dimensions, and group sessions were regularly held to reach consensus on conceptualizations. Methodological and theoretical notes were also made to track directions in these initial conceptualizations. Theoretical memos were periodically written to describe the context of the study, including particular environments on the nursing units and characteristics of staff members, and to elaborate on ideas about important dimensions found in the data and the relationships between the dimensions.

After several interviews and field notes for each group of participants were analyzed in this manner, team members began to detect patterns and relationships within the coded dimensions and to examine the relative importance of these patterns and relationships. In this phase of analysis, the differentiation phase, data expansion shifted to data limitation. The most prominent dimensions within and across the groups of participants were selected and organized into a meaningful framework in order to move the analysis from description to explanation. This work proceeded through group reviews of the data until the research team reached consensus on the key dimensions and the relationships between the dimensions.

In the differentiation phase, these key dimensions and their relationships were configured in an explanatory matrix to specify them as particular conceptual components such as context, conditions, process, or consequences. Context is the situation in which the dimensions are embedded; conditions are dimensions that somehow contribute to or block an action or
interaction; process is a set of actions or interactions that are generated by specific conditions; and consequences are the outcomes of a given process. In dimensional analysis, the explanatory matrix is considered the “structural and procedural centerpiece for analysis” rather than an analytic tool as in traditional grounded theory method.

Dissonance in care, defined as friction or conflict in the experience of care, was a prominent thread that tied the experiences of the 4 groups together. In order to configure the explanatory matrix, however, a higher order dimension, divergence in expectations, was selected as the perspective from which to group the dimensions into their various components (see Table). Divergence in expectations reflected the difference between participants’ expectations for care during hospitalization and the actual nursing care experienced; these different expectations, in turn, created the dissonance in care that was the major finding throughout the interviews.

The selection of divergence in expectations as the perspective enabled the research team to specify each conceptual component of the explanatory matrix. Integration of the data analysis was then achieved by describing and explaining the relationships between these components of the explanatory matrix. From this final matrix, a narrative report on the findings was prepared, which was reviewed and critiqued by the members of the research team.

Several steps were taken to ensure the credibility of the research findings. The research team included members with expertise in CHD, human development, chronic illness, and pediatric, family, and adult nursing as well as expertise in dimensional analysis and grounded theory method. This combination of experts ensured that data were examined from multiple perspectives. Scientific rigor was enhanced by sustained team interactions about the data, confronting team members’ assumptions and biases, and testing working hypotheses and conceptualizations.

Multiple sources of data (patients, patients’ family members, nurses, and researchers’ field notes) and methods of data collection (observations and interviews) made it possible to cross-check data. Further, the high level of consistency and redundancy in the data across participants lent support to the achievement of saturation.

Finally, the process and products of the analysis were systematically documented, and an audit trail of raw data, individual open coding, and field notes summarizing group sessions was maintained to enable evaluation by someone independent of the research team. One limitation of the analytical process was the absence of member validation; financial constraints prohibited the verification of study findings by the 4 groups of participants in the study.

Results

Characteristics of the Sample

Of the 10 patients approached to participate in the study, 1 declined to do so, explaining discomfort in discussing his experiences. After giving verbal consent, 1 patient became critically ill and died before participating in the study. One PICU nurse refused to participate because of fear of loss of confidentiality in

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the workplace. All of the nurses from the adult unit who were approached agreed to participate. As data collection progressed, we noticed that PICU nurses known to be critical of the practice of hospitalizing adults on the pediatric unit were not represented. Two additional PICU nurses were sampled to gain the perspectives of this subgroup.

A total of 34 participants were interviewed. The 8 patients were 4 men and 4 women 22 to 40 years old (mean age, 28.63 years). Of these, 6 were white, 1 was Asian American, and 1 was Hispanic. Seven were single, 4 lived independently, 4 lived with family, and 2 had children. Five were students, 2 were employed (1 full-time and 1 part-time), and 1 was disabled. Family members interviewed included 5 mothers, 2 fathers, 1 spouse, and 1 significant other. A total of 8 PICU nurses and 9 nurses on adult medical-surgical units participated in the study. The nurses on the adult unit were older than the PICU nurses (mean, 42.7 years vs 34.5 years), had more years of nursing experience (mean, 14.33 years vs 10 years), and had similar educational attainment (both groups: 1 diploma, 1 associate’s degree, 6 BSN degrees; adult unit nurses: 1 master’s degree). The nurses on the adult unit were a more diverse group, with 6 whites, 2 Asian Americans, and 1 African American; all 8 PICU nurses were white.

The Hospital Context and Conditions

Hospitalization for young adults with CHD, their family members, and nurse caregivers was distinguished by divergent expectations, which led to dissonance in care. The different expectations of the various participants and the consequences of dissonance were the major findings of this study. The hospital context influenced these expectations and consequences.

Hospital Environment. Most patients who were hospitalized for surgical or medical intervention followed a typical hospitalization trajectory for young adults with CHD. During the phase of hospitalization with the highest acuity (eg, immediate postoperative period, stabilization for medical crisis), the patient was hospitalized on the PICU, on the assumption that PICU nurses were most knowledgeable about the patient’s disease pathophysiology and medical needs. After the patient’s condition was stabilized, he or she was transferred to an adult cardiology medical-surgical unit. Communication between these units and/or services was often lacking or unclear, or it contained conflicting information, and care was not always coordinated. One mother reported the following scenario:

She [the patient] wants to be informed because they’ve got all these separate little groups, these teams: the pain team, the management team—team, team, team, team. And each one comes in and tells her a different thing . . . . It’s like the right hand doesn’t know what the left hand is doing.

Like other PICUs, the PICU at the study institution was structured to serve critically ill infants and children. It was noisy and filled with high-tech equipment for monitoring indicators of medical status and administering medications or other treatments. The equipment was tailored to children, for example, small electrocardiographic leads and small emesis basins. Equipment appropriate for adults was not always available or even considered. One female patient reported the following:

They forgot that I was not a pediatric patient . . . and they did not give me a call button, and they weren’t in the room all the time. Twice I had to vomit, and twice they weren’t there, and they didn’t give me a basin or anything, and I had an ET tube down my throat . . . . I got a little stressed out, but then I just turned my head to the side and vomited on the bed.

The adult cardiology medical-surgical unit served patients with adult-onset cardiac problems. Nurses on this unit typically had generalist experience in adult medical-surgical nursing. Relatively few had cared for patients with CHD, and these nurses were unfamiliar with the condition and care of such patients.

Expectations for Hospitalization. Each group of participants had a characteristic set of expectations for the hospital experience. Regardless of which hospital unit they were assigned to, patients expected to be treated as experts about their condition and to be active participants in their treatment. Many had extensive knowledge of the pathophysiology and medical management of their defects, and they actively sought information from their physicians, the literature, and the Internet. One young woman exemplified this as follows:

I read a lot about it. I was at UCSD [University of California, San Diego] a couple of months ago, and they have a pretty good med school there. I looked up a bunch of stuff about the surgery, and then there’s a bunch of stuff that I looked up on the Internet.

Many used their past experiences to make recommendations to the nursing staff about pain control or other needs. One patient expressed frustration at her inability to get the nurses to take seriously her past experience in treatment decisions about nutritional support:
I didn’t think they’d take me seriously. I didn’t think they’d realize that, you know, they don’t know me as well as I know me. And they didn’t. And they said, “Well, it’s real hard to put in a central line for this total parenteral nutrition and blah, blah, blah,” and I said, “I realize that but . . . it’s a lot easier for me to go through a couple weeks of the tube in me than it is 10 years trying to gain the weight back.”

Patients wished to have information shared with them by members of the staff and wanted their questions about progress, procedures, and medication addressed willingly and directly. A young man on the adult unit recounted the following experience when he requested information about a medication:

I asked him [the nurse] for an anxiety drug today, because I felt like I just had to get out of here; I was just feeling like I had to leave. He started to give it to me, and I asked him what it was. He was like, “What do you want me to explain, the whole molecular process?” I said, “No, but I want to know what kind of drug you’re giving me and what part of my body it’s going to affect.” He seemed like he answered me in a kind of condescending way or just some way that could have been done better.

Patients wanted their parents to be involved in their care but to take a secondary role in decision making. However, when patients were very sick or in pain, they expected parents or other family members to advocate for their needs. One woman said, “I told my parents beforehand, ‘Hey, take over if you see that I am having too much trouble on my own,’ and my parents have.” Her mother, in a separate interview, validated this statement.

Patients expected competent nursing care and clear, consistent communication and coordination between members of the healthcare team. One young man in the PICU expressed fear because of the staff’s unfamiliarity with his treatment protocol, which involved the use of a patient-controlled pump for administration of postoperative pain medication:

. . . they would go to her first and talk to her, because she’s the patient. Whatever they need to know, they talk to her first; they don’t go to me, which is fine. And then, afterwards, when they realize I’m the mother; then they talk to me more because they realize that I’m not just a person visiting, that maybe I have something to do with her life . . . somehow they sense I’m the mother cause I kind of walk on in like I own the world. I don’t mean to do that, but I just do it because I’ve been in ICU before.

Family members and significant others considered it their role to closely monitor the care of their loved ones and advocate for the loved ones’ needs. A patient’s girlfriend described the role she played after his surgery:

I was helping him with his tubes. Every time his little machine went off, I was silencing the alarm until his breathing went back to normal. Of course, I was keeping an eye on it. I didn’t just shut it off and leave. If I wasn’t here, I am assuming that he would have to call the nursing staff several times during the course of the night.

Nurses in the PICU considered themselves to have special expertise in the management of patients with CHD. However, they found adults a challenge before they have the surgery, instead of when they’re so incoherent when they come in there [PICU].

Having enough trained staff available to meet their needs on the unit in a timely fashion was identified as a problem by several patients. One said the following:

. . . they took my chest tube out and then it started dripping a lot, like, even though they had sutured it up, and then the patient care assistant, you know, she couldn’t do anything about it. She had to wait for the nurse, and then the nurse had to call the doctor, and then finally they put a pressure dressing on it . . . but that took awhile and so I kind of had to, like, hold a towel there for about a half an hour.

Patients’ family members expected the patients to be treated with respect and the patients’ expertise to be acknowledged and incorporated into nursing care. Parents also expected competent, coordinated care and wanted to be included in the flow of information. Because of their experiences, the parents considered themselves experts and wanted their expertise respected. A mother discussed her extensive experience in the PICU during the course of her daughter’s surgical treatments and how she developed expertise in her daughter’s care:

. . . they had problems operating it at night. I mean, all the nurses and staff were sitting there reading the instruction books and like, “How do we do it?” So it was just kind of chaotic, and I just ended up calling the nurse and having her come shoot my IV with morphine whenever it hurt. But I guess that night—I was talking to the doctor today—and he said it was bad, and they hope they don’t have anything like that happening again. They want to show the patient how to use the machine.
because the physical parameters of the adult patients differed from those of children, the adults tended to be more verbal and involved in their care, and the adults generally needed other, less familiar means of comforting. One PICU nurse summarized the differences as follows:

. . . it’s the size thing that has been much different than what we’re used to. . . . Most of my experience has been with children, and so getting used to different drug dosages and different fluid volumes and how much chest tube output is significant, different things that you notice on an EKG that would be more pertinent in an adult than it would be in a child. Some of the frustrations . . . I think the adults seem to be more awake and on the ventilator, able to try to communicate. And I think it becomes frustrating when I don’t know what they need or what they want or they’re not comfortable. With the kids, you just kind of position them and get them where you think they look comfortable. I think with the adults, we’re not used to getting input from the patients.

Because of these patients’ high level of acuity and brief stay in the PICU, pediatric nurses considered it the nurses’ role to monitor, assess, and stabilize patients’ conditions in order to quickly transfer the patients to the adult unit. A nurse described her frustration at having to deal with adult patients:

I’ll tell you the biggest frustration is the fact that they’re so large and trying to move them and that sort of thing. It’s a lot different than a little infant in a crib, and you can flip them and move them and do whatever it is you have to do. With an adult, you have to go through the process of explaining everything, why you need them to be on their shoulder, but it’s sore and they don’t want to be there. And sometimes it’s hard to get that point across or even just helping them to move or do some deep breathing kinds of things. If they don’t want to do it, they’re just not going to do it. So, I think that’s really frustrating.

PICU nurses were used to integrating patients’ family members into patients’ care and, at times, much of the nurses’ communication was directed to the patient’s parent(s), as was usual with pediatric patients. One nurse said the following:

I think they [adult patients] need more information than what we’re used to giving children. We tend to give the families the information, but talking directly to the patient . . . what’s going to happen or what we need to do or what the x-ray showed—I think it’s different than going over it with the family. I think, for me, I need to remember to do that because there’s not the family in the room that I need to talk to. The patient is the person.

Nurses on the medical-surgical unit viewed themselves as experts in the management of adults with cardiac problems but were unfamiliar with the management of CHD. They expected independent behavior of adult patients as manifested by patients’ self-care and self-control (eg, control of pain). Behavior perceived as excessively dependent or demanding was not well tolerated. One nurse recounted a situation in which she perceived a patient as unreasonably dependent:

At one point, I asked him if he had servants at home, because I was irritated with it. I said, “Do you have servants at home?” He said, “No, no.” I said, “Because your mother seems to be doing everything for you.” Yesterday, I brought him some towels and wash cloths and I said, “You’re on your own today; you need to get cleaned up. If you need help with your bath, I’ll help you, but this is it.” And he did it.

These nurses also expected patients’ family members to promote patients’ independence and self-care and frowned on behavior that seemed to encourage dependence. A nurse related an interaction with a mother she viewed as overinvolved:

. . . the mother kept telling me that the patient had pain. The daughter wasn’t asking for pain medicine. The mother kept saying she had pain. They were about to take out the chest tube and the mother said, “Well, she needs something for pain.” I said, “Yes.” She said it again, and I said, “Yes, I’m going to go get it.” When I came back, I gave the patient the pain medication, and she said, “Well, how much did you give?” I said, “2.0 mg of morphine,” and she said, “Well, she’s been getting 4.0 mg.” Now, the daughter never said, “I need pain medication. I’m in pain.”

Nurses on the adult unit provided care according to institutionally prescribed critical pathways that focused on physical indicators of progress. They considered it their role to enhance patients’ self-care and prepare patients for discharge. One nurse summarized the goal of care as follows:

. . . we’ll just say, “Listen, John Henry [name used by the nurse; not the patient’s real name], my goal and your goal is for you to get out of here by the end of the week. I know what we need to do to get you out of
here. There are some things that you may not like to do. There are some things that I may have to do to you that I may not like to do, but since ultimately, the goal is to get you out of here, then that’s what I will do to the best of my ability to get you home where I know that you will heal better.”

Nurses on pediatric and adult units often referred to these adult patients with CHD by descriptors such as “the congenital hearts.” Patients with this designation were often assumed to be “needy,” “dependent,” “demanding,” and “regressive.” One nurse described a patient as follows:

He’s a whiner, and he perseveres if he has a desire or a need, and this may be a theme throughout this group [adults with CHD], but I think he’s a little on one end of the spectrum. Yesterday, he wanted grape juice. And he could not stop asking for it, even when we were settling him in the bed, starting his oxygen, running his IVs, assessing his lungs, doing things that were essential. I was instructing him about the use of the call light and our general routine, and he would respond to what I was saying and then he’d say, “And speaking of my grape juice . . . .” It went on for hours. When I brought it into the room, he goes, “It’s not Welch’s.”

The nurses viewed patients’ family members as “demanding,” “symbiotic,” and promoting dependence. For example, the nurse quoted in the preceding passage said the following:

We got him his grape juice, but I told him he had to quit talking about his grape juice; I didn’t want to hear about his grape juice anymore because it wasn’t appropriate. But his family was getting involved in this grape juice, and then his wife’s at the desk, and she is playing into the problem . . . . Everybody was very involved . . . . I call it enmeshed.

The nurses’ assumptions supported their perception that these patients and the patients’ families interfered with the normal work flow and increased the workload of nurses. One nurse described the extra work involved with adults with CHD:

. . . when you get people who are chronic [like this patient], I know that she is going to be demanding . . . . “Do it for me right away” versus “Oh, can I have this?” and “I need this.” This is sort of a distinction. I have more problems with what I am going to face now . . . . She will be on the light continually in a demanding way.

The Process of Dissonance in Care

Because expectations were inadequately met or in conflict with the expectations of others, dissonance in care was experienced. The dissonance was especially manifested in conflict over who was in control of care (patient, patient’s parent, physician, nurse), who made care-related decisions, and who was entitled to what information. Efforts to maintain control often precipitated conflict.

It was often unclear who was the expert in the patient’s management and whose expertise was acknowledged and valued and under what circumstances. One patient described her concern that her expertise was not valued:

I’m very familiar with what gauge needles I need. I’m a very, very difficult needle stick. I know the name of my heart problems; I know the terminology, the physiology, the anatomy; I’ve taken classes on EKG strips so that I could read my own. I’m interested in what I’ve got, and I don’t know whether the medical community is not used to a patient knowing that much about medications. I would say, “What gauge needle are you using?” and they’d laugh and pat me on the head and say, “It’s okay, honey. We’ve got it under control.” But the thing is, they didn’t. They would end up hurting me. We would end up blowing a vein. I would end up being in a lot of pain, and afterwards, they would come back and apologize, which I thought was very nice that they apologized, but the thing is, they didn’t listen to me, and I ended up getting hurt.

Pain management provided a poignant illustration of divergent expectations and the resulting dissonance in care. Most of these young adults with CHD had had hospitalizations that involved pain from medical or surgical procedures. As a result, they came to the current hospitalization with some anticipation of pain and were anxious about how well the pain would be managed. Some had sophisticated knowledge of their body responses to various pain medications and dosages and wanted to use this expertise in their pain management.

Patients’ family members also came to the hospitalization with experience in the management of their adult child’s illness. They worried about the outcome of surgical procedures and postoperative pain, and they expected staff to be immediately responsive to the patient’s need for pain medication. A father remarked as follows on his son having to wait for medication:

And last night, the nurse was notified that he was out of the medication, the morphine drip, and it took her about
30 minutes to replace it, and although she was busy, there were other people standing around that could have done it just as easy, but somehow, it never got communicated. Eventually, she came in, yes. After about 20 minutes, I sort of went out into the hall, and she said she was coming and she was coming, and she was a busy lady, she was hopping from room to room. I was a little incredulous to the fact that there were other people sort of standing around, because the ward didn’t seem really full at that time last night.

Many parents played the role of overseer, assessing whether their child’s pain needs were met quickly and adequately. When pain management was adequate, they stepped back and let their child take on the primary responsibility; but when pain was not well controlled, family members became active advocates for patients. In instances in which pain was not well managed, the involved family member was ever-present, was hypervigilant in monitoring the nursing care, and took active measures to get the pain more adequately controlled (eg, going out to find the nurse, calling the physician). One parent said the following:

. . . I’m just worried that if she needs something, they can’t get to it as fast as I think they should, and maybe they don’t need to get to her as fast as they should, and only I think they should because I’m her mother. . . . I’m not worried; that’s why I’m here. But if I weren’t here, I would worry that she’s not being cared for as well as I think she should be after having come from ICU only one day.

Pediatric nurses expected adult patients in the PICU to experience postoperative or procedural pain, and the nurses were prepared to control it, but these nurses’ expertise was with children. They were less familiar with indicators of pain and strategies for pain management for adults. One nurse said the following:

. . . we’re doing bigger things, we need to give bigger volumes, we need to give bigger amounts of drugs. I think that’s been a hard thing to get used to doing when you’ve only taken care of children; to think in terms of giving a whole bag of fluid instead of 20 cc or something like that.

Nurses in the adult unit expected patients to quickly reduce the patients’ needs for pain medication by exercising self-control. They viewed these adults with CHD as excessively dependent on high dosages of pain medication. For example, one nurse said the following:

No, I really don’t go in with a preconceived idea what’s going to go on, but if you take care of a [CHD] patient, you know that pain is going to be an issue. And 99 out of 100 times, with pediatric patients, usually, there is always something that’s not right, that we have to deal with kind of a problem.

Many of the nurses were concerned about addiction and drug dependence. They thought physicians contributed to this dependence by overprescribing medication and supporting patients in excessive use of medications. In discussing the need to set limits on a patient’s use of pain medication, one nurse stated, “She’s not really moving along . . . . See, the doctors really aren’t pushing her. It seems like the pediatric doctors don’t really push them out . . . .”

When nurses’ expectations for pain management diverged from those of patients and patients’ families, the dissonance was evident. Power struggles ensued over whose expertise was more valuable in making decisions about how much and how often pain medication would be used. Patients thought their verbalized needs and questions were ignored, challenged, or devalued. Parents questioned the competence of the care and viewed nurses as unresponsive to patients’ needs.

Consequences of Dissonance in Care

These conflicts contributed to several negative consequences reported by participants. Patients and families experienced an erosion of trust in staff competence. One young woman said the following:

It [not listening to her] has happened many times. Unfortunately, now I’ve got a mistrust, and I ask questions over and over and over, and I don’t want to be obnoxious, but the thing is, I’ve got a mistrust now because it happened.

These dissonant experiences increased the distress of patients and their families, as manifested by increased anxiety and worry. Pain management is a powerful illustration of the underlying dynamics of dissonance in care. With inadequate pain control, patients became intensely focused on pain management, and family members had difficulty decreasing vigilance and advocacy. One patient said the following:

. . . for some reason, I was having a lot of problems with the pain management team. It’s like we had several different teams working on me, and none of the teams were working together, so I was getting a different story every time I talked to these people, which made me very
anxious and very upset. So after surgery, from about 3 in the afternoon until 11 at night, I had no pain medica-
tion after major open heart surgery.

All of the participants in the study were often left
dissatisfied with the hospital experience. Patients and
their families reported not feeling listened to or
acknowledged for their expertise. Nurses saw these
patients and the patients’ families as difficult or chal-
lenging and not always gratifying to work with. An
adult unit nurse remarked, “I know some of my col-
lleagues, and they have actually expressed this, that ‘if
the pedi patient comes to the floor, I’d rather not take
that patient.’”

In summary, divergence between expectations and
care experienced created conflict and role confusion
between patients, patients’ families, and the nurses.
Unintended consequences of these care experiences
were distrust and dissatisfaction with the nursing care
given and received. Opportunities to work together
toward a positive recovery were lost.

Discussion

This study is the first exploration of the subjective
experience of hospitalization of young adults with
CHD and the experience of their families. Multiple
perspectives were elicited to illuminate the hospital
context: interactions between patients, patients’ fami-
lies, and nurses (PICU and adult medical-surgical);
and the impact of the context and interactions on man-
agement of the acute phase of illness.

A major finding was that each group of partici-
pants had different expectations about the manage-
ment of physical needs and about the behavior of
patients and patients’ families. For example, nurses
expected patients and patients’ families to defer to
nurses’ knowledge and expertise on pain manage-
ment, and the practical knowledge and expertise of
patients and patients’ families were not consistently
elicited, acknowledged, or valued. The failure to
effectively manage patients’ pain resulted in
increased anxiety among patients and parental worry
and hypervigilance.

Two major factors may have contributed to these
experiences of dissonant care. First, patients in this
study spent minimal time in the PICU and were quickly
transferred to an acute care adult unit, where treatment
followed standardized clinical pathways based primar-
ily on physical indicators for evaluation of progress.
Because hospitalization was brief, nurses had to
emphasize self-care by patients. Indeed, the value of
independence was a strong underpinning of the care
of these patients, and deviations from independent
behavior resulted in perceptions of increased work-
load by nurses and failure of patients to achieve criti-
cal pathway goals. This approach to nursing practice
provided little room for dependence.

Second, our understanding of the needs of and
appropriate interventions for adults with CHD and
the families of these patients has not kept pace with
the increased length of survival of the patients. This
group of patients differs from the patients typically
served in both the PICU and adult medical-surgical
units, and many nurses in these units lack familiarity
and comfort in caring for adults with CHD. In par-
cular, greater needs for pain medication were
reported in this study by both patients and patients’
families, and this need was an area of conflict with
nurses on the adult unit. Additionally, these patients
were in the midst of a transition from long-standing
parental management to self-management of CHD
and its treatment. Behaviors of patients that were
perceived as excessively dependent and behaviors of
patients’ families that appeared to encourage depend-
ence were viewed unfavorably by many of the nurses.
The lack of fit between patients and staff members
may have led to frustration on the part of staff and
concerns about the competence of care on the part
of patients and patients’ families. The call for
healthcare professionals, including nurses, to assist
patients and patients’ families in the transition from
pediatric to adult care is not new. However, despite
the wide acceptance of the need to assist in
this transition, many obstacles to its actualization
still exist, as illustrated in this study.

The small sample size and the use of a single site
for the study limit the generalizability of the findings.
The way that adults with CHD and their families are
cared for may differ across hospitals. Wide variation
may exist in assignment to hospital units, care coordi-
nation between units and disciplines, pain manage-
ment practices, and staff development for improving
the care of adults with CHD.

Implications for Practice

These findings suggest a need for changes in both
system and philosophy to address the divergent expec-
tations and dissonance in care for adult patients with
CHD and their families. Clearly, some concrete
changes to the hospital context are necessary to
reduce the misfit between patients and type of care
unit. For example, appropriate equipment should be
readily available, and the staff should be well trained
in its use. Nurses on both pediatric and adult units
need educational programs to enhance their under-
standing of the special healthcare needs of adults with
CHD, including the physical and psychosocial ramifications of CHD and the principles of developmentally appropriate and family-centered care. This specialized knowledge could be used to tailor clinical pathways for adult patients with CHD. An understanding of the relationship between physical and psychosocial needs and an awareness of individual and family processes in chronic illness, especially in relation to transitions in care across the life span, are essential. Further, in any instance of multiunit care, better interunit and interdisciplinary communication is needed to ensure that patients and patients’ families receive clear, consistent information.

Finally, it is important to recognize and value the expertise of patients and their families. In this study, patients and their families desired to be included as members of the treatment team and wished to be respected for their practical knowledge and expertise based on their experience of living with a chronic illness. The need to maintain control under the threatening circumstances of surgery and recovery is especially evident in this group of young adults who are striving to accept more responsibility for their healthcare. Acknowledgment by nurses of the roles of patients and patients’ families in postsurgical or medical management would be an important gain.

ACKNOWLEDGMENTS
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REFERENCES
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**CE Test Form**

Hospital Experiences of Young Adults With Congenital Heart Disease: Divergence in Expectations and Dissonance in Care

**Objectives**
1. Understand the role of the patient and family in the management of congenital heart disease
2. Recognize themes found in the different interview groups related to differing expectations of care between patients, families, and intensive care nurses
3. Describe implications for enhancing nursing care of the young adult with CHD during hospitalization

Mark your answers clearly in the appropriate box. There is only one correct answer. You may photocopy this form.

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CE Test Questions

Hospital Experiences of Young Adults With Congenital Heart Disease: Divergence in Expectations and Dissonance in Care

1. Which one of the following statements best describes the developmental tasks faced by patients with congenital heart disease (CHD)?
   a. Adolescents and young adults with CHD deal with the issue of developing a positive body image.
   b. Patients with CHD generally face the same developmental tasks as do their non-CHD counterparts.
   c. Developing a sexual identity and intimacy are tasks encountered by CHD patients.
   d. All of the above are true.

2. Which one of the following statements best describes the role of the parent of the child with CHD, as the child moves through adolescence into young adulthood?
   a. Parents maintain the primary role of managing their child’s health and CHD.
   b. Parents begin to relinquish control, allowing the adolescent to take on increasing levels of responsibility.
   c. Parents allow the adolescent to take on complete responsibility for their CHD management.
   d. Parents defer to the healthcare team to take responsibility for management of the adolescent’s CHD.

3. Which one of the following individuals was NOT included in the interview groups during data collection?
   a. Young adults with CHD hospitalized for surgical or medical intervention.
   b. Family members of the patient who attended the hospitalization.
   c. Cardiac surgeon or cardiologist who assumed primary care of the patient with CHD.
   d. Nurses on the pediatric intensive care units who cared for the patient with CHD.

4. Who was the preferred family participant interviewed during data collection?
   a. Spouse
   b. Parents
   c. Significant other
   d. Significant other

5. What did the study findings point to as the primary rationale for dissonance in care experienced by this population?
   a. Demanding behavior of the patients
   b. Incompetence of the nursing staff
   c. Demanding behavior of the patients’ families
   d. Divergent expectations of patients and caregivers

6. Which one of the following best describes one of the underlying themes found in patient interviews?
   a. The nurses did not listen to or value my expertise.
   b. The patient’s family members are demanding and promote dependence of the patient.
   c. The adult patients need more information than we are used to giving patients.
   d. The patients are so large and difficult to reposition that it makes care difficult.

7. Which one of the following best describes underlying themes found in interviews with adult ICU nurses?
   a. Independent behavior of adult patients was an expectation, and behaviors perceived as excessively dependent or demanding were not well tolerated.
   b. The patients had expertise that was valued and acted upon.
   c. Care was difficult due to the large size of the patients.
   d. Family members were expected to act as patient advocates.

8. How are dissonant experiences often manifested by the CHD patient?
   a. Increased withdrawal
   b. Increased anxiety and worry
   c. Decreased need for pain medication
   d. Decreased self-care efforts

9. Failure to adequately manage the adult CHD patient’s pain often led to which of the following responses from families?
   a. Aggression
   b. Inappropriate behavior
   c. Parental worry and hypervigilance
   d. Verbal abuse of nursing staff

10. Which one of the following best reflects author recommendations to enhance care of this patient population?
    a. Nursing educational programs to enhance understanding of special physiological and psychosocial needs of the CHD patient
    b. Better interunit and interdisciplinary communication to ensure that patients and families receive clear, consistent information
    c. Availability of appropriate equipment, with staff well trained in its use
    d. All of the above
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