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As some of you know, I have recently taken a new job and moved back to Atlanta. Increasingly, I am in meetings where the topics of the nursing shortage and the future role of nurses are being discussed. Health care administrators repeatedly cry out for the production of more nurses at a faster rate. Often, the underlying message is that the health care system needs registered nurses to keep business as usual going. It seems that advanced or professional preparation for nurses is not the focus of many potential nursing employers. Rather, there is a need for “bodies” at the bedside to keep the system running. Many health care administrators have decided that if there is a lack of nurses or if nurses complain about the work environment, it is acceptable to replace them with less educationally prepared technicians. This would certainly seem to support the idea that the emphasis is on having someone (anyone) on the job. Although such technicians have been promoted as support staff for registered nurses (extenders, if you will), there is no denying that the workload and the role of the nurse has drastically changed in most health care systems in recent years. My personal experiences would support that this change has not been for the better.

Many nurse leaders believe that there is not so much a lack of nurses as there is a misuse of nurses within the health care system that has let an emphasis on the bottom line overshadow the interest of nurses and the public. Such a negative work environment has resulted in a growing number of nurses electing to leave the workforce, directing their skills and talents toward more rewarding careers. Nurse educators have a clear understanding that dissatisfaction among nurses can be a barrier to the recruitment of students to nursing, which can have a devastating effect on the nursing profession and the public welfare. Appropriately, a national dialogue focusing on how to respond to the current nursing shortage, as well as how to move nursing into the future, has begun among nurses at many levels. You do not have to look very far to find articles, commentaries, and conferences that address the nursing shortage and the future role of nurses in the health care system. Clearly, the current situation raises questions as to who the nurse of the future will be and what will be the nurse’s role in providing for the health and well-being of the public. Can one group of health care providers (i.e., registered nurses) continue to be everything to everyone? Perhaps a more important question is, what will be the personal and professional cost to nurses (individually and collectively) if we continue to try to run faster to produce more bodies to plug into an ailing health care system?

My own observations over the past 25 years would suggest that those who are managing the health care system continue to do as much to undermine the willingness of young people to enter nursing and experienced nurses to remain active in nursing as they have to eliminate the very shortage they now decry. When there has been a shortage of nurses in the workforce, health care systems have been quick to throw recruitment or “sign-up” money at the problem. However, they have been unwilling, if not unaware of the need, to make the work experience of the nurse more satisfying. Additionally, when the “health business” climate changes, due to the latest federal regulation or approach to cost containment, there is no reluctance to lay off these valuable nurses who have been so hard to find or to redesign their work environments in such a
way that nurses’ ability to do nursing is limited. If you talk to nurses who have stayed the course over a number of years, it is nursing and the contact with patients that have sustained them. In my own career, my fondest memories are of patients. For the most part, I had to tolerate the “system people” to gain access to the wonderful experience of working with patients. Nurse colleagues who remain in clinical practice tell me that work environments in which the registered nurse is valued for “caring” for patients are becoming harder to find.

I have heard it argued that because nurses make up the largest component of the health care workforce, they represent a substantial investment. If nurses want better compensation for their work, they will have to take on heavier workloads and change the way they manage patients. They will have to learn to delegate responsibility to other less expensive personnel (technicians) who can be trained to do routine tasks. After all, nurses are expensive. Hasn’t it been nurses themselves who have demanded better pay for the work they do? Interesting, isn’t it, that the caring aspect of patient care is perceived by some health care administrators (and maybe some nurses) as time consuming and not justifying the expense of a registered nurse.

I realize that most of the readers of the Journal of the Association of Nurses in AIDS Care are practicing nurses and certainly do not need me to describe the challenges nurses currently face in clinical practice. However, I wanted to put my following observations as a health care consumer, who happens to be a nurse, within the context of my understanding of the problems nurses face in the health care system and how system barriers affect nurses’ ability to provide nursing care. Yet, I would propose that blaming the system without examining negative nurse behaviors as part of the system will not solve our problems.

I recently had the misfortune of becoming a consumer of emergency health care during my move back to Atlanta. This experience reinforced for me how brief encounters can influence how you perceive a whole group of people or profession. Somehow, during the move, I fell over a suitcase late one night and gashed my foot. Suddenly, I was in particular need of emergency health care. Anyone who has worked in health care and then had to become a consumer knows that you suddenly enter a new world in which you gain a different perspective of health care and health care providers, a world in which you have little influence or control.

I used to think “blood” got you to the front of the line—not so. That night, having a blood-soaked towel wrapped around my foot only got me a “sit down and we will get to you when we can.” I survived the almost 2-hour wait to see a doctor and was pleasantly surprised by the way I was treated once I finally saw the doctor. When he learned I was a nurse, he joked with me and explained what he was doing as he stitched up my foot. When I explained I was in the process of moving and would be out of town, he told me to monitor the foot for infection and gave me directions on how to take out the stitches. Then, the emergency tech came in and dressed the cut. He gave me a pack of gauze and a suture removal set, saying, “There is no need for you not having what you need to take care of this foot.” All in all, my experience once I got out of the waiting room had been very positive. I was ready to go. However, before I could leave, I had to see a nurse who would give me a tetanus shot and discharge me. After a long wait, a very professional looking nurse came in the room. She was immediately rude to the person who had brought me to the emergency room. She then began barking orders at me about how to care for my foot and when to return. I tried to explain that the doctor had said I could monitor the cut and remove the stitches because I am a nurse. She sarcastically told me, “You can suit yourself,” and left the room.

What is my point? Just this. I am aware that this nurse may have been the only registered nurse on duty in the emergency room. I am sure her workload was heavy and she felt there was little time to “individualize” my care. Even so, I would have expected a little more caring or at least courtesy from a registered nurse. As a patient, even a patient who is a nurse colleague, I received what might be called “that is not my table” service. On my way home, I could not help but evaluate my emergency room experience. The doctor had been great, the emergency tech had gone out of his way to be collegial, and the nurse... well, that is the point... the nurse was everything you would not want to encounter. It is unlikely that anyone experiencing such nursing care would have gotten the image of a caring health care professional whose role in the system is vital to the well-being of patients.
You might say this was just one nurse, so don’t over-react. Yet, several previous encounters with nurses, and conversations with friends who have used health care in recent years, suggest this type of treatment from nurses is more frequent than any of us would like to think. It will not take many encounters such as the one I experienced to undermine the perception of nurses as the caring patient advocate. In a time when nurses are fighting for appropriate compensation and working environments, we need to remember that patients are our greatest allies. Patients are the reason we exist. As much as any other factor, how the public views and values nurses will help determine our future. It may be important to remember that while we don’t always have control of the system, we always have control over our own actions. Demonstrating the ability to care may be one of the most important actions we can take to secure a positive future for nursing. When I have asked nursing students why they entered nursing school, often it was because of experiences with compassionate nurses. You have to wonder how many potential nursing students have been deterred from a career as a nurse by negative nursing care they have experienced or observed.

Nurses in AIDS care have always understood the value of a partnership with our patients. In fact, one of the characteristics of nurses who make the choice to work with persons with HIV/AIDS seems to be the ability and willingness to fight the system to make sure their patients receive the best care. In making sure you remain a caring advocate of patients, even when your work environment is less than optimal, you demonstrate your professionalism and invest in the future of nursing. Although my experience represents only one encounter with one nurse, the experience has reminded me of the importance of demonstrating a caring attitude to every patient in every setting. Such caring behavior is not only the right thing to do, it is good for nursing. We do have a choice in how we are viewed.
Correlates of HIV Risk in a Random Sample of Street Youths in San Francisco

Martha W. Moon, RN, PhD, MPH
Diane Binson, PhD
Kimberly Page-Shafer, PhD, MPH
Rafael Díaz, PhD

In a random sample of 203 street youths recruited in the Haight-Ashbury neighborhood of San Francisco, the authors found significant differences between those who reported that they could go home if they wanted to compared to those who perceived that they could not go back home. Those who could not go home were significantly more likely to report having been away from home for more than 3 years, having run away before age 13, having been kicked out of their home, and not being in touch with their parents compared to the other group. Those who could not go home reported significantly more injection drug use, which puts them at high risk for HIV. Health care providers can identify street youths at highest risk by asking the question “Could you go back home today if you wanted to do so?”

Key words: street youths, homeless youths, HIV, risk behavior, San Francisco

In the course of 1 year, an estimated 500,000 to 1.5 million young people in the United States run away from or are forced out of their homes, and an estimated 200,000 are homeless and living on the streets at any given time (U.S. Department of Health and Human Services Administration for Children and Families, 1999). These adolescents are at particularly high risk for HIV infection (Heffernan, Chiasson, & Sackoff, 1996; Kipke, Unger, Palmer, & Edgington, 1996). In seroprevalence surveys conducted in 1996 among 570 youths attending clinics at runaway/homeless youth centers in San Francisco, HIV seroprevalence was 25.1% in men (55/219) and 1.4% in women (5/351) (McFarland, Kellogg, & Scheer, 1997). It is not known whether these youths were infected with HIV prior to arriving on the streets, but it has been established that while on the streets, runaway and homeless youths engage in behavior that puts them at high risk for sexually transmitted disease (STD) and HIV, such as experimenting with sex and drugs without taking effective precautions against infection.

Several studies have examined risk for HIV in youths living on the street and found high levels of sexual activity, engagement in survival sex, drug use including injection drug use, and low condom use, all risk behaviors for HIV and other STDs (Anderson, Freese, & Pennbridge, 1994; Clements, Gleghorn, García, Katz, & Marx, 1997; Kipke, O’Connor, Palmer, & MacKenzie, 1994; Kipke et al., 1996). Street youths in the Haight-Ashbury neighborhood have been studied as part of a larger study of out-of-school youths in the state of California (Clements et al., 1997; Gleghorn et al., 1997; California Department of Health Services Office of AIDS, 1993). These authors sampled youths who were staying at runaway youth shelters or participating in programs specifically for runaway, homeless, or prostituting teens, and also included a number

Martha W. Moon, RN, PhD, MPH, is an assistant professor at the Virginia Commonwealth University School of Nursing. Diane Binson, PhD, is an assistant adjunct professor at the University of California, San Francisco, School of Medicine. Kimberly Page-Shafer, PhD, MPH, is an assistant professor at the University of California, San Francisco, School of Medicine. Rafael Díaz, PhD, is a professor and director of research at San Francisco State University.
of youths who were recruited on the streets in the Haight-Ashbury district using systematic street-based sampling methods. The investigators documented high levels of injection drug use and risky sexual practices in the sample. In the same population, Martínez et al. (1998) assessed predictors of high-risk behavior among street youths and found a correlation between injection drug use and traumatic personal histories (defined as being kicked out, forced institutionalization, physical abuse, parental substance abuse, sexual abuse, and others). Peer group affiliation has also been shown to be predictive of differences in risk behavior among street youths (Kipke, Montgomery, Simon, Unger, & Johnson, 1997; Kipke, Unger, O’Connor, Palmer, & LaFrance, 1997).

Other studies assessed associations between predictors of risk such as history of sexual abuse and same-sex sexual history and outcome behavior in clinic-based samples of street youths in San Francisco (Moon, 1995; Sherman, 1992), with similar results. It is unlikely that venue- and clinic-based studies are representative of all youths on the street. To fill this gap, we explored predictors of risky behavior in a random sample of street youths who may not interact with the health or social services systems.

Method

Study Design and Setting

This study was an interviewer-administered survey of youths on the streets of the Haight-Ashbury district in San Francisco. This neighborhood attracts youths from across the United States, in part because of its reputation for tolerance and personal freedom, as epitomized by the easy availability of sex and drugs during the “summer of love” in 1969. Data collection occurred between March and May 1998. This study used the street intercept sampling method, which has been used successfully to capture representative samples of hard-to-reach populations such as African American men (Miller, Wilder, Stillman, & Becker, 1997) and injection drug users (Watters & Biernacki, 1989). The street intercept method can yield a more representative sample of street youths than clinic- or agency-based samples or traditional population-sampling methods that rely on telephones or door-to-door sampling (Miller et al., 1997).

When using the street intercept method, the city block is the sampling unit. All blocks within the catchment area (the Haight-Ashbury neighborhood) were enumerated and selected at random according to a list of numbers. A team of two interviewers stood on randomly selected street corners at randomly selected times and approached youths as they walked by or as the interviewers found them seated on the sidewalk. If no youth passed by during a 15-minute period, the interviewers moved to the next randomized block. If they were successful in recruiting on a particular block, they continued to recruit there until 1 hour of recruitment time had passed. Interviewers were on the street at various times of the day between noon and 10 p.m. In this way, this study captured a cross-sectional representation of the street youth population in the Haight-Ashbury neighborhood.

The interviewers approached all youths who appeared to be between 12 and 21 years old. Eligibility criteria included being within this age range and having stayed on the street, in a park, in a car, or other transient domicile for at least 2 days during the past 30 days. Four hundred and fifty one youths were intercepted, of whom 170 (37.7%) refused to participate (most of them were “too busy”) and 72 were approached and did not meet the screening criteria (of those, 45 [62.5%] were too old and 27 [37.5%] were not staying on the streets), resulting in a 55% completion rate. Of the 209 surveys completed, 5 were not usable due to incompleteness or because the interviewer did not think the participant was reliable. Participants were judged to be unreliable if they gave contradictory answers (such as “never” drinking alcohol but having sex “while drunk”) or if they volunteered to the interviewer at the end of the survey that they had lied about their answers.

Most youths were eager to participate in the survey and seemed very willing to tell their stories. Participants were individually interviewed as privately as possible in doorways, coffee shops, and on the sidewalk. Each participant received a $5 phone card upon completion of the survey.
Measures

After screening participants and obtaining verbal informed consent, the interviewers administered a 30- to 45-minute structured survey instrument that was developed and piloted by the authors. The survey included questions with regard to (a) demographics, (b) history of leaving home, (c) alcohol and other drug use history, (d) sexual behavior, (e) condom attitudes and use, (f) beliefs about HIV and vulnerability to HIV, and (g) social affiliation. Demographic information collected included age, ethnicity, gender, education level completed, and the education levels completed by the participant’s mother and father. Data were collected about whether the participant had ever run away from home, been kicked out of home, or been removed from home by social service agencies and, if so, at what age and how often. These questions were followed by questions including “How long have you been away from home this time?” and “Could you go back home if you wanted to do so today?”

The alcohol and drug use behavior scale included questions that assessed participants’ drug use history (ever used), current use (past 30 days), injection drug use, and injection drug use behavior. Sexual behavior was assessed using a series of questions about behavior in the past year and in the past 30 days with primary and non-primary partners, including oral, anal, and vaginal sex, with and without condoms. Inconsistent condom use is defined for the purpose of this study as not using condoms 100% of the time for vaginal sex with a primary partner. A series of questions that assessed attitudes and beliefs about HIV was asked, including questions such as “If there were a vaccine for HIV, would you take it?” “Do you worry about getting AIDS?” and “Do you think there will be a cure for AIDS in the next 5 years?”

Social affiliation was assessed using several questions including “Is there an adult who is very supportive of you?” “Is there someone else in your life you are responsible for (financially, emotionally, or otherwise)” “Are you a member of a special group, street family, or gang?” “Do you have several close friends that you hang out with?” “Do you have friends you can trust and count on when you need them?” and “If you need to talk with someone, do you have a friend you can go to who will listen?” The study and all procedures involving participants were approved by the University of California, San Francisco, Committee on Human Research prior to initiation of the surveys.

Data Analysis

A total of 204 usable anonymous surveys were completed. To prevent duplicate surveys, a unique set of identifiers was collected. Summary statistics included frequency tables for categorical variables and medians and interquartile ranges for continuous variables. The associations between gender and risk variables were evaluated using the chi-square test of association. Two multiple logistic regression analyses were conducted to identify independent predictors of injection drug use and inconsistent condom use. Injection drug use and inconsistent condom use were selected as outcome variables because they represent the highest risk behavior for HIV transmission in this population. Models were constructed based on results found to be significant in bivariate analyses ($p < .05$), a priori hypotheses (such as history of abuse), and other variables of interest or potential confounders (such as age and race/ethnicity). Models were examined using both a backward and forward stepwise process. Variables were held in the models if they reached a significance level of .05 or less.

Results

Description of Sample

Demographics. Of the 204 participants, 108 (52.9%) were male, 95 (46.6%) were female, and 1 was a male-to-female transgender (0.5%). The data on the transgender youth were excluded due to the small number. There were no significant differences in age, education level, mother’s educational level, or other demographic characteristic, except being in touch with parents and history of sexual coercion or sexual abuse, between the two genders (see Table 1). Data on mother’s education level were collected as a gross indicator of socioeconomic status of the youth. The length of time away from home ranged from less than 1 week to 11 years, with a median time away from home of 3 years. A majority of the youths reported
having run away from home (75.9% of males and 73.7% of females) multiple times and having been kicked out of their homes (69.4% of males and 60.0% of females).

**Domicile.** Participants had been staying in many different places during the past 30 days, including in parks, on the streets, in squats (abandoned buildings), in shelters, on the beach, in vehicles (abandoned and not abandoned), in hotels, and in boarding houses. More than one half had spent nights on the street or in a park. Of those who had stayed 30 days in one place, nearly one half had stayed on the street or in abandoned cars.

**Sexual coercion and abuse.** More than 70% of females responded “yes” to the question “Has someone ever tried to force you into doing something sexually that you did not want to do?” (coercion) and about half responded “yes” to the question “Have you ever been forced by someone into doing something sexually that you did not want to do?” (abuse) (see Table 1). A little more than one third of males reported coercion and 13.9% reported abuse. Among those who were

<table>
<thead>
<tr>
<th>Variable</th>
<th>Males (n = 108)</th>
<th>Females (n = 95)</th>
<th>Significance of Pearson’s χ²&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median age in years (IQR)</td>
<td>19 (18-20)</td>
<td>18 (17-20)</td>
<td>ns</td>
</tr>
<tr>
<td>Range</td>
<td>(16-21)</td>
<td>(14-21)</td>
<td>ns</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>91 (84.3%)</td>
<td>79 (83.2%)</td>
<td>ns</td>
</tr>
<tr>
<td>Black/African American</td>
<td>2 (1.8)</td>
<td>1 (1.0)</td>
<td>ns</td>
</tr>
<tr>
<td>Latino</td>
<td>3 (2.8)</td>
<td>3 (3.2)</td>
<td>ns</td>
</tr>
<tr>
<td>Native American</td>
<td>4 (3.7)</td>
<td>3 (3.2)</td>
<td>ns</td>
</tr>
<tr>
<td>Multiethnic</td>
<td>8 (7.4)</td>
<td>9 (9.5)</td>
<td>ns</td>
</tr>
<tr>
<td>Did not complete high school</td>
<td>54 (50.0%)</td>
<td>50 (52.6%)</td>
<td>ns</td>
</tr>
<tr>
<td>High school graduate only</td>
<td>38 (35.2%)</td>
<td>30 (31.6%)</td>
<td>ns</td>
</tr>
<tr>
<td>Some college education</td>
<td>14 (13.0%)</td>
<td>15 (15.8%)</td>
<td>ns</td>
</tr>
<tr>
<td>Mother did not complete high school</td>
<td>10 (9.3%)</td>
<td>9 (9.5%)</td>
<td>ns</td>
</tr>
<tr>
<td>Mother graduated from high school or GED only</td>
<td>38 (35.2%)</td>
<td>26 (27.4%)</td>
<td>ns</td>
</tr>
<tr>
<td>Mother had some college or college graduate</td>
<td>39 (36.1%)</td>
<td>52 (54.7%)</td>
<td>ns</td>
</tr>
<tr>
<td>Does not know mother’s educational level</td>
<td>20 (18.5%)</td>
<td>8 (8.4%)</td>
<td>ns</td>
</tr>
<tr>
<td>From single-parent household</td>
<td>76 (70.4%)</td>
<td>67 (70.5%)</td>
<td>ns</td>
</tr>
<tr>
<td>Ever ran away from home</td>
<td>82 (75.9%)</td>
<td>70 (73.7%)</td>
<td>ns</td>
</tr>
<tr>
<td>Median age (in years) first ran away (IQR)</td>
<td>13 (11-15)</td>
<td>14 (12-15)</td>
<td>ns</td>
</tr>
<tr>
<td>Median number of times ran away since then (IQR)</td>
<td>2 (0-4)</td>
<td>2 (0-4)</td>
<td>ns</td>
</tr>
<tr>
<td>Ever removed from home by social services</td>
<td>47 (43.5%)</td>
<td>31 (32.6%)</td>
<td>ns</td>
</tr>
<tr>
<td>Ever been kicked out of home</td>
<td>75 (69.4%)</td>
<td>57 (60.0%)</td>
<td>ns</td>
</tr>
<tr>
<td>Could go home today if wanted to</td>
<td>44 (40.7%)</td>
<td>53 (55.8%)</td>
<td>ns</td>
</tr>
<tr>
<td>In touch with parents or guardians</td>
<td>72 (66.7%)</td>
<td>79 (83.2%)</td>
<td>0.013</td>
</tr>
<tr>
<td>In touch with mother</td>
<td>34 (31.5%)</td>
<td>38 (40.0%)</td>
<td>ns</td>
</tr>
<tr>
<td>In touch with father</td>
<td>7 (6.5%)</td>
<td>3 (3.2%)</td>
<td>ns</td>
</tr>
<tr>
<td>In touch with both</td>
<td>29 (26.8%)</td>
<td>37 (39.0%)</td>
<td>ns</td>
</tr>
<tr>
<td>Has a supportive adult in life</td>
<td>68 (63.0%)</td>
<td>63 (66.3%)</td>
<td>ns</td>
</tr>
<tr>
<td>Someone has tried to force them to do something sexually that they did not want to do</td>
<td>37 (34.3%)</td>
<td>68 (71.6%)</td>
<td>0.000</td>
</tr>
<tr>
<td>Someone has forced them to do something sexually that they did not want to do</td>
<td>15 (13.9%)</td>
<td>45 (47.4%)</td>
<td>0.002</td>
</tr>
</tbody>
</table>

NOTE: IQR = interquartile range; ns = not significant.

a. Pearson’s χ²<sup>a</sup> is for the comparison between males and females.
coerced, 35.1% of the males and 36.8% of the females reported that the incident(s) occurred while they were staying on the streets.

**Sexual Experiences and Behavior**

More than 8% of males reported having sex with other males during the past year, and more than 78% of males reported having sex with females during this time. More than 28% of females reported having sex with other females during the past year, and more than 82% of females reported having sex with males. Twelve percent (12%) of both males and females reported having sex in exchange for food, money, drugs, or shelter in the past year.

Five males (4.6%) and 12 females (12.6%) reported having sex with same-gender partners during the past 30 days. Two thirds of females (66.3%) and 55.6% of males reported having sex with the opposite gender. Only 5 males (4.6%) and 3 females (3.2%) reported exchanging sex for food, money, drugs, or shelter during the past 30 days. Of those who had sex during the past 30 days, more than 58% of the males and 76% of the females reported being in a primary relationship. This was defined as “a relationship with a person where you feel committed to him/her above anyone else and where you have sex together.” Primary relationships ranged in length from 1 day to 8 years, with males reporting a median of 2 months and females a median of 5 months. More than 70% of both males and females in primary relationships reported living with their partners. None of the reported primary relationships in the past 30 days were with persons of the same gender. Participants reported mainly oral and vaginal sexual activity and very little condom use with their primary partners.

Among those youths who reported having sex in the past 30 days (n = 140, or 68.9%), approximately the same number of males reported nonprimary relationships as primary relationships (53.0% compared to 58.2%), but fewer females reported nonprimary relationships (47.1% compared to 75.7%). Both males and females reported less sexual activity but higher rates of condom use with nonprimary partners than with primary partners. Of the males who reported being in primary relationships, 83.3% reported not using condoms consistently; of those in nonprimary relationships, 53.6% reported not using condoms consistently. Eighty percent of females in primary relationships reported not using condoms consistently, whereas 50.0% of females in nonprimary relationships reported inconsistent condom use. Inconsistent condom use was significantly associated with not being able to go back home, history of injection drug use including speed and heroin use, and having sex while drunk (see Table 2). Those reporting inconsistent condom use also were significantly more likely to report that the people they hang out with used needle exchange or bleach and that they think they were likely to be HIV infected. They also reported that it was hard to think about using a condom in the “heat of the moment.”

**Substance Use**

Reported polysubstance use was high in this sample, both as “ever used” and “used in the past 30 days” (current use). Tobacco was the most common cur-

---

**Table 2. Bivariate Correlates of Inconsistent Condom Use Among Street Youths in San Francisco**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can’t go back home</td>
<td>5.96</td>
<td>1.51-23.54</td>
<td>.011</td>
</tr>
<tr>
<td>Ever injected drugs</td>
<td>10.19</td>
<td>2.75-37.72</td>
<td>.001</td>
</tr>
<tr>
<td>Ever used speed</td>
<td>9.38</td>
<td>2.08-42.34</td>
<td>.004</td>
</tr>
<tr>
<td>Ever used heroin</td>
<td>9.11</td>
<td>2.48-33.47</td>
<td>.001</td>
</tr>
<tr>
<td>Ever had sex while drunk</td>
<td>8.43</td>
<td>2.13-33.38</td>
<td>.002</td>
</tr>
<tr>
<td>Most of the people they hang out with needle exchange or bleach</td>
<td>2.77</td>
<td>1.25-6.14</td>
<td>.012</td>
</tr>
<tr>
<td>What do they think their chances are of being HIV infected now?</td>
<td>7.18</td>
<td>1.49-34.63</td>
<td>.014</td>
</tr>
<tr>
<td>“It’s hard to think about using a condom in the heat of the moment with someone”</td>
<td>3.59</td>
<td>1.49-8.69</td>
<td>.004</td>
</tr>
</tbody>
</table>

NOTE: Inconsistent condom use is defined as not always using condoms for vaginal sex with primary partner.
Currently used substance in this group (91.7% of males and 86.3% of females), with marijuana second in popularity (88.0% of males and 88.4% of females). More than one half of the sample (males and females) reported using beer, liquor, and LSD in the past 30 days. Forty-two percent (41.7%) of males and 34.7% of females reported using methamphetamine in the past 30 days; 34.3% of males and 33.7% of females reported heroin use. More than sixty percent (60.2%) of males and 54.7% of females reported ever injecting drugs; 41.7% of males and 41.0% of females reported current injection drug use. There were no significant differences between males and females with regard to current use of drugs. Eighty-eight percent (87.9%) of males compared to 73.7% of females (p = .012) reported having sex while drunk, and 91.7% of males and 89.5% of females reported having sex while high. Those reporting injection drug use (see Table 3) were significantly more likely to report not being able to go home, not having a supportive adult in their lives, having been on the street for a longer period of time, being forced by someone into doing something sexually while staying on the street, and having run away from home at age 12 or younger. They were also more likely to report having seen a health care provider since being on the streets, smoking tobacco, that most of the people they hang out with use needle exchange or bleach, having sex while drunk, having sex while high, and not using condoms 100% for vaginal sex with their primary partner.

### Multivariate Logistic Regression Analyses Predicting High-Risk Behaviors

Logistic regression analyses were conducted on two outcomes defining high-risk behavior: ever injected drugs and inconsistent condom use. Age and gender were controlled for in both analyses.

Variables found to be independently associated with inconsistent condom use (defined as not using condoms 100% of the time for vaginal sex with primary partner) are shown in Table 4. The best-fitting
model for this outcome included “can’t go back home” and “hard to think about using a condom in the heat of the moment.”

Table 5 shows variables found to be independently associated with injection drug use. Collinear variables relating to drug use (such as sharing needles) and other drugs were excluded from the analyses. The best-fitting model included “can’t go back home” and “ever having sex while drunk” as predictors of injection drug use.

**“Could You Go Back Home?” as a Discriminating Variable**

The variable “Could you go back home if you wanted to do so today?” was a significant predictor of both selected outcome variables. We did additional analyses to determine whether this variable discriminated risk behaviors for HIV and STD among this sample. Dividing the sample into two groups based on the response to this question resulted in 97 youths who responded that they could go home, the “chosen homeless,” and 97 youths who said they could not, the “forced homeless.” Fifty-three males and 44 females felt they could not go back home if they wished, thus being categorized as forced homeless (see Table 6). These labels are meant as shorthand for distinguishing between the two groups based on their perceptions and are not intended to trivialize the complexities of the participants’ lives.

There were no significant differences between the chosen homeless and forced homeless youths with
regard to age, ethnicity, educational level, mother’s educational level, and being raised in a single-parent household. The forced homeless youths were significantly more likely to have run away before age 13 and to have been away from home for more than 3 years (see Table 6). The forced homeless youths were also more likely to have been kicked out of their homes and to not be in touch with their parents. Of those youths who had spent nights on the street or in abandoned vehicles \((n = 88)\), 65.9% were forced homeless, whereas 59.6% \((n = 47)\) of those who had spent nights in nonabandoned vehicles were chosen homeless. Sixty-four percent of those who had been staying on the beach \((n = 25)\) and 65.3% of those who had been staying in a motel, hotel, or boarding house \((n = 49)\) were forced homeless. Although the majority of youths reported having a supportive adult in their lives, significantly fewer forced homeless youths did so. Forced homeless youths reported more history of sexual abuse and reported that the abuse had occurred while they were staying on the streets.

There were no significant differences between the chosen homeless and forced homeless youths with regard to the number or gender of sexual partners and with using condoms 100% of the time for vaginal sex with primary partners, except that more forced homeless females reported inconsistent condom use \((22, \text{ or } 50\%)\) than chosen homeless females \((14, \text{ or } 31.8\%)\) \((\rho = .036)\). Of the forced homeless youths, 2 males and 3 females reported exchanging sex for food, money, drugs, or shelter compared to 1 chosen homeless male and 0 chosen homeless females.

Although close to 90% of the street youths sampled used tobacco, the forced homeless youths \((93, \text{ or } 95.9\%)\) were significantly more likely to use tobacco than the chosen homeless youths \((81, \text{ or } 83.5\%)\) \((\rho = .012)\). The forced homeless were more likely than chosen homeless to have used methamphetamine and to have injected drugs in the past 30 days. However, forced homeless youths were more likely than chosen homeless youths to report that they did not use a group cooker (a vessel, such as bottle cap, in which black tar heroin is heated and dissolved as part of the preparation process prior to injecting). Similarly, forced homeless were more likely to respond “yes” in response to the question “Do most of the people you hang out with use needle exchange or bleach?”

No significant differences were detected in agency visitation or HIV testing practices between the two groups. Sixty-eight \((70.1\%)\) forced homeless and 56 \((57.7\%)\) chosen homeless youths reported having seen a health care provider since being on the streets, and 76 \((78.4\%)\) forced homeless and 70 \((72.2\%)\) chosen homeless youths reported being tested for HIV antibodies.

Forced homeless youths were more likely to report that they would eat more meals if they could. There were no differences between the groups in their responses to whether they have close friends with whom they hang out; whether they are responsible for another person; and whether they consider themselves part of a street family, group, or gang. However, forced homeless were significantly more likely to answer “no” to the questions “Do you have friends you can trust and count on when you need them?” and “Do you have a friend who you can get $20 from if you need it?” In response to the question “Do you think your future is hopeful and bright?” more forced homeless responded “no.” There were no significant differences between the two groups in response to the questions “Do most of the people you hang out with worry about getting AIDS?” and “Do you worry about getting AIDS?” However, forced homeless were more likely to respond “no” to the question “Are you willing to have sex with HIV-positive partners?”

Discussion

This study adds to the documentation of street youths’ high-risk sexual and drug behavior that puts them at risk for HIV and STD. Although others have reported gender differences (Clements et al., 1997), we found few demographic or other life history differences between male and female participants in this study. However, this study identifies a significant relationship, previously unreported, between high-risk behavior and perception of the ability to return home. We determined that we can discriminate between moderate-risk and high-risk youths by asking about whether they feel they can go back home. The participants fall into two roughly equal size groups based on whether they could return home if they wished. The differences between the groups are dramatic. Al-
though both groups engage in high-risk behavior at alarming rates, those who cannot return home appear to be significantly more vulnerable to HIV and STD than their counterparts who can go home. The data describe a group of youths, termed forced homeless, who have been on the streets for a long time with no supportive adults in their lives, not enough to eat, and nowhere else to go. Forced homeless youths were also more likely to respond with answers that suggested social isolation, such as not being in touch with their parents, not using a group cooker, not having friends they can trust and count on when needed, and not having a friend from whom they can get $20 if needed.

The responses of the chosen homeless youths reflect more accessibility to resources. More of them were staying in hotels or in nonabandoned vehicles, and they were significantly less likely to be hungry. Although they had been experimenting with drugs during the past 30 days, they were less likely to have injected drugs. Chosen homeless youths perceived that they could go home if they wanted to do so.

Not being able to return home was highly correlated with the highest HIV risk behavior. Self-reported prevalence of HIV infection was very low in the sample (n = 1). Nonetheless, high-risk sexual practices and needle use among street youths create a situation in which HIV infection, if present, could spread rapidly through the population.

A limitation of this study is the reliance on participants’ self-reported data, which cannot be verified. However, because risk behavior is likely to be underreported, the risk estimates are likely to be conservative in this sample. No data were collected on those who refused to participate in the study, so how they differ from the participants is unknown. The investigators are also cognizant of the fact that there may be seasonal variations in the population of street youths who populate the Haight-Ashbury neighborhood, with an influx of chosen homeless youths during the spring and summer. Furthermore, no causality can be imputed due to the cross-sectional nature of this study. However, by using a systematic street-based sampling strategy, the investigators were able to survey youths who might not interact with the health or social service systems. Although these results cannot be generalized to other geographic areas or even to all street youths in the Haight-Ashbury neighborhood, we believe they can be taken as substantially representative of street youth in this area at the time of the study.

HIV prevention efforts must be enhanced among street youth, and efficient, specific screening tools can help focus such efforts to those at highest risk. In addition, we should intervene with newly arrived younger street youth before they become enmeshed in the street culture of risky behavior. Our analysis suggests that asking the question “Could you go back home today if you wanted to?” provides a simple and powerful screening tool for this purpose. This screening question can be especially useful for nurses and other health care providers who may have very limited time for risk assessment. Participants’ relatively high reported willingness to seek health care affords a prime opportunity for health care providers to identify those at highest risk and to provide information, counseling, and other interventions and resources to reduce risk behavior. Additional research should be done to validate this question as a screening tool for highest risk behavior among street youths.

Much work remains to be done in developing and refining HIV risk reduction interventions for street youths. The data from this study provide a profile of those at highest risk that may help to inform the development of interventions. However, they also reveal a complex array of problems faced by those at highest risk, including prevalent histories of sexual abuse and lack of resources such as reliable friends or supportive adults. Effective interventions will have to address HIV risk in the context of the complex lives of street youths.

Acknowledgments

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References


Anemia in HIV-infected individuals, still a common hematologic complication in the highly active antiretroviral therapy (HAART) era, is associated with shortened survival, increases in the rate of disease progression, and reduction in quality of life. Based on a thorough review of the literature, guidelines were developed for the assessment, diagnosis, monitoring, and treatment of anemia in patients with HIV/AIDS by a consensus committee consisting of nurses from academia and clinical practice. A major goal of this committee is to increase awareness within the nursing community of the prevalence of anemia in HIV-infected patients and its impact on their lives. Anemia developed in close to 90% of HIV-infected patients before the introduction of HAART, and it is still found in up to 46% of patients in the HAART era. Another goal is to encourage screening for anemia and the adaptation of a proposed classification system of anemia based on a graded decrease in hemoglobin levels.

Key words: anemia, guidelines, HIV/AIDS, survival, quality of life, epoetin alfa

Nursing guidelines for the assessment, diagnosis, monitoring, and treatment of anemia in patients infected with HIV were developed by a consensus committee consisting of nurses from both clinical practice and academia across the United States who are experts in the management of patients with HIV/AIDS. A major goal of this committee was to increase awareness in the nursing community of the prevalence of anemia and the impact of below-normal hemoglobin levels on survival, disease progression, fatigue, and other quality-of-life (QOL) parameters in patients with HIV infection. The treatment recommendations advanced by this committee were based on the following:

- A thorough review of the medical literature on the prevalence and etiology of anemia in HIV-positive patients and the consequences of not treating or undertreating anemia;

Richard S. Ferri, PhD, ANP, ACRN, FAAN, is an HIV/AIDS nurse practitioner and consultant in Provincetown, Massachusetts. Anthony Adinolfi, MSN, ANP, ACRN, is an assistant clinical professor at Duke University Medical Center. Allen J. Orsi, PhD, RN, is an associate professor at Hahn School of Nursing at the University of San Diego. David J. Sterken, MN, CNS, CPNP, is a pediatric infectious disease nurse practitioner at DeVos Children's Hospital, Grand Rapids, Michigan. Jeannie C. Keruly, BSN, RN, is a research assistant and manager of HIV clinical services at Johns Hopkins University. Sheila Davis, MSN, ANP, ACRN, is an adult nurse practitioner at Massachusetts General Hospital, Boston. Richard C. MacIntyre, PhD, RN, is a professor and division chair of nursing and health sciences at Mercy College, Dobbs Ferry, New York.
Current assessment/monitoring practices, diagnostic procedures, and treatment strategies for anemia in patients with HIV/AIDS;

A focus on basic nursing care for patients with anemia;

The clinical expertise of the consensus committee members.

The development of these guidelines was supported by a grant from Ortho Biotech Products, LP. Ortho Biotech was not involved in determining the membership of the committee or the content of the guidelines.

In this first of two articles, a comprehensive review of anemia in HIV-infected patients in terms of its prevalence, etiology, and impact on survival, disease progression, and QOL is presented to provide the reader with a framework for assessing these guidelines. This section is followed by the recommended guidelines for the assessment, diagnosis, monitoring, and staging of the severity of anemia in patients with HIV infection. Guidelines for managing HIV-related anemia, pediatric considerations, and nursing care of patients with HIV infection and anemia are presented in the second article.

Prevalence/Incidence of Anemia in Adults and Adolescents With HIV Infection

Anemia is frequently observed in adults and adolescents with HIV infection, although the reported prevalence varies based on the definition of anemia, the severity of HIV disease, sex, race/ethnicity, and the prolonged use of myelosuppressive chemotherapeutic and antiretroviral agents. Thus, in different observational studies, anemia has been defined by threshold hemoglobin levels ranging from <9.5 to <14 g/dL (Creagh et al., 2000; Mocroft et al., 1999; Moore, Keruly, & Chaisson, 1998; Sharp, Paredes, & Steinbock, 1999; Sullivan, Hanson, Chu, Jones, & Ward, 1998). Results from the Multistate Adult and Adolescent Spectrum of HIV Disease Surveillance Project involving 32,867 patients showed that the percentage of patients with anemia (hemoglobin <14 g/dL in men and <12 g/dL in women) at baseline increased from 28% to 31% in HIV-infected patients without AIDS to 77% to 87% in patients with AIDS-defining illness (Sullivan et al., 1998). In this same study, the 1-year incidence of anemia (hemoglobin <10 g/dL), defined differently from the prevalence of anemia, was 16.7% overall, 31.6% in patients with CD4 lymphocyte counts less than 200 cells/µL, and 4.6% in patients with CD4 lymphocyte counts of at least 200 cells/µL (Sullivan et al., 1998). Moreover, in patients who had CD4 lymphocyte counts of less than 200 cells/µL and who were not prescribed chemotherapeutic agents (e.g., zidovudine, didanosine, and ganciclovir), the 1-year incidence of anemia was higher in women than in men (34.1% vs. 23.6%) and higher in Blacks (30.4%) than in Whites (23.6%) or Hispanics (18.8%). Among the 1,410 adult HIV-infected patients treated at a large HIV clinic in New York City, more women than men (22% vs. 10%) and more African Americans than Whites or Hispanics (17% vs. 10% to 11%) were anemic (hemoglobin <11 g/dL) (Sharp et al., 1999).

Although the prevalence of anemia in HIV-infected patients has declined since the introduction of highly active antiretroviral therapy (HAART), anemia continues to be problematic for many patients (Creagh et al., 2000; Mocroft et al., 1999; Moore, Keruly, & Chaisson, 1999; Sharp et al., 1999). For example, the annual prevalence of anemia in 1,791 patients with HIV infection and hemoglobin levels between 9 and 11 g/dL changed only slightly, from 12.8% in 1995 to 11.5% through June 1998 (Moore et al., 1999). However, the decline in the annual prevalence of more severe anemia (hemoglobin <9 g/dL) was more apparent (from 5.8% in 1995 to 3.9% in 1998). In a subset of 1,624 HIV-infected patients in the EuroSIDA study, 34.5% had no anemia, 64.0% had mild anemia (hemoglobin 8 to 14 g/dL in men and 8 to 12 g/dL in women), and 1.5% had severe anemia (hemoglobin <8 g/dL for both men and women), whereas 12 months after initiation of HAART, these proportions changed to 53.8%, 45.6%, and 0.6%, respectively (Mocroft et al., 1999). Among 361 HIV-infected patients seen at an urban infectious diseases clinic, 80% had received HAART sometime between 1996 and 1998 and 21% were diagnosed with anemia (hemoglobin <11 g/dL) (Creagh et al., 2000).
Etiology of Anemia in Patients With HIV Infection

Anemia is not a specific disease entity but, rather, a sign of an underlying pathology (Corrigan & Stockman, 1992). The multiple causes of anemia in HIV-infected patients can be categorized into those that arise from decreased erythropoiesis, ineffective erythropoiesis, or increased red blood cell (RBC) destruction (see Table 1) (Levine, 1999). Anemia will also develop in patients who experience excessive blood loss. Types of anemia caused by decreased erythropoiesis include those resulting from bone marrow damage due to infiltration of certain cancers or opportunistic microorganisms or to the use of myelosuppressive agents (Bain, 1999; Coyle, 1997; Henry, 1998; Kreuzer & Rockstroh, 1997; Levine, 1999). Early in the HIV epidemic, *Mycobacterium avium* complex (MAC) disease was frequently observed in patients with AIDS (Havlir & Ellner, 2000) and was a common cause of severe anemia in HIV-infected patients (Gardener et al., 1988). More recently, there has been a marked decline in MAC disease, which has been attributed to the use of HAART (Palella et al., 1998). Parvovirus B19 also induces anemia in HIV-infected patients, but there is evidence that the incidence is similar to that seen in HIV-negative individuals (Kreuzer & Rockstroh, 1997). Cytomegalovirus (CMV) infection is commonly seen in patients with AIDS and is associated not only with reduced erythropoiesis but also with hemophagocytic syndromes (Bain, 1999). However, the time to progression of CMV retinitis has increased in recent years due to the use of HAART (Labetoulle et al., 1999). Other pathogens, such as *Pneumocystis carinii* and *Leishmania* species, may cause anemia in patients with HIV infection in rare circumstances (Kreuzer & Rockstroh, 1997).

Because of the frequency of recurrent opportunistic infections in patients with AIDS, anemia of chronic disease is the most common type of anemia seen in this population (Coyle, 1997). However, anemia of chronic disease is underdiagnosed and often inappropriately treated and misunderstood (Abramson & Abramson, 1999). In this condition, RBCs are typically normochromic and normocytic, but during chronic or recurrent opportunistic infection they may become hypochromic and microcytic (Bain, 1999; Coyle, 1997). Anemia of chronic disease is further characterized by an inadequate production of erythropoietin; resistance to the action of endogenous erythropoietin;

Table 1. Causes of Anemia in Patients With HIV Infection

<table>
<thead>
<tr>
<th>Mechanism</th>
<th>Cause</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decreased red blood</td>
<td>Tumor infiltration of the bone marrow (e.g., Burkitt’s lymphoma, Kaposi’s sarcoma, or Hodgkin’s lymphoma)</td>
</tr>
<tr>
<td>cell production</td>
<td>Opportunistic microorganisms (e.g., <em>Mycobacterium avium</em> complex, <em>Mycobacterium tuberculosis</em>, <em>Candida</em> species, cytomegalovirus, <em>Pneumocystis carinii</em> pneumonia, and parvovirus B19)</td>
</tr>
<tr>
<td>Anemia of chronic disease</td>
<td>Drug therapy (e.g., zidovudine, ganciclovir, amphotericin B, trimethoprim-sulfamethoxazole, paclitaxel, and vinblastine)</td>
</tr>
<tr>
<td>Iron deficiency</td>
<td></td>
</tr>
<tr>
<td>Ineffective red blood</td>
<td>Vitamin B12 deficiency</td>
</tr>
<tr>
<td>cell production</td>
<td>Folic acid deficiency</td>
</tr>
<tr>
<td>Thalassemias</td>
<td></td>
</tr>
<tr>
<td>Increased red blood</td>
<td>Coombs-positive hemolytic anemia</td>
</tr>
<tr>
<td>cell destruction</td>
<td>Hemophagocytic syndrome</td>
</tr>
<tr>
<td></td>
<td>Thrombotic thrombocytopenic purpura</td>
</tr>
<tr>
<td></td>
<td>Disseminated intravascular coagulation</td>
</tr>
<tr>
<td></td>
<td>Drugs (e.g., sulfonamides and oxidant drugs in patients with G6PD deficiency)</td>
</tr>
<tr>
<td></td>
<td>Sickled cell anemia</td>
</tr>
</tbody>
</table>

abnormalities of iron metabolism, including an impairment in the transport of iron from the liver and bone marrow to erythrocytes; decreased erythrocyte life span; and an increased expression of inflammatory cytokines (e.g., tumor necrosis factor-α, interferon-γ, and interleukin-1) (Abramson & Abramson, 1999; Bain, 1999; Coyle, 1997; Friedman-Kien et al., 1990). The increase in the level of circulating cytokines has been correlated with the severity of anemia and may interfere with the production of erythropoietin (Coyle, 1997).

The use of myelosuppressive drugs, such as zidovudine, ganciclovir, ribavirin, and vinblastine, is frequently associated with decreased erythropoiesis and the development of anemia (Coyle, 1997; Dieterich, Weisz, Goldman, & Malicdem, 1999; Fischl et al., 1989; Gabrilove, Einhorn, Cleeland, Livington, & Winer, 1999; Gabrilove, Einhorn, Livingston, Winer, & Cleeland, 1999; Levine, 1999; Richman et al., 1987). Zidovudine monotherapy at high doses causes marked myelosuppression, which is associated with macrocytosis and megaloblastic erythropoiesis (Bain, 1999). An early study with zidovudine showed that 24.5% of patients using this agent had hemoglobin levels less than 7.5 g/dL and 12.6% had hemoglobin levels less than 6.5 g/dL (Richman et al., 1987). The prevalence of zidovudine-induced anemia has declined since the recommended dose was reduced from 1500 mg/d to 500 to 600 mg/d (Henry, 1998). Although nucleoside reverse transcriptase inhibitors and protease inhibitors appear to be less toxic to bone marrow than zidovudine (Bain, 1999), a recent study has demonstrated that the protective effect of HAART on the development of anemia was lost when zidovudine was included in the HAART regimen (Berhane et al., 2000). Finally, one of the most myelosuppressive drugs used to treat opportunistic infections is ganciclovir, which is commonly used for the treatment of CMV infection (Bain, 1999).

Iron deficiency anemia resulting from chronic blood loss or a dietary deficiency can also impair erythropoiesis (Coyle, 1997; Kreuzer & Rockstroh, 1997; Levine, 1999). A deficiency in vitamin B12 or folic acid can lead to ineffective erythropoiesis and megaloblastic anemia (Kreuzer & Rockstroh, 1997; Levine, 1999). Vitamin B12 deficiency has been noted in up to 30% of HIV-infected patients (Kreuzer & Rockstroh, 1997) and probably results from HIV-related malabsorptive complications (Levine, 1999). The thalassemias, which produce microcytic hypochromic anemia, are caused by a deficiency in normal globin genes (Beutler, 1998; Hillman, 1998). The prevalence of β-thalassemia is very common in parts of southern Europe (Beutler, 1998). For example, 12% of the population of Sardinia has the thalassemia trait (patients are usually heterozygotes) (Beutler, 1998).

Oxidant-induced RBC destruction has been identified in patients who are deficient in glucose-6-phosphate dehydrogenase (G6PD) and receiving oxidant drugs such as dapsone for *P. carinii* prophylaxis or primaquine for the treatment of *Pneumocystis* species infection (Bain, 1999). It has also been shown to occur in patients (Levine, 1999) who have developed autoantibodies to RBCs (Bain, 1999; Coyle, 1997; Levine, 1999). Epstein-Barr virus (EBV) and CMV are the viral infections that most frequently result in hemophagocytic syndromes (Bain, 1999). EBV can affect any organ system and may cause a variety of hematologic abnormalities, including hemolytic anemia, aplastic anemia, and hemolytic uremic syndrome (Beaulieu & Sullivan, 1997). Ribavirin may induce hemolytic anemia in patients coinfected with hepatitis C virus (HCV) and HIV (Bodenheimer et al., 1997; Dieterich et al., 1998). Thrombocytic thrombocytopenic purpura and hemophagocytic syndrome are also causes of anemia in HIV-infected patients (Coyle, 1997; Levine, 1999). Sickle cell anemia develops in patients who are homozygous for hemoglobin S (Beutler, 1998). Approximately 1:650 African Americans are predicted to have sickle cell anemia (Beutler, 1998).

**Impact of Anemia in Patients With HIV Infection**

**HIV Disease Progression and Survival**

Numerous studies have demonstrated that anemia in HIV-infected patients increases the risk of disease progression and death (Chene et al., 1997; Creagh et al., 2000; Creagh-Kirk et al., 1988; Graham et al., 1993; Mocroft et al., 1999; Moore et al., 1998; Sullivan et al.,
An analysis of the survival data \((n = 19,213)\) from the Multistate Adult and Adolescent Spectrum of HIV Surveillance Project revealed that anemia (hemoglobin <10 g/dL) was associated with a 148% increase in the risk of death for patients with baseline CD4 lymphocyte counts of at least 200 cells/µL, irrespective of the presence of clinically manifested AIDS and the use of antiretroviral therapy (Sullivan et al., 1998). Across all CD4 categories (baseline counts of 0 to 49, 50 to 99, 100 to 149, 150 to 199, and ≥200 cells/µL), median survival was significantly shorter for patients with anemia than for those without anemia. For example, in the CD4 category of 150 to 199 cells/µL, median survival was 29 months in anemic patients compared to 48 months in nonanemic patients \((p = .0001)\). Additionally, failure to recover from anemia was associated with a 170% increase in the risk of death.

In the EuroSIDA study \((n = 6,725)\), a 1 g/dL decrease in the most recent hemoglobin level was associated with a 57% increase in the risk of death, independent of the viral load or CD4 lymphocyte count (Mocroft et al., 1999). Kaplan-Meier analysis for progression to death according to baseline hemoglobin levels showed that 3.1% of patients without anemia (hemoglobin >14 g/dL for men and >12 g/dL for women), 15.9% of patients with moderate anemia (hemoglobin 8 to 14 g/dL for men and 8 to 12 g/dL for women), and 40.8% of patients with severe anemia (hemoglobin <8 g/dL for men and women) were estimated to have died 12 months after entry into the study. Additionally, the median annual change in hemoglobin level was −2.41 g/dL in patients who died versus +0.25 g/dL in patients who did not.

Studies conducted during the HAART era have shown that anemia is still prognostic of disease progression (Creagh et al., 2000; Lundgren et al., 2000) and death (Levine et al., 2000; Lewden et al., 2000).

**Fatigue and QOL**

Anemia is associated with fatigue, reduced energy and activity levels, poorer overall QOL, and an increased risk of dementia in HIV-infected patients (Abrams, Steinhart, & Frascino, 2000; Cosby et al., 1998; McArthur et al., 1993; Revicki et al., 1994; Saag, Levine, Deyton, & the Community HIV Anemia Management Protocol Sites [CHAMPS], 1999).

Fatigue is generally recognized as a highly prevalent symptom in patients with HIV infection (Barroso, 1999; Breitbart, McDonald, Rosenfeld, Monkman, & Passik, 1998; Cella, Mo, & Peterman, 1996; Groopman & Piper, 1998; Sullivan & Dworkin, 2000; Tindall et al., 1988), occurring transiently in the majority of patients at the time of acute infection (Groopman & Piper, 1998; Kaslow et al., 1987; Lang et al., 1987) and then reappearing with the progression of HIV disease (Darko, McCutchan, Kripke, Gillin, & Golshan, 1992). An analysis of 17,630 HIV-infected patients showed that the fatigue rate was 14.1/100 patient years for those without a diagnosis of AIDS versus 49.6/100 patient years for those with an AIDS-defining opportunistic illness (Sullivan & Dworkin, 2000).

Although fatigue is a subjective perception, it is typically characterized by a loss of energy and a feeling of weakness, lethargy, malaise, or asthenia (Groopman & Piper, 1998). The etiology of fatigue is multifactorial, and although anemia is considered to be the primary cause of fatigue in patients with HIV infection (Groopman & Piper, 1998), there are other physiological and psychological causes of fatigue, such as hormonal and nutritional deficiencies, pain, infection, depression, sleep disturbances, and excessive inactivity (Barroso, 1999; Groopman & Piper, 1998; Sullivan & Dworkin, 2000).

**Guidelines for the Assessment, Diagnosis, and Monitoring of Anemia in Patients With HIV Infection**

Based on the high impact of anemia in patients with HIV infection, the Nursing Guidelines Committee for Anemia in Patients With HIV Infection recommends that screening for anemia should begin with the first visit and be repeated at the same time that CD4 lymphocyte counts and viral loads (HIV-1 RNA concentration) are assessed—every 2 to 3 months. The frequency with which laboratory values are obtained should increase with disease progression, the presence of opportunistic infection or malignancy, low baseline hemoglobin levels, and the use of myelosuppressive drugs.

The approach for evaluating the presence and etiology of anemia involves a complete history, a physical
examination, and documentation of the signs and symptoms of anemia (see Figure 1) (Hillman, 1998). A history relevant for the diagnosis of anemia should focus on the history of blood loss, country of origin or history of recent travel (for the possibility of parasitic infection), medication history, drug or alcohol abuse, eating habits, malignancies or hematologic disorders, other comorbidities (e.g., HCV infection), changes in bowel habits, and altered menstruation patterns. A patient’s ethnic background or race may provide important information for the diagnosis of anemia (Hillman, 1998). For example, β-thalassemia is more frequently seen in patients of Greek and Italian descent, whereas α-thalassemia is more common in Blacks, Native Americans, and Asians (Abramson & Abramson, 1999).

Symptoms and Signs of Anemia

Symptoms of anemia are particularly important in cases of a borderline diagnosis of anemia based on laboratory tests. Additionally, symptoms may be key diagnostic features that raise the index of suspicion and lead to closer evaluation/diagnosis of the patient’s condition. Key anemia symptoms are shown in Table 2. As indicated previously, fatigue is a commonly reported symptom. Exercise intolerance, palpitations, and pallor of the skin, mucous membranes, and nail beds are indicative of a more severe degree of anemia (Hillman, 1998; Koeller, 1998). Hemoglobin levels are usually less than 8 g/dL when the palmar creases of the hand are lighter than the surrounding tissue (Hillman, 1998). Other physical signs of anemia may include weight loss, glossitis, cheilitis, lymphadenopathy, hepatosplenomegaly, rectal or pelvic mass, a guaiac-positive stool, mild peripheral edema, and retinal hemorrhages. Severe iron deficiency may be present in patients who report a sore mouth, difficulty swallowing, or pica (Hillman, 1998).

Relevant laboratory tests used for the differential diagnosis of anemia in all patients with HIV begin with a complete blood count and a reticulocyte count corrected for the hematocrit (absolute % reticulocytes = % reticulocytes × hematocrit ÷ 45) (Hillman, 1998). Additional tests are performed to determine serum iron, transferrin iron-binding capacity, serum ferritin, the presence of vitamin B12 or folic acid deficiency, and the presence of occult blood (Hillman, 1998).
Finally, bone marrow examinations, free testosterone levels, G6PD activity (if the patient is receiving oxidant drugs), and other tests may be necessary in identifying the cause of anemia.

Although endogenous erythropoietin concentrations are not routinely measured, it may be necessary to do so under certain circumstances. For example, if the patient is to receive recombinant human erythropoietin (epoetin alfa) therapy, noting the baseline erythropoietin concentration, which normally ranges from 4 to 26 mU/mL (Spivak, Barnes, Fuchs, & Quinn, 1989), may assist the clinician in managing HIV-related anemia. Earlier studies showed that HIV-infected patients with endogenous erythropoietin concentrations of 500 mU/mL or less were more likely to respond to epoetin alfa therapy than those with higher concentrations (Fischl et al., 1990; Henry et al., 1992). However, a recent analysis of data from more than 1,200 cancer patients receiving chemotherapy demonstrated that endogenous erythropoietin concentration was not a significant factor in the hemoglobin response to epoetin alfa (Glaspy, Demetri, & Cremieux, 1999).

### Traditional Chinese Medicine and Anemia

Traditional Chinese medicine (TCM) has several diagnostic categories that roughly correspond to the different types of anemia identified in Western medicine. These diagnoses include deficiencies in blood and qi (energy) and blood stasis. Ryan and Shattuck (1994) noted that the TCM diagnosis of blood deficiency “does not equal anemia although the latter may imply the former” (p. 139). Using TCM, the authors classified aplastic anemia, which is not commonly seen in patients receiving HAART, as a “kidney deficiency,” which in turn causes a “spleen deficiency.” It is important to remember that “kidney, spleen, liver, heart, lung and blood” are English translations of Chinese concepts. In TCM, these terms do not refer exclusively or literally to the respective organs. The terms are broader theoretical concepts that refer to TCM’s organization of “systems.” In TCM, the kidney system controls the bone marrow, and the spleen system has a major role in the regulation and production of blood even if the respective organs have been removed (Casey, Cohen, & Hughes, 1996).

The TCM diagnosis is primarily based on examination of the patient that evaluates the patient’s history; the evolution and present state of clinical symptoms; and the patient’s pulse, tongue, and countenance, since laboratory values are not used. However, TCM practitioners are increasingly incorporating Western data into their diagnoses. For example, Zhang and Hsu (1995) reported seeing patients with low RBC counts (normal counts 4.7 to 6.1 × 10¹² cells/L) in their TCM practice as follows: AIDS, 4.14 × 10¹² cells/L; AIDS-related complex, 3.88 × 10¹² cells/L; and HIV-positive, 4.68 × 10¹²/L. The authors developed herbal formulas to correct their patients’ blood stasis and then to “tonify” their blood and kidney systems. Additionally, Ryan and Shattuck (1994) identified four major “patterns” of anemia in patients with HIV infection and listed acupuncture treatment points for each pattern.

TCM distinguishes among at least seven patterns of “disharmony” that correspond to the major etiologic causes of iron deficiency anemia identified in Western medicine. Treatment goals of TCM for this condition consist of not only increasing dietary iron but also improving underlying patterns that interfere with absorption of nutrients. The modern TCM literature outlines the similarities and differences between Western medicine and TCM approaches to the diagnosis and treatment of anemia (Becker, 2000; Maciocia, 1981). Further research is needed to determine whether TCM might be used effectively and safely in the treatment of the aplastic and iron deficiency types of anemia seen in people with HIV disease.

### Table 2. Symptoms of Anemia in Patients With HIV Infection

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>Insomnia</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>Decrease in cognitive function</td>
</tr>
<tr>
<td>Pain</td>
<td>Malaise</td>
</tr>
<tr>
<td>Weakness</td>
<td>Agitation</td>
</tr>
<tr>
<td>Depression</td>
<td>Headache</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Loss of libido</td>
</tr>
<tr>
<td>Palpitations</td>
<td>Impairment of activities of daily living</td>
</tr>
<tr>
<td>Dizziness</td>
<td>Pica</td>
</tr>
<tr>
<td>Exercise intolerance</td>
<td>Amenorrhea</td>
</tr>
<tr>
<td>Pallor</td>
<td>Cold intolerance</td>
</tr>
<tr>
<td>Increased use of stimulants to combat fatigue (e.g., caffeine, nicotine, amphetamines)</td>
<td>Edema</td>
</tr>
</tbody>
</table>

QOL Assessment

QOL is an important factor that should be assessed routinely at every regular medical visit (every 2 to 3 months), now that patients with HIV infection are living longer and often returning to work and other daily activities due to improved therapeutic regimens and management strategies (Moore & Chaisson, 1999; Palella et al., 1998; Wong et al., 2000). Several QOL questionnaires have been developed to evaluate the status of patients with cancer or HIV infection, including the Medical Outcomes Study HIV Health Survey (MOS-HIV) (Wu, Revicki, Jacobson, & Malitz, 1997), the revised Functional Assessment of Human Immunodeficiency Virus Infection (FAHI) (Peterman, Cella, Mo, & McCain, 1997), the Functional Assessment of Cancer Therapy-Anemia (Yellen, Cella, Webster, Blendowski, & Kaplan, 1997), the Linear Analogue Scale Assessment (Coates et al., 1983), and the Piper Fatigue Scale (Piper et al., 1998). The advantages and disadvantages of selected assessment instruments are described in Table 3. It is recommended that upon diagnosis of anemia, patients should be given a standardized QOL questionnaire, such as the revised Functional Assessment of Human Immunodeficiencies Virus Infection (FAHI) or the Medical Outcomes Study HIV Health Survey (MOS-HIV), to obtain a baseline score. Both assessment instruments have been translated into several languages. On subsequent visits, a shorter QOL questionnaire may be administered that is directed more to patients with anemia. A six-item questionnaire adapted from the MOS-HIV has been proposed by the Anemia in HIV Working Group, an expert panel of physicians and researchers involved in the care of patients with HIV infection (Volberding, 2000). Abbreviated QOL questionnaires may be developed by clinicians using selected questions from the MOS-HIV or revised FAHI that assess fatigue, functional status, and activities of daily living, which are tailored to specific demographic groups.

Table 3. Assessment Tools for Evaluating Quality of Life

<table>
<thead>
<tr>
<th>Tool</th>
<th>Description</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAHI</td>
<td>Consists of 44 questions distributed among five subscales (physical, functional and global, emotional [living with AIDS], social well-being, and cognitive functioning) for calculation of a total QOL score</td>
<td>Validated questionnaire with internal consistency and reliability Designed for patients with HIV infection Easy to administer and score Suitable for use in clinical trials and clinical practice</td>
<td>May be too long for routine assessment of QOL in a busy HIV/AIDS clinic</td>
</tr>
<tr>
<td>MOS-HIV</td>
<td>Consists of a 35-item questionnaire to measure total QOL and 10 dimensions of health (health perceptions, pain, physical functioning, role functioning, social functioning, cognitive functioning, mental health, energy, health distress, and QOL)</td>
<td>Validated questionnaire with internal consistency and correlation with measures of health Designed for patients with HIV infection Capable of predicting future outcomes Can be completed in approximately 5 minutes</td>
<td>Limited use in women, injecting drug users, and African Americans Requires comparison to other health-related QOL assessments in early HIV disease</td>
</tr>
<tr>
<td>FACT-An</td>
<td>Consists of 28 questions that measure different types of well-being (physical, functional, emotional, social, and family) plus an anemia subscale (13-item fatigue component and seven-item nonfatigue component)</td>
<td>Validated questionnaire with internal consistency, test-retest reliability, and the ability to discriminate patients by hemoglobin level</td>
<td>Developed for patients with cancer May be too long for routine assessment of QOL in a busy HIV/AIDS clinic</td>
</tr>
</tbody>
</table>


reflecting age, sex, and race/ethnicity. A symptom distress scale or visual analog scale may be most appropriate for some demographic groups.

**Guidelines for the Diagnosis and Staging of the Severity of Anemia in Patients With HIV Infection**

Reference ranges for normal hemoglobin levels, threshold hemoglobin levels for the diagnosis of anemia, and the severity of anemia defined by the hemoglobin level vary among organizations such as the Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, 1998), the National Cancer Institute (Groopman & Itri, 1999), the World Health Organization (World Health Organization, 1968), the Adult AIDS Clinical Trials Group (ACTG) (Division of AIDS Regulatory Operations Center, 1998), and other sources (see Table 4) (Hillman, 1998). Moreover, maximum hemoglobin levels and hematocrit values for anemia are influenced by age, sex, and pregnancy (see Table 5) (Hillman, 1998). Finally, some degrees of anemia relate to the reporting of adverse events in clinical trials (e.g., those used by the ACTG) and may be too strict for defining clinically relevant anemia seen commonly in medical practice. This results in underdiagnosis and a lack of appreciation for the impact of lesser degrees of anemia on the patient’s quality of life and energy level.

To standardize screening procedures and avoid differences in values between normal reference ranges from different laboratories and the effects of age and sex, the Nursing Guidelines Committee for Anemia in Patients With HIV Infection recommends that for adults and adolescents, a diagnosis of mild, moderate, and severe anemia should be based on a graded decrease in hemoglobin level from that considered to be normal for the individual patient or laboratory (see Table 6). These guidelines also acknowledge that milder forms of anemia not associated with an underlying cause can be treated without a blood transfusion. Even with severe anemia, the risks and benefits of blood transfusion need to be carefully considered.

The guidelines committee recommends that mild anemia be defined as a hemoglobin level that is 1 to 1.9 g/dL below the lower limit of the normal range (12 to 16 g/dL for women and 14 to 18 g/dL for men) with no significant symptoms. Similarly, a hemoglobin level

---

**Table 4. Definition of Anemia Based on Hemoglobin Level**

<table>
<thead>
<tr>
<th></th>
<th>NCI</th>
<th>ACTG</th>
<th>WHO</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Normal values</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>14-18 (NL)</td>
<td>—</td>
<td>≥11</td>
</tr>
<tr>
<td>Women</td>
<td>12-16 (NL)</td>
<td>—</td>
<td>≥11</td>
</tr>
<tr>
<td>Adolescents</td>
<td>—</td>
<td>—</td>
<td>≥11</td>
</tr>
<tr>
<td><strong>Mild</strong></td>
<td>10.0-NL</td>
<td>8.0-9.4</td>
<td>9.5-10.9</td>
</tr>
<tr>
<td><strong>Moderate</strong></td>
<td>8.0-10</td>
<td>7.0-7.9</td>
<td>8.0-9.4</td>
</tr>
<tr>
<td><strong>Severe</strong></td>
<td>6.5-7.9</td>
<td>6.5-6.9</td>
<td>6.5-7.9</td>
</tr>
<tr>
<td><strong>Life threatening</strong></td>
<td>&lt;6.5</td>
<td>&lt;6.9</td>
<td>&lt;6.5</td>
</tr>
</tbody>
</table>

**Source:** Division of AIDS Regulatory Operations Center (1998) and Groopman and Itri (1999).

**Note:** NCI = National Cancer Institute, ACTG = AIDS Clinical Trial Group, WHO = World Health Organization, NL = normal limit.

**Table 5. Normal Hemoglobin and Hematocrit Ranges**

<table>
<thead>
<tr>
<th></th>
<th>Hemoglobin (&lt;g/dL)</th>
<th>Hematocrit (&lt;%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>14-18</td>
<td>42-52</td>
</tr>
<tr>
<td>Female</td>
<td>12-16</td>
<td>37-47</td>
</tr>
<tr>
<td>Child</td>
<td>11-16</td>
<td>31-43</td>
</tr>
<tr>
<td>Infant</td>
<td>10-15</td>
<td>30-40</td>
</tr>
<tr>
<td>Newborn</td>
<td>14-24</td>
<td>44-64</td>
</tr>
</tbody>
</table>

**Source:** Pagana and Pagana (1997).

**Table 6. Proposed Classification of Anemia Based on Hemoglobin Level**

<table>
<thead>
<tr>
<th>Anemia Severity</th>
<th>Hemoglobin Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild asymptomatic anemia</td>
<td>1 to 1.9 g/dL below the lower limit of the normal range</td>
</tr>
<tr>
<td>Moderate anemia</td>
<td>2 g/dL below the lower limit of the normal range to an absolute value of 8.1 g/dL</td>
</tr>
<tr>
<td>Severe anemia</td>
<td>≤8 g/dL²</td>
</tr>
</tbody>
</table>

*a. Normal for the specific laboratory and in the absence of significant symptoms of anemia. For example, if the lower limit of the normal hemoglobin range for a particular laboratory was 14 g/dL in men and 12 g/dL in women, a diagnosis of mild anemia would apply to men and women with hemoglobin levels of 13 g/dL and 11 g/dL, respectively. Men and women with mild symptomatic anemia or hemoglobin levels of 12 g/dL and 10 g/dL, respectively, would be diagnosed with moderate anemia.
that is 2 g/dL below the lower limit of normal defines moderate anemia. That is, a man would be diagnosed with mild anemia if his hemoglobin level dropped from 14 g/dL to 13 g/dL. Similarly, a woman would be diagnosed as mildly anemic if her hemoglobin level decreased from 12 g/dL to 11 g/dL. However, the presence of anemia symptoms or changes in functional status (e.g., energy and activity levels) are critical in defining the severity of anemia and the need for treatment. For example, if a patient has been diagnosed with mild anemia, but several symptoms are present (e.g., fatigue, malaise, insomnia), the anemia (mild symptomatic) should be considered moderate because of its clinical impact. Thus, absolute numbers alone are not sufficient in classifying mild versus moderate anemia; clinical interpretation of the patient’s status is also required. Finally, a diagnosis of severe anemia is recommended for a patient with a hemoglobin level of 8 g/dL or less.

In summary, anemia, a frequent complication of HIV infection, negatively impacts survival, HIV disease progression, fatigue, and other QOL parameters. The Nursing Guidelines Committee for Anemia in Patients With HIV Infection recommends that screening for anemia begin with the first visit and be repeated at 2- to 3-month intervals. A complete history, a physical examination, and an evaluation of the signs and symptoms of anemia should be the approach used to evaluate the presence and underlying cause of anemia. In addition, the committee proposes that anemia be defined by hemoglobin level (normal range is 12 to 16 g/dL in women and 14 to 18 g/dL in men) and categorized as mild (1 g/dL below the lower limit of the normal range), moderate (2 g/dL below the lower limit of the normal range, or “mild” anemia with symptoms), or severe (≤8 g/dL).

Part 2 of this article will describe therapeutic strategies and relate them to the different levels of anemia severity. A treatment algorithm will also be presented.

Acknowledgments

Members of the Nursing Guidelines Committee for Anemia in Patients With HIV Infection include Anthony Adinolfi, MSN, ANP, ACRN, Duke University School of Nursing; Rachel Davis, RN, South Texas Family AIDS Network, San Antonio; Sheila Davis, MSN, ANP, ACRN, Massachusetts General Hospital, Boston; David Feldt, MSN, RN, ACRN, AIDS Taskforce of Cleveland, Ohio; Richard Ferri, PhD, ANP, ACRN, FAAN, Provincetown, Massachusetts; Sandra Gracia Jones, PhD, ACRN, ACNP, CS, C, Miami, Florida; Jeannie Keruly, BSN, RN, Johns Hopkins University; Richard MacIntyre, PhD, RN, Mercy College, Dobbs Ferry, New York; Allen Orsi, PhD, RN, Temple University; Patrick Robinson, MSN, RN, ACRN, Loyola University Medical Center, Chicago; David Sterkin, MN, CPNP, DeVos Children’s Hospital, Grand Rapids, Michigan; Lyn Stevens, MS, SUNY Upstate Medical University Medical Center, Syracuse, New York; and Gary Wolfe, RN, CCM, San Francisco.

References


etin are associated with human immunodeficiency virus type 1-related anemia. Journal of Infectious Diseases, 180, 2044-2047.


HIV/AIDS Care in KwaZulu-Natal, South Africa: An Interview With Dr. Leana Uys

Ellen Giarelli, EdD, RN, CRNP
Linda A. Jacobs, PhD, RN, CRNP

Human suffering from the HIV/AIDS epidemic in Africa has reached unprecedented proportions. In 1998, an estimated 50% of all new infections in sub-Saharan Africa occurred in South Africa; and it is predicted that by the year 2003, South Africa will be experiencing a negative population growth. Besides the toll in human lives, the estimated cost for basic care and prevention services in Africa is 10 times the current expenditure. Three unique factors are critical in the South African HIV/AIDS epidemic: HIV transmission patterns, the effect of this disease on women and children, and the role that traditional healers play in the treatment of HIV/AIDS. In a recent interview, Dr. Leana Uys, an educational leader in the School of Nursing at the University of Natal in Durban, Republic of South Africa, provided an insightful perspective on HIV/AIDS policies and related sociocultural issues that have a direct effect on the HIV/AIDS epidemic. She communicated her personal experiences as well as the experiences of South African nurses working as caregivers, educators, and policy makers with AIDS patients and their families in KwaZulu-Natal.

Key words: HIV/AIDS, KwaZulu-Natal, nursing, South Africa

South Africa (SA) is located at the southern tip of the African continent with the Indian Ocean on its eastern and southern coasts and the South Atlantic Ocean on its western coast. The country is nearly three times as large as California or slightly less than twice the size of Texas. It consists of nine provinces: Eastern Cape, Free State, Gauteng, KwaZulu-Natal, Mpumalanga, North-West, Northern Cape, Northern Province, and Western Cape. In 1994, apartheid (the separate development of the races) ended and political control returned to Black majority political rule (Central Intelligence Agency [CIA], 2000).

SA is the most highly developed country in Africa (Byrnes, 1997). However, growth has not been strong enough to reduce the 30% unemployment and the daunting economic problems that remain from the apartheid era. Poverty persists, especially among Black citizens. Problems related to poverty and lack of economic empowerment among disadvantaged groups contribute to crime, corruption, and the prevalence of certain communicable diseases such as HIV/AIDS (CIA, 2000). The link between poverty and AIDS is undisputed (Gie, Schaaf, & Barnes, 1993), with every group and social strata affected. As of July 2000, 15% of SA adults were HIV-positive and most had been infected in the past 7 years (Swarns, 2000). It is predicted that this number may actually be higher due to underreporting of AIDS in individuals living outside mainstream society (Byrnes, 1997).

Scientific evidence supports the claim that AIDS is caused by HIV (National Institutes of Health, 2000). AIDS is transmitted from person to person through body fluids such as blood or blood products and sexual...
fluids and from mother to fetus or to children through breast milk. Transmission patterns, the effect on women and children, and the role of traditional healers are three factors unique to the SA epidemic. However, in SA, misinformation, ignorance, and folklore act as barriers to understanding the disease process, implementing prevention strategies, and utilizing effective treatment options.

In this article, the authors provide an overview of several issues related to the HIV/AIDS crisis in SA, including the role that traditional healing plays in HIV/AIDS patient care, and explore the perspective of a nurse leader in KwaZulu-Natal regarding the nurse’s role in AIDS care. On a recent trip to SA, Dr. Ellen Giarelli conducted a personal interview with an educational leader in the School of Nursing at the University of Natal in Durban, Republic of South Africa. The transcribed interview with Dr. Uys provides an insightful perspective on HIV/AIDS policies and related sociocultural issues that have a direct effect on the HIV/AIDS epidemic. She also relays her personal experiences as well as the experiences of South African nurses working as caregivers, educators, and policy makers with AIDS patients and their families in KwaZulu-Natal. Finally, Dr. Uys shared her personal insight, hope, and expectations for the future of HIV/AIDS nursing care in her country.

HIV/AIDS: Health Crisis in SA

Sub-Saharan Africa holds almost three quarters (70%) of the global total of HIV-positive people, and sub-Saharan nations are suffering devastating health consequences in their populations from HIV/AIDS infection. In 1990, projections estimated the number of HIV cases at 4 to 8 million (Zwi & Bachmayer, 1990). HIV/AIDS is considered to be the main cause of death in SA and has moved to fourth place among all causes of death worldwide (United Nations Programme on HIV/AIDS [UNAIDS], 1999). Presently, SA reports infection at an epidemic proportion. The Ministry of Health estimates that 4.2 million South Africans carry HIV, and 1,700 more people are infected every day. In 1998, an estimated 50% of all new infections in sub-Saharan Africa occurred in SA (Winter, Jacobs, Delate, & O’Malley, 1998), and an overwhelming majority of the people being infected are of African decent. As a direct result of HIV infection in the population, by the year 2003, SA will be experiencing a negative population growth; and by the year 2010, the life expectancy in SA will fall to 30 years (CIA, 2000; Horton, 2000). Besides the toll in human suffering and life, the estimated cost for basic care and prevention services for HIV/AIDS in Africa is $3 billion, 10 times the current expenditure (Horton, 2000). HIV/AIDS is listed as one of the top four health priorities by the SA Department of Health (United Nations, 1997).

HIV/AIDS has been described as an illness of marginalized persons, such that it affects the poor, disenfranchised, and disadvantaged (Van Rooyen & Bernstein, 1992). Apartheid in SA historically fostered the creation of a political and economic environment that marginalized a dominant portion of the population, and there has been little sociological resistance to the spread of HIV/AIDS (Mitton, 2000) since apartheid was dissolved in 1994. Despite the fact that the first death from AIDS occurred in 1982 in SA, the health care system in SA continues to be grossly inadequate and unable to deal effectively with HIV/AIDS-related issues (Zwi & Bachmayer, 1990).

Transmission Patterns

Although transmission rates of HIV during heterosexual intercourse vary dramatically around the world and scientific data is weak from Africa, investigators believe that more than 80% of all HIV infection cases in Africa are transmitted through penile-vaginal intercourse (Louria et al., 2000). Up to 10% appear to be related to transfusions with contaminated blood products (Pilot & Harris, 1990). According to a report by the United Nations (1997) heterosexual contact has been responsible for 75% of the HIV infections affecting women between the ages of 15 and 49, the peak reproductive years.

Sexually transmitted diseases (STDs) promote HIV transmission, particularly those that cause ulceration (Greenblatt et al., 1988). Socially displaced people and the poor and Black are at the highest risk for STDs, as are those with certain behaviors that are deemed high risk. Compared with industrialized countries and other less developed parts of the world, SA and other sub-Saharan African countries experience a higher prevalence rate of STDs such as gonorrhea, syphilis,
chlamydia, and chancroid, as well as higher proportions of antimicrobial-resistant organisms (Greenblatt et al., 1988). The incidence of STDs, socioeconomic factors, and employment opportunities place South Africans at high risk for HIV infection. Individuals at highest risk are migrant workers; truck drivers; sex workers; and miners in rural areas and their wives, girlfriends, and children at home (United Nations, 1997). In addition, an examination of studies in sub-Saharan Africa identified that high viral loads may increase the rate of HIV transmission (Erbelding, 2000).

Vertical transmission, or transmission from mother to child during breast feeding or perinatally, contributes to the prevalence of infection and is a serious problem in SA. In the absence of interventions, 20% of infants born to women infected with HIV acquire infection from their mothers at or before delivery (Ades, Ratcliffe, Gibb, & Sculpher, 2000). Maternal viral load at the time of delivery has been identified as a significant risk factor in transmitting the virus (MacDougall, 1999). HIV disease progression in children who have acquired HIV infection vertically is more rapid in developing countries compared with developed countries (Tudor-Williams, 2000). Interventions to reduce risk and inhibit transmission could save approximately 15,000 infants’ and children’s lives per year in SA (Dabis et al., 1999; Guay et al., 1999).

Effect on Women and Children

A disproportionate share of the burden of poverty in the world rests on women. The World Health Organization (WHO) (2000b) reported that 70% of the 1.2 billion people living in poverty are female. Women who are economically dependent are more likely to exchange sex for survival as a way of life, including prostitution and social and economic arrangements in which males exert control over their female partners (WHO, 2000a). These women are more vulnerable to HIV infection partly because of their lack of control over their own sexuality and sexual relationships, neglected health care needs, sexual abuse, and coerced sexual relations (Democratic Nursing Organization of South Africa [DENOSA], 2000). The incidence of rape and sexual attacks of children is increasing. More than 50,000 rapes were reported in SA in 1999, but this is described as a mere fraction of the actual rate, which is estimated at 1 million annually (Epstein, 2000). In addition, the stigma associated with HIV causes many women to hide their positive status and continue to transmit HIV (Bowden, 2000).

Treatment With Antiretroviral Drugs

Antiretroviral drugs such as zidovudine (AZT) have been used effectively to delay the development of AIDS from HIV infection and to prevent vertical transmission. Transmission of HIV from mother to fetus can be decreased by providing a short course of AZT to infected pregnant women around the time of delivery. In a recent study, Guay and colleagues (1999) compared the efficacy of nevirapine to that of AZT for prophylaxis in reducing vertical transmission of HIV from 626 infected pregnant women to their babies. Nevirapine lowered the risk of HIV transmission during the first 14 to 16 weeks of life by nearly 50% in the breastfeeding population (98.8%). This simple, inexpensive regimen could decrease mother-to-child HIV transmission (Ades et al., 2000). Approximately 200 babies are born in SA every day with HIV, and HIV infection could be prevented in as many as half of these babies if their mothers received antiretroviral agents during delivery (Guay et al., 1999). In developing countries, these interventions have not been offered on a routine basis, and the main reason for this is the perceived high cost rather than lack of evidence of effectiveness (Soderlund, Zwi, Kinghorn, & Gray, 1999).

The use of antiretroviral treatment in SA could have an immediate and substantial impact on the AIDS epidemic. Wood and colleagues (2000) predicted that with no antiretroviral use, between 2000 and 2005 there will be about 276,000 cumulative HIV-1-positive births, 2,302,000 cumulative new AIDS cases, and the life expectancy at birth will fall to 46.6 years.

Pilot projects to test treatment with various combinations and dosages of antiretroviral drugs in SA were supported by provincial governments and Doctors Without Borders based on reports from the Centers for Disease Control and Prevention (CDC) regarding the effectiveness of this treatment (CDC, 2000). However, in 1998, Nkosazana Zuma, the minister of health in SA, established a policy that suspended AZT pilot projects there.
Caring for children infected with HIV/AIDS in SA is a complex problem. One study reported that physicians caring for children with HIV admitted lacking confidence in their counseling skills and felt they had inadequate clinical skills to manage HIV pediatric patients (Fransman, McCulloch, Lavies, & Hussey, 2000). Fransman and colleagues also reported that 70% of medical officers and 69% of registrars in area hospitals thought they should have the right to refuse treatment of HIV-infected children. Major concerns were lack of management protocols and policy guidelines, lack of resources, lack of support for families in the community, risk of infection from patient needlestick/sharps injuries, and the feelings of these providers regarding the hopelessness and fatality of this disease for infected children. Some felt that time and resources were being “wasted” on children who were going to die anyway. These researchers identified no formal support mechanisms in the health services for staff working with HIV-infected children (Fransman et al., 2000).

In the past, there was speculation that AIDS was caused by malnutrition, chemical pollution, recreational drug use, and rogue pharmaceuticals; however, these explanations have proven to be scientifically inaccurate (Swarns & Altman, 2000). It is interesting that discussion regarding alternative explanations for the cause of AIDS was renewed at the 13th International AIDS Conference held in SA in July 2000. At this conference, SA and African National Conference President Thabo Mbeki revived the old views and debate over whether HIV causes AIDS and shifted public and political attention away from mainstream prevention efforts and pharmacological treatment with antiretroviral drugs such as AZT to less conventional means of therapy (Swarns & Altman, 2000). This resurgence of suspicion and doubt among politicians in SA has generated criticism from the scientific and medical community. AIDS researchers warn that the controversy is unwarranted and detracts from issues that need immediate and unequivocal attention such as prevention and early treatment of symptoms (Swarns & Altman, 2000).

In response to these actions, in September 2000 the Congress of South African Trade Unions and the South African Communist Party publicly stated that HIV causes AIDS and called on the president to do the same (Cauvin, 2000). On October 9, 2000, a report in the newspaper The Natal Witness (Sapa, 2000), reported that President Mbeki and all military personnel enjoy state-subsidized access to the AIDS drug AZT, which the state decreed should be given to HIV-infected people at public hospitals. This news report followed an announcement by the health minister that the government could not afford to administer the drug (Sapa, 2000).

Since February 2001, several important steps have been taken to control the disease. Five pharmaceutical companies significantly reduced the cost of AIDS drugs for SA patients. Insurance companies in SA began to offer “triple-therapy AIDS cocktails” to thousands of employees enrolled in their health benefits plans. Additionally, Doctors Without Borders planned to initiate a pilot project in April 2001 that would offer drugs for free to patients at public clinics near Cape-town (Swarns, 2001). However, many South Africans are unemployed and uninsured and still cannot afford the drugs at reduced cost. Those who cannot afford standard AIDS pharmaceuticals may rely on traditional healers, rather than conventional or biomedical healers, and folk medicine for treatment.

A survey conducted in SA in 1992 found that traditional healers were relatively knowledgeable about AIDS symptoms, transmission patterns, and causes of the disease. However, 40% of the same group of healers believed AIDS could be “cured by either traditional or modern treatments,” and the majority of the traditional healers did not know if AIDS could be prevented (Good, 1987, p. 187).

Traditional Healers

A traditional healer is also called an indigenous healer, and although there is a fairly complex social order among tribes, there are primarily two types of traditional healers in South Africa: the herbalist, or *Inyanga*, who tends to work primarily with natural *materia medica*; and the diviner-medium, or *Sangoma*, who has additionally cultivated a relationship with ancestral and other spirits believed to assist in divination and healing (Fenn, 1998; Green, 1994).

Ethnomedical studies in Africa have identified that traditional healers and their clients believe that certain conditions are managed better by traditional practitio-
ners. These conditions include mental illness, epilepsy, high blood pressure, fertility, heart failure, and STDs (Good, 1987). Many Africans suffering from STDs may not seek Western-style biomedical treatment but instead rely on traditional healers for treatment (Matthe, 1989). There is a higher prevalence rate of certain STDs in SA, and the association between STDs and HIV infection in SA is especially important to explore because STDs often go untreated or are ineffectively treated by traditional healers (Green, 1994).

In SA, and especially in KwaZulu-Natal, traditional healers have a rich heritage of indigenous knowledge of the use of the botanical diversity. Substantial published records of herbal medicines exist, but much more knowledge remains unwritten, retained by practitioners of traditional healing and passed on through the oral history of the Zulu people. The Zulu use more than 1,032 species of plants from 537 genera and 147 families of flora (Hutchings, Scott, Lewis, & Cunningham, 1996). Traditional healers use roots, leaves, branches, bark, seeds, and flowers. Botanical substances are made into inhalants, poultices, teas, baths, emollients, and purgatives that are worn, eaten, chewed, inhaled, applied, and sprinkled. Of the 1,032 plant substances recorded by Hutchings and colleagues, 154 are used as aphrodisiacs, 134 as protective emetics, 57 for infertility and impotence, 46 for venereal diseases, and 254 as protective charms. Other categories for which plants are used include swellings and growths, sores and rashes, febrile conditions, headaches, fractures and sprains, renal and urinary problems, and antiemetics.

Beginning in 1996, government officials, health planners, practitioners, policy makers, and other interested parties in SA determined that the social and psychological powers of traditional healers needed to be examined and addressed. One proposal was to pursue active programs of collaboration or cooperation with traditional healers, with or without formal recognition. This type of collaboration, in combination with training programs for traditional healers aimed at improving their effectiveness and discouraging practices inimical to public health, was suggested. It was proposed that this effort could result in improved psychological support for families and earlier and more frequent referrals by traditional healers to medical healers. It could also define and limit traditional practices, and enable African patients to retain elements of their cultural past (Green, 1996). It was also proposed that a collaborative effort could lead to the development of a “syncretic health care system that combines the best elements of biomedical and African health care” (Green, 1996, p. 23). In 1997, the national HIV/AIDS program enlisted the services of three traditional healers as consultants to mobilize other traditional healers around the issue of STDs. The following year, the SA parliament proposed that a statutory council be set up to regulate the 35,000 traditional healers in a effort to legitimize traditional medicine. This process has been slow in SA, and the traditional healers continue to practice in their traditional style.

Nurses are educated on the cultural issues that may affect how health care is interpreted and received by patients and their families. Nursing care when delivered in a culturally sensitive manner incorporates cultural factors with research-based interventions. Therefore, culturally sensitive nursing care in SA will integrate some aspects of traditional medicine with biomedical practices. Professional nurses in SA are encouraged to consider cultural factors when designing nursing interventions to promote and restore health. To contribute to our understanding of HIV/AIDS in SA, culturally sensitive nursing care of infected patients, and social issues, an interview was conducted with Dr. Leana Uys (pronounced ace), Dean of the Nursing School in Durban, SA.

**An Interview With Dr. Leana Uys**

The University of Natal in Durban, SA, is a WHO Center for Nursing and Midwifery Development in the African Region. Durban is located in the eastern province of KwaZulu-Natal. The School of Nursing began training nurse educators in 1956, and in 1962 a basic 4-year degree-granting program leading to nurse registration as a nurse was introduced. The first professor of nursing was appointed in 1971. In the 1980s, a degree for registered nurses was initiated, leading to registration as a nurse administrator or a nurse educator. Postgraduate studies were gradually added, and the first PhD candidate graduated in 1990. Five principles guide the School of Nursing. Primary health care is the most important component of SA health care; rehabili-
tative nursing is emphasized; research should address urgent health care questions; research should serve the community; and the research product belongs to the larger scientific community (School of Nursing, 2000).

Dr. Leana Uys, D Soc Sc, is an Afrikaner, a White South African of Dutch descent. She is a professor in and head of the Nursing School. Dr. Giarelli conducted an interview with Dr. Uys on the morning of October 9, 2000, in her office in Durban. In this interview, she shared her perspective on HIV/AIDS policy and related sociocultural issues as well as her personal experiences and the experiences of SA nurses as caregivers, educators, and policy makers in KwaZulu-Natal. The questions were structured to acquire information on the issues identified and described above and to provide insight into some of the cultural factors that act as barriers to HIV/AIDS care in SA.

Q: Tell me about yourself and how you became interested in HIV/AIDS care.

A: I started training in 1967 in a degree program in Pretoria. It was a 4-year program and after that I went to a Black rural hospital in the northern part of SA. Even though it was in a rural area it was a very big hospital with a large psychiatric section. Now we had psychiatry as part of our training but I wasn’t interested at first. But, when I arrived I met a Dutch doctor who was doing research about the traditional treatments like ritual dance for psychiatric illness. The traditional healers used dancing and rituals—a lot of dancing actually, and very specific dancing to treat psychiatric disorders. He was doing a doctorate on that and incorporated it into the care on the psychiatric unit. So that stimulated my interest in psychiatric care. After that experience I went to a lectureship in the Free State. There I spoke to my professor about doing either psychiatric or orthopedic nursing—which were two areas I was interested in. She said to me, “Oh we don’t need orthopedic nurses anymore, we need psychiatric nurses.” So I took my master’s in psychiatric nursing. I then went to Cleveland, Ohio for a year-long fellowship at Case Western Reserve where I took as many master’s courses as I could pack in because the fellowship was just for 1 year. I returned to the Free State and stayed there until I finished my doctorate. I applied for a position at the University of Natal and stayed mostly in psychiatric nursing, but when I became the head of the department I generalized my practice and included HIV/AIDS care.

Q: How did you become involved in HIV/AIDS research?

A: In SA you have to do the research that is essential, you can’t really choose what you do. So I went into quality control because it was identified as a national need. Then I returned to my own field and did quite a lot of work in psychosocial rehabilitation especially in rural areas. But all the time I had contact with hospice because I was the external [liaison] of the palliative care course in the SA Hospice Association. When the AIDS epidemic became intense the Hospice Association was in the midst of home-based palliative care. They asked if I would be willing to go in with them to set up home-based care research. This was my first head-on confrontation with the epidemic.

Q: In what ways does the School of Nursing prepare nurses to address and respond to this urgent health care challenge?

A: The most generally used instrument in preparing nurses for their task in the HIV/AIDS epidemic is the HIV Counseling course. This is a 3-week course offered by the HIV offices across the country. It teaches all people, lay and professional, to be HIV/AIDS counselors. Included in this course is comprehensive information about the illness, and training in pretest and posttest counseling. It seems that this is a powerful tool in changing the attitudes of participants to a more HIV-friendly mode. However, it does little to prepare nurses for the role of assisting HIV-positive people to live positively with the disease. It is also inadequate in preparing people for the counseling needs of children with HIV/AIDS.

In this country the main educational approach is to teach people the “wear condoms” message. To date this has not changed sexual behavior, and is now widely seen as inadequate. Although there are small initiatives across the country, in which nurses are active partners, to develop more coherent approaches to prevention, this is not widespread.

Our School of Nursing puts all students through the HIV Counseling course. They also get significant input at the beginning of their training about ensuring
their own safety. These include universal precautions, how to deal with needlestick injuries and changing sexual practices. Since we use a problem-based curriculum in which students study actual patients they are nursing, and since the prevalence of the illness is so high in the institutions in which they are placed, they are confronted with the nursing implications repeatedly during their training.

Q: What was your impression of the impact of the 13th International AIDS Conference held in Durban in July?

A: I was not personally involved with the conference but there were nurses on the planning committee, and nurses also held a preconference workshop on their own. These were well attended, and seemed to have been very good sources for information and the exchange of ideas. However, President Mbeki’s pronouncement on HIV/AIDS and the way in which our health minister followed his lead, was a major disappointment to health workers in this country. We watched as each opportunity that arose for him to correct himself came and went with no change in his basic stance. I am afraid it has had a major impact on the level of denial in individuals and communities, and does not bode well for our fight to have a total and integrated approach to HIV/AIDS prevention, treatment, and care. The most vocal opponents to his view have been Dr. William Makgoba, the president of the Medical Research Council, and Professor Jerry Coovadia, a local professor in the medical school, who was also the chair of the HIV/AIDS conference committee. Both of these individuals are highly respected scientists and health practitioners.

Q: Dr. Uys, would you describe the patient populations and how the HIV/AIDS epidemic has impacted the overall delivery of care in SA?

A: In SA about 12% of the total population is HIV-positive, and in the age groups 15 to 40 years, it is probably much higher. In our province, KwaZulu-Natal, the last survey of women in antenatal care showed an infection rate of 40%. Nurses and midwives are encountering these patients in every area of their practice. To understand the situation, you have to be cognizant of two facts: (1) Testing is usually only done on the patient’s request; and (2) since there is a general fear of the disease, not many people have themselves tested. Most cases of HIV/AIDS are therefore diagnosed by the clinical picture, not by testing. This allows for denial of the seriousness of the epidemic by health workers and consumers alike. Based on the clinical presentation, our students work in medical wards where about 80% of patients are HIV-positive.

For the majority of the population no treatment by antiretroviral drugs is available. This, coupled with widespread denial of the reality of the disease leads to rapid deterioration and death in many cases. For instance, in May I saw a skeleton of a young girl, dying of full-blown AIDS. On her bedside table was a picture of her as a bride, taken in early December. In the picture she looked perfectly healthy. Six months later she was dying.

The cost of HIV/AIDS care has drained resources from many other urgent health problems. It has also led to the death of many nurses, mainly through infections picked up outside of the work setting. This is expected to increase. It has also led to positive changes, such as a greater integration of home-based care, nongovernmental welfare organizations (NGO) and communities into the formal health service structure.

Q: What health promotion strategies have you found most effective and why?

A: I cannot really say that I have found any effective in this country. We have been looking at things done in countries north of us, which seem to be promising but proof of success has only come from Ugandan figures. The people involved in the Home Based Care projects, feel that the approach of moving into communities as community caregivers (CCG), and getting patients to disclose to their immediate circles, has the best chance of changing attitudes and practices. I have seen that the home-based approach increases the human dignity of the clients, and gives them and their families hope. This has allowed for more openness. This could be the only way of influencing sexual behaviors. This “micro” approach seems very slow, but the “macro” approach of TV and radio slots talking about using condoms has definitely not worked.

Many traditional healers still maintain that they can cure AIDS. The problem is that they usually define a significant improvement as a cure. They use tonics and
special foods, which makes clients feel much better, and then say the person is cured. The traditional healers also insist that the government should not have declared AIDS an incurable disease without giving them a fair chance of proving that they can do it.

This allows people to deny the seriousness of the illness, and to deny that they even have it, if they have been “cured” by the traditional healers. There are also indications that certain practices originated with the traditional healer such as the myth that if you sleep with a virgin, you are cured. This has directly led to incidents of rape and child abuse. There have also been “muti” murders, which are the killing of people to use their body parts for medicines, which has been linked to AIDS cures.

These unconventional cures have had little impact in the long run. At this time they also undermine the credibility of the government in the eyes of the scientific community, but they probably did not have the same impact on the general population as the Mbeki pronouncements have had.

Most nurses in SA see themselves as Western practitioners, and look down on the practice of traditional healing (TH). However, many of them use TH in their own illnesses. Black people can accommodate different systems in their worldview, and do not find these contradictory systems problematic. South Africans are not linear thinkers, but rather have a comprehensive and inclusive approach to things.

Q: Can you describe the environments in which nurses provide care for HIV/AIDS patients and their families?

A: I have recently done a study on seven sites across the country where a formal home-based HIV/AIDS care system is in place. Community caregivers who are community women with 3 months’ training, visit patients’ homes regularly. They train family members in caregiving, and assist with difficult procedures such as washing, wound care, and symptom control (pain and wounds, mostly). Afterward, most of the care is given by family members. The community caregivers are in turn supervised by registered nurses, who also visit the clients when necessary. These patients get their supplies (medication, gloves, linen saver, etc.) from the nearest community clinics, where the nurses are in charge of all the care. If there is a need, patients are admitted to the district hospital. This usually happens when the client develops symptoms that the family cannot cope with. This integrated service is probably the ideal, and it definitely does not happen all over the country.

Q: Would you describe how the home-based care program started, how it was set up, what kinds of barriers you faced, and what helped you along?

A: The program was started nationally by the Hospice Association that has a number of hospices around the country. They have always been into cancer care but when the HIV epidemic was recognized they said they would not get into HIV care because that would swamp them. But, that didn’t last very long. Soon they just had to become involved, so they started setting up home-based care using what they had always used, which was registered nurses. They realized that it wasn’t viable and the South Coast hospice (about 100 kilometers south of Durban), pioneered a community-care approach. They had 500 clients within a period of 1 year. There was just no way they could cope with this number using registered nurses, so they proceeded to use community workers.

The model of care combines an NGO, which in this case is the Hospice Association, with the clinics in the rural areas and with the hospitals. The NGOs have experience with community-based work, the clinics are the main centers for treatment of AIDS patients, and the hospitals are where most of these people will pass through at some stage during their illness. So, you have to have a model that incorporates all these as full partners, and where the health care provider can facilitate the movement of the patient among all three, while getting the support where and when it is most appropriate. So a system like that was set up in seven sites across the country and I evaluated implementation and impact. I think one of the barriers we found was that hospitals are not used to working with NGOs. They are used to working with a formal health sector, not community-based organizations. They are not used to community-based workers (CBWs) coming into their hospitals, and so on. The model calls for the hospital to accept patient referrals from CBWs. In other words, if the CBW decides that the patient should be hospitalized, the hospital should comply, it means that the CBW has done what they can, they have assessed the
home situation, and they know that the patient now needs hospitalization. The hospital shouldn’t block the admission simply because they are not accustomed to this procedure. If the hospitalization gets blocked the community loses faith in the home-based system.

Q: Was the problem that the hospital administrators were not recognizing the authority of the community-based worker?

A: Yes, and they wanted to keep to their usual practice, their usual routines, in which they did the assessment and they made the decisions, in which they did not want to hand it over to anyone else. Also, it was just very difficult to change the way things were done because hospitals are set up so that every two months they have a new doctor in the outpatient section. The communication process has to start all over again, by building a relationship and developing trust, and so on. The system is usually not community-caregiver friendly and we’ve coined a new phrase to describe it. We talk about community-friendly hospitals. In our seven sites we had two that were CBW friendly and could actually build and support this kind of model relationship. The other five could not.

Q: Are all seven sites still operating?

A: Yes, the whole system is still going on. We are hoping the government will take this model on board and implement it more widely.

Another barrier we found all over is how difficult communication is in rural areas. It’s difficult to arrange for transport of patients from one service to another, or for the worker to communicate with the clinic, or the hospital. Often we have found there are no working ambulances, no phones and no public transport. So, it is not easy to make an integrated system work, especially in the sites where there is no transportation for the workers, so the CBWs have to walk from one house to another. That is difficult. For example, if the CBW has to get medication from the clinic they have to either walk to the clinic or take a taxi. It is the only way of getting out to the patients.

Caring for a person with full-blown AIDS is not easy. You may be living in a little house with no running water, and no efflution facilities. The washing gets done in the river, which is 300 meters down the hill and up the hill again, and you have a patient with diarrhea, so you are washing all the time. You’re also the only person looking after this patient and helping them out of bed and onto toilets, and so on. It’s very difficult work. For the patient and the family, the fact that somebody is coming in and giving a little bit of assistance, and giving advice, and making sure that pain medication is available makes a massive difference.

Q: How do you prepare the home-based worker for these responsibilities?

A: The actual caregiving is done by the family; however, the CBWs, are trained by the hospice system. The hospice system demands 3 months’ training, with 6 weeks in theory and 6 weeks doing practical work in the hospitals, clinics, and in the homes, so that they can get enough confidence in their ability to give care. But my research shows that the physical care is not the most important thing, it’s the emotional support, the advice and the instruction matters most, and that part is the most important thing that the families value. This is not easy to give because of the stigma attached to HIV/AIDS.

Almost in none of the families do you start off with both the patient and the family disclosing the AIDS condition. Many of them go right through to death without disclosure. They acknowledge that there is a disease but don’t talk about it. It is much more difficult to support the person emotionally if you can’t mention that the person is dying. It is very difficult to counsel them if you can’t say, “You are dying and you need to make provisions for your children.” That is the skilled counseling that we find the home-based-care people need to engage in. They need to get the client to actually talk openly about it so that the issues can be addressed, and then try to get the patient to disclose to the family or at least one family member. We try to make it wider because our feeling is that unless we start getting disclosure at the community level, education on prevention is not going to work.

We try to get them to disclose to their family and a close circle of friends so that at least there can be acknowledgement, and no talk about witchcraft, and no ostracizing of the family, and so on. They can then get the support from the community that they need and not be stigmatized because of it. This counseling process takes a lot of time and if the home-based caregiver
comes early enough in the illness they can work through these issues. If they come into care during the final stages, which is often the case, they don’t have time to work through these family issues.

Q: What kind of emotional support do you give to the family members after the patient has died?

A: One site was quite interesting, it was up north of Empangeni in a rural area. The setting is in the north and the epidemic came from the north so they have had longer experience with it. When we got there they started a support group for patients and family members, because the community-based workers had to walk to homes and they couldn’t get to everybody individually. So they asked all the patients, who could walk, “Please come to a central place once a week so we can see you there and help you.” The first few weeks no clients came, only family members came, and most of the time it was the family of people who had already died. The counselors found that the family could never really express their sorrow. It was not acceptable. On the one hand, some people thought that their relative had died of AIDS, so they were not supposed to grieve for him. He was this bad sinner. On the other hand, if he was not supposed to have died of AIDS then they had to work through that lie. So, the support group started out being a support group for family members, and they were often family members of people who were deceased. It was just a group for grieving for a long time. After a while the patients started coming, and then it turned more into a support group for the patients. So, yes, there is a lot of unresolved grief around the issue because of the lack of talking. Also, at first family members came to the groups because their emotional needs were greater.

Many patients were children whose mothers and fathers had already died. What we then had was grannies looking after 7, 10, or 18 orphans. One of these came first to the support groups to deal with the sorrow of having three of her daughters die, and the last one now sick at home. And, she is sitting there with the orphaned grandchildren. That is why the family comes first. Then when they have dealt with their grief we can get access to the children, and some of them are HIV infected and some of them are not. There still remains the problem of an elder person sitting with numbers of sick children and all the problems that come with that.

Q: You have commented that the care of infected children is inadequate, would you describe how this is so?

A: When we started, our counseling courses, for instance, only taught you how to counsel adults. They didn’t teach how to counsel children. So, how do you deal with a child of 4 who realized that the mother is already gone, the father is already gone, and she herself is now sick? I mean, how do you help this child deal with both the losses they have already had and the fact that she herself is now sick? This child knows about death, and knows she is dying, but nobody knows how to support the child of 4, especially not the person with 6 weeks of training. There are no resources in our community. There are no child workers. There are no child psychologists. There are no social workers. They don’t have anything. Often the senior children are the caregivers. I’ve gotten a letter from one girl who is 16 years old telling me how she has two children to look after now that her mother has died. One is HIV infected and 3 years old. She tells me, “I can’t go to school because I have to look after this little one, and we have no money coming in and I don’t really know how to look after this child.” And, then these three children have to deal with their grief for the parents who have died. You’ve got the grieving and the massive responsibility, the economic needs, and the physical care of a 3-year-old HIV-infected child. There are not enough resources to help them.

Q: Do you see a role for schools? What is the relationship between the School of Nursing and the public schools?

A: If you think broadly about schools, nursing, and health education in our country, you see that we have a young population that means we have literally thousands of schools, and volumes of school children, and every single school is overextended. You have classrooms of 40–60 children with one teacher who may not be college trained. There are inadequate facilities, and sometimes no electricity. And every responsibility, at the moment, keeps funneled down to the schools. The government says that the school has to do this, the school has to do that. They are sitting with inadequate facilities to start off with and inadequately trained staff. So yes, ideally they can do something, but they have their hands full. Also, unlike public schools
in the United States, there are no school nurses. We used to have a school nursing service consisting of a team of two nurses going around to all the schools to see the children at certain developmental periods. Usually the first visit was in Grade 1 when the nurses just did screening of urine for sugar and acetone. The nurses returned at standard Grade 5 and that was it. Even that has broken down. Now it’s just totally inadequate.

Q: Educators are expecting a crisis in the teaching system, predicting a loss of 25% of the teaching staff over the next 10 years to AIDS. This will be devastating to school-age children and further diminish resources.

A: You have to remember that we are loosing the same number of nurses.

Q: Is there a professional nursing organization in South Africa, and how is this organization addressing this problem?

A: Well, we are not doing much. One of the reasons is that we are not seeing the statistics on nurses currently reflected in our national statistics. The Nursing Council keeps the annual registration of nurses. This is a living register. We have not seen an increase in the deaths of nurses at this stage nationally and because we can’t show anything there is not a national panic. However, what we have seen provincially is an increase in deaths.

Q: How do you reconcile the fact that professionally trained nurses are getting infected outside of their professional practice?

A: Many of the nurses are Black women who are still living in a patriarchal society, and they are still responsible to their husbands for their sexual behavior. Nobody has changed their behavior in this country, none of the men have changed their behavior. This morning there was a report on the radio about a politician who went to Beauford West to talk about the upcoming local elections. He said, “I will come back to Beauford West because I have seen that there are such beautiful women here and I want to come back and talk to them.” I mean, there is no commitment to make public statements that we have a one-man-one-woman policy in SA. The men keep on giving the message that the more powerful they are the more women they have. As long as this message remains strong, educational programs will not be effective.

Q: I noticed as I walked the streets of Pietermaritzberg that there are posters advocating for condom use. This approach to public health has been embraced by educators and health care workers. But this approach is not working. Are there alternative ways to change behaviors that contribute to the problem?

A: True, the messages as delivered by the educational programs are not working. There are programs in the schools that I think are more hopeful. They deliver messages such as “delay sex,” “limit sexual partners,” and “wait until marriage.” These kinds of messages one hopes will be of benefit, but there are so few of these educational efforts spread over too many schools. We are not reaching enough people. I believe the way to go is through the home-based care system, where you infiltrate the community, right at the bottom and start making them see AIDS for what it is. And for how it happened. They can talk to people they know who are dying of AIDS and ask how they got it. They can hear their neighbors say, “This is how I got it.” Confront the issues right at the grassroots, not only through the public venue, but in the house among their own circle of family and friends. There, I think the changes must come. Both public and private messages must be the same. But, I think the most important change will come in the private sphere.

Q: Next to the sign that said, “use condoms” was a sign that said, “Mbeki uncovers CIA plot in AIDS epidemic.” These opposing messages are creating confusion as to the cause and ultimately the cure.

A: Yes, it’s so nice to have somebody to blame, the CIA, whatever, it could have been people from Mars for all intents and purposes. As long as people don’t have to confront the problem in their own backyard. Yes, the mixed messages are not helping to solve the problem at all. And, people are really taking those things seriously. I’m doing a project in the northern part of Zululand with women empowering rural women and from one woman in this group I heard she had been told by the traditional healer that if you toast bread and then you have sex you won’t get AIDS. So we are getting so many wrong messages and we don’t have a national information source that specifically
addresses the myths about HIV/AIDS and treatments, such as eating toast, and having sex with a virgin to cure you of AIDS. There are no projects to correct this misinformation, and I think we need that.

**Q:** Do you see this as an area for nursing research and intervention? Can nurses move into this area of researching and uncovering the inconsistencies associated with traditional healing for HIV/AIDS?

**A:** Somebody needs to do this research. Nurses can do this research. What we have been having in this country is post-1994, end of apartheid euphoria, that thinks that because we have a government that is popularly elected African National Congress (ANC) governed, and cares for the people, that they will always do the right thing and take the initiative. Even from the nurses who used to be the “movers and shakers” you now get this thing of sitting back and waiting for the government to make the first move. In the case of the HIV/AIDS epidemic, the delay on the part of health care workers has been particularly significant because the government has not been doing anything. And, the progressives keep saying, Why is this? but are themselves sitting back feeling baffled instead of jumping in and being as critical as they would have been 10 years ago if the government did then what this one is doing now. But it’s almost this sense of incomprehension of what is happening with this government, with this problem.

**Q:** I sense the frustration in your voice must reflect the frustration of others in nursing and health care.

**A:** There are millions of Rands set aside for AIDS care and we who try to do home-based care or educational programs can’t lay our hands on any money. Because all the money goes into the big AIDS coffers of the government, and they are doing nothing. The money is just sitting there, they’re not doing anything with it. It’s not corruption. I think it is because they can’t get their policy in place, and because they have these funny paranoid ideas. So, I think we have been paralyzed because of this disappointment even bafflement about the government’s inaction. If they had just shown some leadership I think people would have followed, but now many are sitting and waiting. Not everybody is waiting, but as an organization at the national level or as a national movement of nurses there is limited engagement with the problem.

**Q:** You mentioned that the government in Uganda is having success with health promotion strategies but that these same strategies are not successful here. What are they doing differently?

**A:** Perhaps we are not where they are yet. Enough people have died in Uganda so that people couldn’t play around anymore. You get to a critical mass of deaths and its impossible to talk about the CIA. Nobody cares who started it. Everybody says just stop it now. I thought we were there but it doesn’t look like we are yet. In Uganda it changed with a total political commitment to stopping it. We are not there yet. Success needs interventions on all levels—systematic, broad based, and targeted. We really are not there yet.

**Q:** In your article in Nursing Ethics [Uys, 2000] you described confidentiality and privacy in the context of HIV/AIDS. You made a provocative statement that “If a patient is rejected by his or her family as a result of learning of the HIV infection, the health care worker could be held responsible to the family for livelihood, support, or other needs resulting.” Could you explain what you meant by that statement?

**A:** The only professional counsel that made any pronouncement on one’s function or role of the profession with regard to HIV secrecy is the Medical Board. They initially said, yes, you should tell. You have a responsibility to tell the spouse or sexual partner if the person does not want to tell them him or herself of their HIV infection. Then the Medical Board came back later with a document that said, yes, you should reveal, but then you have to take full responsibility for your decision. Now if the patient has only one caregiver and that is a family member. And, you tell the wife or the mother that this is an HIV-positive person and that family pushes him out of the house, he can go to legal aid to make a court case against you. He can argue that it is because of your actions to reveal his HIV status that he is now without a home or someone to care for him. That has enormous implications, financial implications for the nurse or doctor. He can say that because, “You told my wife and now I have no one to look after me.”

**Q:** And the fact that he is infected and can infect his partner is irrelevant?

**A:** Yes
Q: Has that legal situation been experienced by nurses?

A: No, but it has happened a number of times that a person has been taken to court because he or she has told somebody another’s HIV diagnosis. So the doctors are not going to take the risk, they are just not doing it. But, instead are saying they are advising the client to tell the family and if they don’t tell the family the medical person is not doing it. Now, I think that is relatively easy for the doctors because they are not living in the same community as the clients. The doctors will be living in relatively affluent areas and the client will be living in areas possibly quite different and removed. It’s not the same with the nurses, the nurses live in the community with the clients. Very often the wife is a friend of yours. I have a colleague right now saying my friend’s son is HIV-positive. I know that to be true because I saw him in the clinic. My friend doesn’t know because her son hasn’t told her. Although she is caring for him. Now what do I do? She is a friend of mine. We’ve been friends for years. How can I not tell her? But if I tell her I’m breaking confidentiality. Because of the strong opposition coming from people with AIDS, all organizations, and from the Medical Board nurses are also keeping quiet. They are also not talking. That, I feel, really is bad for our long-term relationship with the communities. Because we live in our communities and we have a long-term relationship with them, they are supposed to trust us. Now we have this lethal secret and we are not telling them. The Nursing Counsel is not saying that we are being held responsible, the Medical Board is saying that, but then, the Nursing Counsel is saying nothing. You rely on the only kind of instruction you can find, and that is the one that is saying yes, you can tell but you take the responsibility for the consequences.

Q: You may also rely on the word of the law and if you have laws that allow individuals to bring charges against others seeking financial compensation because of a breach of confidentiality, that is enough of a deterrent to effectively gag the professional who wishes to help a family member or the community.

A: We are a litigious society at the moment. People are beginning to be very conscious of their human rights, and their legal rights, and so on, which is a good thing, but you still have to look after the rights of the community. Especially with a disease like this. You can’t just have an individual ethic without looking at the wider effect. That has not been tested and I don’t think any nurse is going to be willing to test it.

Q: It sounds as if home-based care is the place to do this, to make the link in trust.

A: I’ve seen a dramatic change in attitudes. Families have said we don’t want anything to do with this person who has AIDS. The community-care workers go back, and back, and back, and they wear them down. Once the person is back in the home and they are getting the support they need, there is healing and there is understanding and it really does make a lot of difference; if you don’t have support in that situation nothing changes.

Q: You talked about the African as thinking nonlinearly, but the process of education is usually linear. We feed information from the top down and we expect a flow from policy to person in a linear fashion. Tell me more about this idea and how would this concept of nonlinear reasoning be used to help people change.

A: It’s tricky, but I think it is a question of being holistic. You can’t, on the one hand, tell the community, “Don’t reject this person, don’t stigmatize this person, care for your friend who is HIV-positive,” but when the person gets full-blown AIDS the bigger system throws him out. We expect him to be cared for without any pain medication, without any linen savers, without any gloves, without any assistance, in a hut with no running water and no toilet. The two things don’t gel. We must create a system in which we can say don’t reject a person because of AIDS. Look at the way I treat this person. He is a human being. He’s a person. He’s still your son, Sipho. Nothing has changed and he is still himself. You can help him to get over the thrush so that he can talk, and you can help to get him on his feet again so he can sit outside of the hut in the sun, and not just lie in his dirty bed. Then they can see the humanity and then it becomes holistic care.

The illness must become part of human experience. It doesn’t become something that is pushed out and not incorporated into their way of thinking about them-
selves and their family. It becomes just that my son became ill. It’s a terrible disease, but we sorted it out the way the grandchildren were sorted out, we sorted out an employment benefit—everything was taken care of. We as a family did that. We gave him a good support at the end. It becomes a human experience, not the inhuman rejecting fragmented thing. To me that seems like the only way we can change people’s attitudes towards the illness, so they can see it as a very dangerous illness that we must deal with. AIDS is not a thing that we can blame on the CIA, or on witchcraft, or on sinning, and therefore just push away, as not part of our daily life or our sexual behavior. AIDS must be part of the way the SA people think about their own life and own family.

Q: Where do you go from here, what would you like to do?

A: What we tried to do is to get the home-based-care research published as widely as possible, but we haven’t gotten permission from the government yet to do that. It was a government-tendered research so the research belongs to them. I haven’t gotten permission to distribute it. We also want to try to get the information to the AIDS activists so that we can lobby for government funding for home-based AIDS projects. We have done some financial projections. We feel that it’s financially a viable proposition. It will take a small proportion of the budget and it can make a dramatic difference. We want to place home-based care on the top of the agenda. Everybody is so involved now with trying to get drugs, like AZT. I’m not into that debate at all, because I’m not convinced that when you look at the situation our best bet is to have more orphans. I think we have to try to keep those mothers alive as long as possible so that the kids are older by the time the mother dies. I am interested in trying to get home-based care in effect so that we can maintain the lives of those people as long as possible, maintain the family unit, and get the kids a little bit older before they lose their parents.

Q: Research efforts seem different here. In the scientific community it is an expectation that research findings will be published as soon as possible. Is the process of research dissemination different in SA?

A: It is different here. They have the written report already, but want that verbal presentation.

Q: What would be the likely outcome of the presentation?

A: So, I must first get permission to get the research published and to be talked about openly, I’ve talked only about it at hospice meetings (hospice was a partner in the research). I can talk only with partners of the research which are the sites, and the provinces involved. Since they were partners they need to know the research results right away. I can’t get to the activist groups because they were not partners. I can’t get to the press to publish it.

Q: How has HIV/AIDS affected you personally?

A: My home-based-care research has greatly impacted my understanding and interest in the disease. Having visited many homes and interacted with families, patients, and their community caregivers and nurses, I am more aware of the human tragedy and suffering. It is just overwhelming. At the same time, the enormous impact of caring, supportive nursing in these situations has again validated the role of my own profession for me.

Q: What role do you see for nursing in the future?

A: Although we are working hard towards a vaccine, it will make little difference to the thousands already infected, and the thousands who are still being infected every day. This epidemic can teach us a lot more about health education for behavior change, about the worth of our profession in total health care, and about comprehensive health approaches which involve all sectors and all people. I hope that our country and the world community will be united by the fight against this devastating illness, and not divided and brought to our knees.

Over the course of an hour, Dr. Uys shared her professional observations and reflected on personal losses. One could hear in her voice the strength of commitment to caring, softness from the love of people, and tension from frustrated energy. She talked fervently about nursing care as a source of hope and health.
Conclusion

The epidemic nature of HIV/AIDS in SA requires consideration of multifactorial causes and microcultural and macrocultural influences. Individual choice, historical and social influences, and environmental and economic factors contribute to a pattern of prevalence and spread. In SA, the complex social reality of poverty, inadequate education, limited access to health care, lack of health insurance, unemployment, and racial prejudice affect humanitarian efforts to treat and prevent HIV/AIDS. HIV transmission patterns are known to be predominantly through heterosexual activity, affected by migrant labor patterns, and difficult to modify. Additionally, the medical reality of HIV/AIDS at epidemic proportions compounds the social problems. In a downward spiral, people with AIDS who cannot work lose income and health insurance. Families are left without one or both parents and with infected children. People without access to biomedical treatment and Western-style health care services must rely on traditional healers and indigenous medicine. The cycle of poverty and ill health is perpetuated.

Miramontes (2000) called on nurses to "go the extra mile" to assist affected societies and countries to face the challenges created by HIV/AIDS. A first step is to recognize the extent, complexity, and severity of the problem. The authors hope that by seeing the HIV/AIDS epidemic in SA through the eyes of Dr. Uys, nurses may apprehend the reality faced by patients, family members, and health care providers and find ways to help.

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References


HIV-Positive Patients’ Experiences of Stigma During Hospitalization

Siobhan Surlis, BN, MMS, RGN
Abbey Hyde, BSS, MSS, PhD, RGN

The aim of this research study was to explore, within an Irish context, HIV-positive patients’ experiences of hospitalization and particularly their experiences of nursing care. This article reports on one of the dominant themes to emerge in the study—the experience of stigma during hospitalization among persons with HIV. A volunteer sample of 10 former inpatients of hospitals in the Republic of Ireland’s capital, Dublin, were interviewed in depth, and the resulting data were analyzed using a qualitative content analysis. Findings indicate that while some participants experienced stigma from nurses, such stigma was stratified according to the means by which the disease had been contracted, with drug users expressing the greatest feelings of stigma from nurses. Data also suggest that the type of nursing care favored by many participants was that of segregated care within specialized units. This type of care was preferred because it enabled the patient to avoid being discredited by other patients who did not have the virus. This environment also offered the potential of social support from other patients with similar diagnoses. Finally, patients experienced breaches in confidentiality because of institutional policies that made their disease conspicuous and from some nurses’ nonchalance in handling information about their disease. The analysis used in this study draws on Goffman’s conceptualizations of stigma to explain the social process underlying the accounts given by study participants.

Key words: HIV, AIDS, nursing care, stigma, confidentiality, homosexuality, drug user, Republic of Ireland

When the AIDS epidemic first emerged in the early 1980s, health care providers, like the general public, were frightened, and many had reservations about caring for people with HIV/AIDS (A. Lewis, 1988). Since then, although enlightenment on the issue has appeased much of that early disquiet, Pratt (1995) has noted that fear, ignorance, and prejudice are the major barriers to effective nursing care of patients with HIV/AIDS. This article reports on research that aimed to explore HIV-positive patients’ experiences during hospitalization, with particular reference to their experiences of nursing care, within an Irish context. A prominent theme to emerge in the study was the experience of stigma, and this concept is the focus of the article.

The argument advanced in this article is that whereas HIV-positive patients experienced stigmatizing attitudes from some nurses, the degree of stigma was related to the mode by which the disease was acquired, with drug users reporting the greatest level of stigma. It is also suggested that segregated care was favored by HIV-positive patients in this study because it prevented them from becoming “discredited” by others who do not have the virus. This type of care environment also offered the possibility of social support from those in the same predicament. Finally, both institutional policies and nurses themselves were
responsible for discrediting HIV-positive patients by paying insufficient attention to matters of confidentiality.

**Literature Review**

The volume of literature on the topic of HIV/AIDS has escalated greatly in the past 15 years. This brief review will focus on issues of most relevance to the experience of stigma among those individuals living with HIV/AIDS while being “cared” for by health care providers such as nurses. These issues center on staff attitudes, the location of nursing care (special vs. general units), and the issue of confidentiality.

Nurses’ attitudes have been found to have an impact on the experiences of persons living with HIV/AIDS (Armes & Higginson, 1999; Beedham & Wilson-Barnett, 1993, 1995; Kermode, 1995; Schietinger & Daniels, 1996). Beedham and Wilson-Barnett (1995) reported that 96% of respondents in their study stated that the aspects of nursing care that were seen as most important related to staff attitudes rather than competence or effectiveness of treatment. Participants in research by Schietinger and Daniels and more recently by Armes and Higginson also highlighted the importance of health care providers’ attitudes. Both studies suggested that this was an area requiring further training.

In a qualitative study, Kermode (1995) explored patients’ perceptions of nursing interventions during hospitalization for their AIDS-defining illness. Being touched, being checked on, and the friendliness of nurses, together with comfort giving and a sense that nurses cared, were identified as the most helpful nursing interventions. A later study by Cederfjäll and Wredling (1999) of gay HIV-infected men’s encounters with health providers echoed much of Kermode’s findings in relation to how participants constructed good experiences from nursing care.

Several studies identified nurse respondents who felt that people with HIV were to blame for getting their illness (Armstrong-Esther & Hewitt, 1990; Breault & Polifroni, 1992; Eliason, 1993; J. A. Kelly et al., 1988; Kemppainen, Dubbert, & Williams, 1996; Melby et al., 1992; Preston, Forti, Kassab, & Koch, 2000; Young, 1988) and intravenous drug users (Carroll, 1993; Melby et al., 1992). In a quantitative study examining nurses’ attitudes regarding homosexual patients with a diagnosis of either HIV or leukemia (J. A. Kelly et al., 1988), homosexual patients were evaluated much more harshly than heterosexual patients regardless of the diagnosis. In contrast, a qualitative study by Breault and Polifroni (1992) found that homosexuals were granted some leniency by the belief that they were not to blame for having AIDS. In the same study, some respondents held that intravenous drug users and prostitutes were partly responsible for their illness. Preston and colleagues (2000) found that among rural nurses, attitudes about homosexuality significantly affected their willingness to nurse HIV/AIDS patients.

Despite these reported negative attitudes of some nurses toward people with HIV/AIDS, there is also evidence in the literature that justice and fairness mediate nurses’ perceptions of those living with the virus. For example, nurse respondents in a number of studies indicated that people with HIV/AIDS deserved fair treatment (Armstrong-Esther & Hewitt, 1990; Dols & Bradley-Magnuson, 1996; Eliason, 1993; McCann & Sharkey, 1998). Furthermore, whereas some studies have found considerable levels of homophobia among nursing students (Eliason, 1998; Schlub & Martolf, 1999), others have reported relatively low homophobic scores among nurses (Erlen, Riley, & Sereika, 1999). In observing nurses’ interactions with AIDS patients (primarily homosexuals) compared to general medical patients, Siminoff, Erlen, and Sereika (1998) noted that nurses used eye contact and touch more frequently with the AIDS patients. Preston and colleagues (2000) found that attitudes about homosexuality, combined with societal and professional reservations, significantly affected nurses’ willingness to care for persons living with HIV/AIDS. In their sample, 81.5% (n = 731) reported that they were open to caring for those with the disease.
Findings from studies that have explored the issue of whether nurses would leave the profession if they were required to care for HIV/AIDS patients are also heartening. Generally, these studies found only a relatively small proportion of nurses declaring that they would leave (Melby et al., 1992; van Wissen & Siebers, 1993). Indeed, nurses who opt to work exclusively with HIV/AIDS patients have been found to value the close nurse/patient relationship and the distinctive nature of AIDS care (Hayter, 1999). It has been noted that better education on HIV/AIDS in nursing programs may be shaping nurses’ attitudes in a positive way, and there is empirical evidence to support this contention (All & Sullivan, 1997; Carney, Werth, & Martin, 1999; Dimick, Levinson, Manteuffel, & Donnellan, 1996).

Issues regarding the most preferred location of care among patients with HIV/AIDS have been addressed in several studies (Beedham & Wilson-Barnett, 1993; Cederfjäll & Wredling, 1999; Kermode, 1995; Ong, Clarke, Dunbar, & Mandal, 1993; Schietinger & Daniels, 1996; van Servellen, Lewis, Leake, & Schweitzer, 1991). With the exception of Ong et al.’s study, this literature suggests that most HIV/AIDS patients have a preference for being cared for in special care units. Reasons for this preference include protection from anti-HIV and antigay prejudices, as well as the opportunity to be cared for by staff with positive attitudes and adequate knowledge of the disease.

Given the stigma of HIV/AIDS, a major concern for many people who are HIV positive is the respect for privacy and confidentiality on the part of health care providers (Armes & Higginson, 1999; Beedham & Wilson-Barnett, 1995; Moneyham et al., 1996; Ong et al., 1993; Petchey, Farnsworth, & Williams, 2000; Schietinger & Daniels, 1996). Ong et al. found that 84% of individuals did not tell their general practitioners of their HIV diagnosis because of fear of transgressions in confidentiality. Moneyham et al. and Armes and Higginson found that fear of breaches in confidentiality often prevented participants in their studies from using resources and services they needed. In Beedham and Wilson-Barnett’s study, 14 out of the 85 participants felt that accepting home help could lead to confidentiality breaches. Participants in a study by Petchey and colleagues were concerned about information management in general practice medicine and the impact that divulged information would have on their lives, particularly in relation to locally provided services.

Overall, the existing literature indicates that nurses’ attitudes about HIV/AIDS patients vary from full acceptance to prejudices against patients who have the virus. In relation to the most preferred location of care, most HIV/AIDS patients prefer being cared for in a special care unit as opposed to a general care area. Finally, studies demonstrate that a fear of breaches in confidentiality by health workers is common among people with HIV/AIDS.

Method

The data set presented here stems from one of the thematic findings of the overall study, which explored the nursing care experiences of people with HIV/AIDS. Because participants contributed useful information about their relations with other patients that likely influenced nursing decisions, the original focus on nursing care was broadened slightly and reframed as “hospitalization experiences.” Criteria for entry to the study were that participants would be HIV positive with the experience of being inpatients in an Irish hospital at some point since diagnosis.

A sample size of 10 was sought, and the logistics of selection were as follows: A letter and a poster outlining the study were mailed to eight agencies and hospitals that provided services to people with HIV/AIDS. The key people at these hospitals and agencies were asked to explain the study’s aims to service users. Individuals who were interested in taking part in the study were given the researcher’s telephone number to enable them to make contact. The poster was also used as a reference for interested participants. After having obtained further details and a guarantee of anonymity, the first 10 to approach the researcher agreed to participate. The sample was composed of 3 women and 7 men. The age range was 29 to 50.

In-depth interviews were conducted during April and May of 1998 at a time when all participants were outpatients. Although an open style was adopted, a topic guide was used, and interviews were audiotaped. Included on the topic guide were issues relating to patients’ positive and negative experiences of nurs-
ing care, their perceptions of their care in relation to other patients, their satisfaction with information received, and demographic details. These broad issues were deemed the most useful in addressing the research aim. As the interviews progressed, concepts became more refined. The term nursing care was used in its normal discourse, and participants were asked to explore their experiences of it. A working definition was not imposed, which allowed participants to identify what they felt nursing practice to be. This facilitated the construction of nursing care as framed by patients, which could contribute to the debate about what constitutes nursing practice.

Data were analyzed using a qualitative content analysis, whereby patterns were first identified and data were then scrutinized for variations and exceptions to these patterns. An attempt to explain the data was conducted without imposing existing explanatory frameworks on data. Where established theoretical insights were used to illuminate aspects of data, the fit between theory and data was not forced.

**The Concept of Stigma**

Stigma is a broad and multidimensional concept, the essence of which centers on the issue of deviance from a norm. A stigmatized person possesses an attribute that makes him or her different from others in the “normal” category and, therefore, less desirable; the person becomes tainted, discounted, and discredited (Goffman, 1963). Alonzo and Reynolds (1995) stated that people with HIV are stigmatized because their illness is associated with deviant behavior, perceived as the responsibility of the individual, viewed as contagious and a threat to the community, and linked with an “undesirable and anaesthetic form of death” (p. 305).

Although much has been written in recent years on the topic of stigma associated with a range of chronic conditions (M. P. Kelly & Field, 1996), none has surpassed Goffman’s writings in establishing a theoretical perspective on the subject. Even more recent attempts by scholars to focus on bodily aspects of identity have been accused of rehashing much of Goffman’s works (among others) (Williams, 1996).

Although there was no attempt made to “force” the data into any particular theoretical framework, the analysis that follows draws heavily on Goffman’s works, the significance of which became clear after data had been collected.

**Conceptual Themes Arising From Data**

HIV-positive patients’ experiences of stigma during hospitalization, with special references to interactions with nurses, have been conceptualized under four themes: participants’ perceptions of nurses’ attitudes toward their HIV status, the stratification of stigma, participants’ preferences for segregated care, and the significance of confidentiality in relation to their care.

**Participants’ Perceptions of Nurses’ Attitudes toward Their HIV Status**

Participants in this study gave very rich descriptions of experiencing stigmatizing attitudes from nurses, some of which they believed to be rooted in existing prejudices associated with the lifestyle or risk behaviors of those who are HIV positive. People with HIV who were infected sexually, or through sharing needles, were particularly vulnerable to “victim-blaming” (Green, 1995).

Study participants commented on the judgmental speech pattern of nurses, as one respondent describes:

Some of them used to give out to us; “We haven’t got time for you, there’s more sicker people than you.” . . . It was because I was a criminal and a drug-user. (Tony)

Clearly, Tony was surmising what the nurses were thinking here, and although Tony’s subjective experiences are valid, Goffman (1963) has noted how stigmatized individuals may readily read unintended meanings into people’s actions. Indeed, Jane, in the next example, was conscious of this tendency:

I am very conscious of the fact that most of us might be over sensitive . . . we might be looking for that. I think it’s doubly so when there’s a drug connection . . . because anyone who is a drug-user is dirt, and that’s how a lot of us would feel.

However, there were a number of other accounts in which nurses were reported to have been extremely
candid about their perceptions that the disease was self-inflicted if acquired through intravenous drug use:

I don’t think she [the nurse] liked drug addicts. She was very abrupt with me. I used to say “I’m in pain.” She used to say “Well that’s what you get for using drugs.” . . . It was terrible when I look back now. Even if I said something, it all depended on who the nurse was on the day. They’d say “Well listen, this is your fault.” . . . The main thing is all this branding the patient. Most of them, when they get sick, they get afraid and they don’t want to be a nuisance because some of them feel it’s self-inflicted on them, what they did, because of the virus. (Tony)

Even to this day, you’d get some [nurses] that would say, “Well you knew the virus was out, so long ago, and why are you still using,” not to me, but to other people that I knew. It’s like a slap on the hand. . . . I think the nurses nowadays should be more caring with people that have the virus. We didn’t ask for it, even though we had problems, like drug addicts. We didn’t ask for that plague. They were no wiser than we were. We don’t want to be knocked. (Kate)

Not all participants were critical of nurses’ attitudes to HIV-positive patients. One participant did not feel nurses blamed him for his illness:

I don’t think nurses hold . . . well I hope not . . . as I said, the staff in one hospital, they come across as, “Don’t blame yourself,” you know like that. Trying to lift your spirits, as if to say “Don’t be blaming yourself for what happened, we all make mistakes.” It’s like being strung out on gear; it’s like someone being strung out on coffee or strung out on tea. So there is support . . . (Frank)

Frank described how the nurses’ nonjudgmental behavior promoted a supportive environment:

There was one particular male nurse that worked there and he was very good to the patients that had HIV, like he’d make a cup of tea or something like that.

Tony, who was quoted earlier criticizing nurses’ judgmental attitudes, described more egalitarian treatment he received at another hospital:

(They) treat them as a normal patient and that’s the way I felt, like a normal patient.

The importance of being treated equally with other patients was also elucidated by Jane:

When you’re going in you do feel very vulnerable and you’re waiting to be judged or to be criticized. So the nurses are in a prime position to make them feel at ease . . . judgment from all over the place, when you’re in the hospital and you’re sick, you’re even more vulnerable so it can really make a difference, psychologically, if a nurse treats you . . . I hate the word normal . . . but as you would any other patient.

The Stratification of Stigma

Goffman (1963) has noted how stigma can be stratified; that is, stigmatized people within the same broad category can display a separation from one another. This seemed to occur in this study, based on the means by which study participants had contracted the disease—with particularly clear divisions among “the gays” and “the drug abusers.” Although the stigma associated with HIV/AIDS is pervasive, findings here suggest that individuals with the disease do not necessarily experience the same degree of stigma. There is evidence in the data that participants believed that the stratum to which they belonged impacted on the quality of the nursing care each group received:

I have nothing against gays, but they were getting treated first and out of the way. (Tony)

You know it’s the ah . . . a lot . . . between drug abusers and ah, between gays that go over to the hospital, I think those that are gay seem to get
more attention than those that are drug abusers.
(Frank)

A third participant, who was not a drug user, described
the difficulties he experienced when there were drug
users in the same ward:

She [nurse] said “Mike, you’re too quiet,” you
know, because people from the IV community
tend to be a bit more vocal on the ward. That can
be a bit overpowering from time to time. And the
way I look at that is they have as much right to be
there as me. But when you’re listening to that,
when it becomes very intense and you’re sick, it
can be very overpowering. (Mike)

In the excerpt below, in the course of a discussion on
nurses’ attitudes to people with HIV, Jane elucidates
the subtle messages she received:

There is still a little tendency, and it can come
across, comments you know, that if someone is
using drugs it’s their own fault. That wouldn’t be
stated but it would be “Oh you poor thing, you
got it from sexual contact, ah God that’s
different.”

A strong theme in the data was the comparatively high
degree of stigma reported by patients who had become
infected with HIV due to drug use.

Preference for Segregated Care

Several participants, for various reasons, stated a
preference for receiving care in a specialized unit
rather than a general ward. Such a preference may be
explained through Goffman’s (1963, p. 31) construc-
tion of two types of people sympathetic to the stigma-
tized individual: the “own” and the “wise.” The own
are described as those who share the same stigma, and
the wise as those who come from working in establish-
ments that cater to the wants or actions of those with
a particular stigma. Goffman has noted how the imme-
diate presence of “normals”—that is, those without the
stigmatizing characteristic—is likely to reinforce the
extent to which individuals perceive themselves as
falling below a particular standard. In a specialized
unit, HIV-positive patients may still have to deal with
tensions among individuals on the basis of how the dis-
ease was contracted. However, they do not have to
confront other patients without the disease whose
presence may intensify their sense of difference.
The preference for segregated care is clearly articu-
lated by Jane:

I had been taken to my local hospital by ambu-
lance, you know the way you have to be taken to
the nearest hospital. If it happened again I would
just go straight to the specialist hospital . . .

In one case, at least, the predilection for separation
was based on the fact that social contacts with others
with HIV were facilitated and patients would be
among people they knew rather than among strangers:

I’d prefer to be on a ward where everyone has
HIV. . . . Yes, yes, because there were young ones
that you knew. Whenever I’m in there I know
somebody. (Mary)

Kate also describes the social cohesion that special-
ized units might foster:

They should make the wards out for HIV only,
and not have other medical patients in there. If
they’re treating HIV they should leave the ward
for the people with HIV, so we can get on with
our own little ward and we don’t have to mix with
other people and at least you have that little bit of
privacy. We’re all in the one boat and if people
want to talk about it they can relate to someone,
it’s helpful . . . you could say what medication
you’re on, and the people are going through what
you’re going through and you could give them a
bit of advice.

In the case of an individual who has been recently
diagnosed with HIV, it is probable that others who
have been diagnosed longer can help him or her cope.
What Kate described (above) was close to Goffman’s
(1963) description of a “welcome . . . to the club”
(p. 50), which can instruct newly stigmatized persons
how to manage physically and psychologically. A
study by J. Lewis (1999) also found evidence of social
networking by HIV-positive gays with others who
were living with HIV in an effort to overcome stigma and isolation associated with the disease.

Significance of Confidentiality in Relation to Care

Confidentiality is important in all realms of nursing practice. However, it is perhaps most critical in areas in which the individual receiving care carries a high degree of stigma and is sharing the care space with others who do not possess the stigmatizing attribute. Goffman’s (1963) distinction between stigmatized persons who are “discredible” and “discredited” is useful in understanding the significance of confidentiality in the care of those with HIV/AIDS. In the case of the discreditable individual, the person’s stigma is neither known to observers (other patients) nor perceivable by them, and the management of information is central. A discreditable person can “pass” as “normal” (p. 58), and clearly most participants in this study hoped to do this in presenting themselves to other patients. For the discredited individual, the stigmatized person assumes that his or her differentness is immediately perceptible, and therefore the management of tension in social encounters is central. Where information is not handled tactfully and confidentially by the staff in question, the stigmatized person can move from being discreditable to being discredited, creating a great deal of tension for him or her in encounters with other patients.

A number of participants referred to issues of confidentiality when discussing the quality of the nursing care they received. Findings from this study suggest that sometimes confidentiality may be breached intentionally or unintentionally and threaten or actually push a person’s identity into the category of discredited:

Sometimes I think nurses are very kind and very serious, but there are patients on either side of the bed, just to be aware. . . . Well I’m thinking of two instances in particular where I started to talk very quietly and then the two nurses got louder and louder and the patient next to me was awake and I had to say “Shush.” . . . And I’m very confident about talking about it, but I know that some people get very, very put off. . . . It’s very important if they’re commenting on stuff. That its not done within earshot, saying things to them in front of others or within earshot of others . . . (Jane)

One man came in and I heard the nurses telling him that I was a drug addict and to be careful of his possessions. And I’ll never forget it. He had a briefcase. He rang his sister, and my girlfriend went out into the hall and she heard him saying, “There is a guy on the ward and he is a drug addict, and I want you to come up and take my briefcase . . .” (Tony)

Red stickers had been placed on patients’ medical and nursing notes to alert health care workers that the patient had an infectious disease. These red stickers had been identified by 4 participants as a breach of confidentiality:

I believe the red dots on the charts are for all the infectious diseases, but I know that was something a lot of us were very uncomfortable about. You know, the way people ask what are the red dots for. And a lot of women believe they are the only ones with the red dots . . . some their families don’t even know, and that’s a real big one. You have families coming in, that’s why you worry the red dots on their chart and what they’re going to say and that kind of thing. (Jane)

I found confidentiality was a big thing, I found confidentiality was broken. . . . The big thing that I had about the hospital was the big red sticker on the chart. That goes with the territory, God I hate red. (Mike)

The way the elderly men knew, or their visitors knew, that we had HIV, would be by a little red mark that would be on your chart and that would be at the end of your bed. (Frank)

That I think is discriminating. That is like saying “Kate, big red dot, she has the virus.” (Kate)

The extent to which nurses had jurisdiction over the placement of red stickers on case notes is unclear, but it is most likely to have been an institutional decision rather than a nursing one.
One participant describes the shame and humiliation she felt when she lost her anonymity:

When I had given birth to Ann, it was a shock birth. She came so fast, they could not have noticed a big red circle on my chart, that’s to say that I had HIV, and I was in the admission room . . . but she [the nurse] did not look at my chart and she had a cut. I’ll never forget this, never forget it and of course she mingleded with my blood, my waters and then she discovered I had HIV. Well I needn’t tell you, it went around the hospital like wild fire, like wild fire . . . and I was the talk of the hospital, because they knew there was a woman in there with HIV who gave birth in the admission room and “now the nurse is infected.” I was never able to show my face because I was in the ward with the women and then I was taken back out and then in a ward on my own, so it was obvious they knew it was me. It was very, very degrading. (Kate)

As in the other examples, Kate’s status had moved rapidly from discreditable to discredited, and created a great deal of distress for her in the process.

**Discussion**

The qualitative data collected in this study have revealed the experiences of HIV-positive hospital inpatients regarding their interactions with nursing staff and, to a lesser extent, with each other. These data support existing study findings pertaining to the judgmental attitudes of nurses toward people with HIV/AIDS, especially regarding the means by which the patient contracted the disease and the extent to which nurses believed this to be self-inflicted (Armstrong-Esther & Hewitt, 1990; Breault & Polifroni, 1992; Eliason, 1993; J. A. Kelly et al., 1988; McCann & Sharkey, 1998; Melby et al., 1992). The preference for segregated care also supports findings from existing research (Beedham & Wilson-Barnett, 1995; Moneyham et al., 1996; Ong et al., 1993; Petchey et al., 2000; Schietinger & Daniels, 1996). Whatever control nurses may or may not have regarding institutional policies to label patients’ case notes with stickers, there is clear evidence that nurses were careless when handling patients’ information. Indirect references to patients may be as damaging to patient confidentiality as more direct ones, where pieces of information may be linked together by observers and collectively identify the patient in question. For nurses to merely refrain from directly naming a patient and his or her disease to others beyond the immediate therapeutic situation would appear to be insufficient to the preservation of confidentiality. Vigilance in handling information that may reveal a patient’s identity or diagnosis is required.

**Limitations of the Study**

There are two main limitations to the present study. The first is the relatively small sample size, and the second is the negative way nursing care is presented in this data set. The limitations of the small sample size are to some extent offset by the rich data gleaned from participants. Although qualitative data are notoriously uneven in quality, the self-selection of participants for the study ensured consistently prolific data that enabled themes and social processes to be identified with a remarkable degree of consistency. In relation to the second issue, the negative portrayal of nursing, the
focus on stigma as an analytical concept in this article lent itself to concentrating mainly on poor nursing practices. On balance, handling data in this manner allowed a degree of depth to be obtained. However, it is acknowledged here that there were very positive aspects of nursing expressed by participants and these will be reported elsewhere.

Conclusion

The preceding data on HIV-positive patients’ experiences of stigma during hospitalization and particularly in nurse-patient interactions have elucidated the complex nature of stigma and how it permeates patients’ experiences in a number of ways. These findings challenge all nurses working with persons living with HIV/AIDS to become more self-aware. Such reflection can serve to maximize practices and to increase the quality of care provided to all, regardless of whether that care is given in a specialized unit or a general care environment.

References

Green, G. (1995). Attitudes towards people with HIV: Are they as stigmatizing as people with HIV perceive them to be? Social Science and Medicine, 41(4), 557-568.
infected with HIV. *Health Care for Women International*, 17(3), 209-221.


Petchey, R., Farnsworth, B., & Williams, J. (2000). “The last resort would be to go to the GP.” Understanding the perceptions and use of general practitioner services among people with HIV/AIDS. *Social Science and Medicine, 50*(2), 233-245.


A Qualitative Assessment of Condom Use Decisions by Female Adolescents Who Use Hormonal Contraception

Carol F. Roye, EdD, CPNP
Brenda Seals, PhD, MPH

Young women who use hormonal contraception are at increased risk of HIV. This study, based on the Health Belief Model, was designed to understand how adolescent women who use hormonal contraceptives make decisions about condom use. Thirty-nine young, minority women participated in open-ended interviews. The interviews were transcribed and analyzed by both authors separately. The results suggest that barriers to condom use include use of a hormonal method of contraception, perceived trust in a partner, and a perception of the condom as “irritating.” Facilitators for condom use included not being with a steady partner and fear of pregnancy and infection. The young women also suggested that being able to talk to their parents about condom use, having condoms widely available, and seeing HIV-prevention messages in many venues would increase their use of condoms. They noted that seeing young, HIV-positive women demographically similar to themselves would also prompt them to use condoms. Nurses should incorporate these factors into HIV-prevention interventions for adolescents.

Key words: HIV prevention, hormonal contraception, adolescents, minority

High rates of sexual activity, human immunodeficiency virus (HIV), and other sexually transmitted diseases (STDs) pose a formidable risk to the health of adolescents (Institute of Medicine [IOM], 1997). Young women constitute the fastest growing category of new AIDS cases. Researchers have found an almost sixfold increase in incidence rates of AIDS in women between 1991 and 1995 (Wortley & Fleming, 1997). The greatest increases were among young women who acquired the infection through heterosexual contact (Centers for Disease Control and Prevention [CDC], 1998; Wortley & Fleming, 1997). Furthermore, young women are at risk for HIV infection at earlier ages than young heterosexual males (New York State Department of Health [NYSDH], 1992). Minority women are at greatest risk (CDC, 1998; Wortley & Fleming, 1997).

Young women who use hormonal contraceptives are a subgroup of minority adolescents that is at elevated risk for HIV for both biological and psychosocial reasons. The primary biological burden of risk stems from cervical ectopy—a normal condition of the cervix during adolescence and young adulthood (Gottardi, Gritti, Marzi, & Sideri, 1984; Mosciki, Winkler, Irwin, & Schachter, 1989), which is increased by the use of hormonal contraceptives (Martin et al., 1998; Moss et al., 1991; Plummer et al., 1991). Cervical ectopy is the presence of columnar epithelium on the ectocervix. It places the vulnerable squamocolumnar junction on the ectocervix where it is in direct contact with sexually transmitted organisms. The columnar epithelium is thinner; thus, it bleeds...
more easily with trauma (CDC, 1998; Clemetson et al., 1993). Therefore, ectopy may facilitate entry of HIV into circulating cells (Clemetson et al., 1993; Moss et al. 1991).

Whereas cervical ectopy partially explains the increased vulnerability of all adolescents to STDs including HIV (CDC, 1997), it is particularly salient for those who are sexually active and using hormonal contraception. Research has revealed that in sexually active adolescents, the area of ectopy remains for more years than in teens who do not experience coitus (Gottardi et al., 1984).

There is mounting evidence from animal and human studies that hormonal contraceptives increase HIV susceptibility and infectivity, probably by increasing cervical ectopy. In one study (Marx et al., 1996), rhesus macaques who had been given progesterone implants were significantly more likely to have contracted SIV, to have a higher viral load, and to have a more rapid onset of disease after vaginal exposure than control animals. Similarly, a study of mice that had been treated with exogenous progesterone (Depo-Provera) revealed an increased susceptibility to HSV-2 infection after intravaginal inoculation with the virus (Parr et al., 1994).

A number of studies designed to look at correlates of HIV susceptibility and infectivity have been conducted with women in Africa. One report discussed a prospective study of 595 prostitutes in Kenya. In that study, oral contraceptive (OC) use was independently associated with increased HIV seroconversion (Plummer et al., 1991). Another prospective study of HIV seronegative women in Africa (Bulterys et al., 1994) revealed a significantly higher incidence of HIV seroconversion in hormonal contraceptive users (OCs and Depo-Provera). A study of African couples in stable relationships found cervical ectopy in 88% of women who had been using OCs for a period of years, compared to 51% of women who were not OC users (Moss et al., 1991). The only independent predictor of HIV seropositivity in the long-term sexual partners of HIV-positive men was the presence of cervical ectopy. A prospective, observational study of female sex workers in Kenya, which controlled for demographic and exposure variables and biologic covariates, found that women who used Depo-Provera had a significantly increased incidence of HIV-1 (adjusted hazard ratio [HR] = 2.2, confidence interval [CI] = 1.4-3.4). The authors also found a trend for an association between use of low-dose and high-dose OCs (Martin et al., 1998).

The use of hormonal contraceptives appears to be associated not only with increased susceptibility to HIV but with increased infectivity as well (Clemetson et al., 1993; Mostad et al., 1997). A study of HIV-1 shedding in the cervical and vaginal secretions of 318 HIV-infected women in Kenya found that hormonal contraceptive use, specifically Depo-Provera and low- and high-dose OCs (odds ratio [OR] = 2.9, 3.8, and 12.3, respectively) were significantly associated with increased shedding of infected cells (Mostad et al., 1997). In addition, OC appears also to be associated with HSV shedding in HIV-infected women (Mostad et al., 2000).

Psychosocial risk behaviors stem from several sources. Developmentally, adolescent women may lack cognitive and communication skills necessary to effectively negotiate for safer sex behaviors such as delaying the onset of sexual activity and decreasing the number of sexual partners (Ammerman, 1995; Berenson & Wiemann, 1995; Roye, 1998). Furthermore, adolescents appear to regard the use of any contraceptive primarily as a measure to prevent pregnancy. If they are protected from pregnancy by another method, they may not be motivated to use condoms (Ammerman, 1995; Berenson & Wiemann, 1995; Roye, 1998). A study of more than 600 adolescent and young adult women in an inner-city neighborhood in New York City found that young women who used hormonal contraceptives were significantly less likely to use condoms than those who used condoms only, even though they all identified AIDS risk as an important concern in their choice of contraceptive method (Roye, 1997, 1998). Another study of condom use by an ethnically diverse population of low-income, urban women (N = 1,073) found that the frequency of condom use declined significantly (p < .001) once respondents initiated use of long-term hormonal agents compared to the 3 months prior to using long-term agents. The change in condom use was most likely to occur among women who reported always using condoms at baseline (Cushman et al., 1998).
Effective use of contraception to prevent STDs, HIV, and pregnancy requires that a young woman who uses a hormonal method has a male partner who uses condoms consistently, regardless of the nature of the relationship between the two young people, for example, long-term or casual. The goal of this study was to gain an understanding of the factors that lead inner-city adolescents who use hormonal contraceptives to use condoms. A second goal was to glean an understanding, from the teens’ perspective, of what interventions to promote condom use in this population would be most effective.

**Method**

**Design**

Adolescent contraceptive behaviors are complex and rooted in multiple factors. To gain a more comprehensive insight into the underlying factors that shape adolescents’ condom use behaviors, a qualitative methodology was used.

**Theoretical Framework**

Prominent among the underpinnings of adolescent sexual behaviors are the teen’s perceptions of reality and circumstances. Therefore, the Health Belief Model (Janz & Becker, 1984) was selected as the theoretical framework for the study. The Health Belief Model, which incorporates perceived susceptibility to and perceived seriousness of a disease as well as perceived benefits of and perceived barriers to health-promoting behaviors, is useful in studies with teens because they are less likely than adults to consider themselves personally vulnerable to AIDS (Villaruel, Jemmott, Howard, Taylor, & Bush, 1998). Furthermore, because AIDS is a latent, not an immediate consequence of unprotected intercourse, adolescents are not likely to consider AIDS a serious threat (Mosciki et al., 1989). Teens are more likely to consider themselves vulnerable to pregnancy, which is a short-term consequence of unprotected intercourse (Mosciki et al. 1989; Roye, 1997).

**Sample**

Thirty-nine young women participated in the study. The participants ranged in age from 15 to 21 with a mean of 18.7. The sample was ethnically diverse. Approximately 15% self-identified as Hispanic (Dominican, Puerto Rican), 56% as African American, 20% as Caribbean, 2% as White, and 5% as other. Seventy-two percent had completed at least 12th grade (see Table 1).

Ninety percent of the sample were using or had used OCs, and almost one quarter (23%) had used Depo-Provera. None of the young women in this sample had used Norplant. More than half of the sample had experienced a pregnancy (56%), and 21% had been diagnosed with an STD.

When asked whether their partners had ever used condoms, 4 young women (10.3%) replied no, whereas 33 (84.6%) replied yes. One respondent stated that her partner rarely used condoms, and

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another replied that her partner used to use condoms but no longer used them (Table 2).

Measures

Interview Schedule

The interview schedule was based on an instrument developed and used by one of the authors in a previous study of adolescent contraceptive behavior (Roye, 1998). The Health Belief Model was used to frame the questions in that instrument. The original questionnaire, which was based on prior research with teens, (DiClemente et al., 1992; Hingson, Strunin, Berlin, & Hereen, 1990) addressed sexual behaviors, contraceptive use, history of pregnancy and STDs, communication about sexuality, and attitudes about preventing pregnancy, HIV, and other STDs. Prior to use, a pilot test of the questionnaire was done with a sample of low-income teens in an adolescent clinic to check for language and readability. The questionnaire was administered at a clinic visit and again 2 weeks later. Needed changes indicated by field testing were incorporated into the instrument. Kappa reliabilities on items ranged from .77 to 1.0, an acceptable level. This article will focus on specific open-ended questions (see the Results section).

The schedule included open-ended questions such as “The reasons I use (or do NOT use) condoms are...” and semistructured questions such as “Are there times when you have sex that you would be more likely to use condoms than at other times?” In the previous study, a ceiling effect was found for questions dealing with self-efficacy about condom use (Roye, 1998). Therefore, those questions were not included in the questionnaire for this study.

Procedure

The study was conducted at a Planned Parenthood center in a large city in the northeast. Research assistants recruited young women in the waiting room. Those who agreed to participate were given a screening questionnaire to determine their eligibility for the study. Eligibility criteria included age between 15 and 21 and current or past use of a hormonal contraceptive, specifically OCs, Depo-Provera, or Norplant. Interested young women who met the criteria were given a consent form and an explanation of the study. Interviews were conducted by research assistants, who were female graduate students in health education. They participated in a 2-day training session that prepared them for conducting interviews with an emphasis on working with adolescents and sexual content. All the interviews were tape-recorded and transcribed by the interviewers. A total of 39 young women were interviewed. The interviews lasted 15 to 20 minutes. Each young woman was paid $20 for her participation.

Analysis

Open-ended questions were coded independently by the two investigators guided by the Health Belief Model. Common themes were sought. Specifically, facilitators and barriers to issues raised in the questionnaire, such as communication and condom use, were sought. In addition, the questionnaire addressed what the young women considered to be effective ways of implementing HIV-prevention interventions. Differ-
ences in codings were resolved by consensus (Miles & Huberman, 1994). Results are grouped by question.

**Results**

“How do you think your partner would feel if you asked him if he had ever done anything that could give him a chance of getting AIDS?”

**Facilitators and barriers.** Eighteen respondents described positive responses such as “We talk, he would not be offended” and “He would not mind . . . .” Eighteen respondents described negative responses: “uncomfortable,” “nervous,” “a little upset,” “suspicious,” “let down, hurt,” “bad,” “insulted,” and “offended.” Two respondents had ambiguous responses: “I would not know. I never really asked. I haven’t asked. But usually every 6 months we go together and get tested. But I never really asked him” and

A lot of guys like to front and they might say “naw,” I don’t really have. And stuff like that. But I really don’t let it stress me because as long as I take my precautions, I will be okay.

Further analysis of participant responses revealed that the syntax used was primarily of the subjunctive manner. That is, coded responses were stated either hypothetically, for example, “he would not” or “he might,” or with a one-word description of a feeling (see the list of negative responses above). In the latter case, respondents did not describe examples of their partner’s being angry, uncomfortable, and so on, as would be expected were respondents answering the question based on their experiences.

“How would your partner feel if you asked him to use a condom?”

**Facilitators and barriers.** Thirty-three responses indicated that the young women felt that their partners would respond to this question with a facilitative response: “No problem,” “He would understand,” “fine,” “protected,” “[He] wouldn’t mind because he does not want me to get pregnant,” “He’ll agree to it,” “He would feel comfortable . . . .” Only 5 respondents had clearly negative responses: “He wouldn’t want to” and “Not comfortable.” Three responses were more ambiguous: “[He would] not feel strange,” “Not necessarily offended,” and “He would not feel bad, but he wouldn’t like it.” Again, analysis of the syntax revealed that these questions were framed mostly in subjunctive responses or as a short description of a feeling not including descriptions of examples from experiences.

“I want you to think back to the LAST time you had vaginal intercourse and did NOT use a condom. What were the reasons that you did not use a condom?”

**Barriers.** The most frequent category, with 13 responses, reflected that other protection, primarily use of OCs to protect against pregnancy, was in place so that the respondents saw no need for using condoms. As one respondent summed it up, “’Cause I was on the pill and can’t get pregnant.” The second most common category, with 8 respondents mentioning it, was, as one respondent said, “we just didn’t want to use it.” Three categories tied for third most commonly mentioned theme, each with 5 responses. Of these, responses categorized as spontaneity were, “[It was the] heat of the moment,” “I was not thinking about it, it just happened,” and “I did not plan on having sex that day . . . .” **Partner trust** was described as, “Because I feel that I can trust my partner, or at least I hope I can,” and “I did not have anything to worry about at that time because I was with my boyfriend.” Respondents noted the lack of a convenient condom that was “handy” by saying, “he didn’t have any,” “It was not at arm’s length,” and “[It was] 3 a.m. and we were too lazy to go out and buy it.” Two people mentioned “irritation,” perhaps referring to an allergy or physical discomfort from condoms. One respondent described what may be a misinformed belief: “It did not go for more than a minute, like 30 seconds, it was an in and out thing.”

“I want you to think back to the LAST time you had vaginal intercourse and you used a condom. What were the reasons that you used a condom?”

**Facilitators.** Twenty-five responses to this question were for safety reasons, underlining the use of condoms to prevent pregnancy and, secondarily, **STDs.** Respondents said, “Because I was not on the pill yet
and I did not want to get pregnant,” “to prevent STDs and pregnancy,” and “fear of pregnancy and STDs.” Five responses were categorized as involving lack of trust and included, “Cause he was not my boyfriend anymore” and “Because I did not know the person that well.” Three respondents said that it was a “habit” or that they “usually” used a condom. Another 3 respondents mentioned specifically having a discussion: “it was discussed between me and my partner to use a condom.” Only 1 respondent mentioned the availability of condoms by saying, “We had them.”

“What do you think would make you use condoms more regularly when you have sex?”

The most commonly mentioned response, by 12 respondents, was related to risk of pregnancy and STDs. Respondents said, “The scare of pregnancy, the scare of STDs and the scare of HIV,” “thinking about having a child,” and “If I did not have any other type of birth control.” In the second largest category, 10 people mentioned reasons that would increase their perceived risk of infection, including lacking trust: “Only if I had real concerns about my boyfriend cheating on me” or “When I don’t trust the person”; having a known STD: “If he had an STD” or “If I had an STD”; and having more than one partner: “If I had more than one partner.” The third category had 4 responses indicating the importance of handiness, ease, or cost of condoms: “If they were cheaper and if it was not so embarrassing for either partner to go and get them,” “If I had them available,” and “Always having it.” One respondent mentioned the importance of improvements in condoms: “If I could find a condom that . . . would be 100% and a condom that does not irritate me . . . ” Another respondent said, “I just need to know that I have to use it and that’s all.” Another respondent said, “Well, I have a friend that got an STD you know, a close friend.” And 1 respondent said, “Nothing.”

“Can you think of ways that we could help teenagers like you use condoms more regularly when they have sex?”

The most common response to this question, by 10 people, focused on improving access to condoms: “Make [condoms] cheaper because they are kind of expensive in the store,” “They were more available,” and “It is not a fact that teenagers don’t use condoms like that, because many of my friends use condoms. It has to be a way that teenagers can carry condoms around.” Note also in this category that some teens talked about the importance of improving condoms as a product, for example, by increasing sensitivity.

Well [teens] will always complain about feelings and stuff like that I guess. Um, usually they have the sheepskin or whatever skin that feels more natural, but, um, it is supposed to really stop the sperm and not to break a lot. They should have those condoms on the market [than] the ones that break a lot.

The second most common response was increasing information: “Showing [teens] the risk of being pregnant . . . ;” “reading about it, see posters, reading newspapers, seeing it on the television . . . ”; and

I think the best method is to have a lot of movies and stuff like that in the school auditorium. And show all of the bad parts . . . really graphic. But it makes them really realize that this is out here and it can happen to you . . .

The third most common responses fell into three categories with 4 responses each. One category was to increase the salience of the health interventions by personalizing the message. One respondent said,

I am going to say it but there are a lot of teenagers that have AIDS. And, if they come out on TV and do like little conventions and stuff like that, [teens] can see that it can happen to teenagers also. Suppose it being someone my age, it would scare me. . . . It would make me think and I would use condoms.

Another category was increasing communication with parents around condoms. Three respondents pointed to the importance of having a parent who could candidly talk about condoms: “Being able to talk to their parents or other authorities,” “Being able to talk to them,” and “Parents should be friends to their kids; and that way they can open up to them and tell them more instead of just going out there and being sneaky.”
Four respondents had remarks indicating that very little could be done. One contended that, “Truthfully, I don’t really think that we can do much . . .” Another said,

I don’t think that anything would help . . . [I]f your mindset is “oh I’m going to use it once in awhile and not every time” then that’s your mindset. And nobody is going to change your mind. And if you don’t want to use condoms to protect yourself, then they’re not changing anybody’s mind . . .

One teen suggested education at an early age. Another suggested programs in which teens could participate.

Discussion

The responses in this study are consistent with those of teens in other studies, in that perceived risk of pregnancy often appears to be a more potent stimulus for condom use than perceived risk of disease, particularly when young women are with their steady partner (Roye, 1998). In response to both questions about condom use and nonuse at previous intercourse, the most common response had to do with already being (or not being) on OCs. Therefore, use of a hormonal contraceptive is perceived by some young women to be the reason not to use condoms.

The issue of trusting a partner also was very important to the teens. They were less likely to use condoms when they were with their boyfriend. Although the teens in the present study were able to recognize when they are at increased risk, such as being with a partner other than their steady partner or when there is a known STD, their ability to know when to trust someone is more difficult to address. The mere fact that a young woman is with her steady partner seems to be perceived as making the experience a safer sexual encounter, although some teens were ambivalent in their expressions of trust: “Because I feel that I can trust my partner, or at least I hope I can.” From the discussions, trust seems to be based on personal factors such as how long they have known the person and whether the partner is faithful at this time, which is independent of whether that person may have a disease. In addition, as earlier questions suggest, the teens often do not know their partner’s risk behavior history. These apparently are issues that many teens do not feel they can talk about.

Again, this is consistent with other studies. The issue of partner trust has come to light in other studies as well (CDC, 1996, 1997). A qualitative study of 100 predominantly Black women with a mean age of 29 found that use of an alternative contraceptive was the primary determinant of condom use altogether. However, the primary determinant of condom use for STD prophylaxis was the woman’s perceptions of the risks her current partner presented (Green, Fulop, & Kocsis, 2000). A study of 128 young African American women (ages 18 to 29) similarly found that women who believed that asking their partner to use a condom implied infidelity on his part were less likely to use condoms (Wingood & DiClemente, 1998).

The young women in the present study also mentioned the importance of having information widely available. They want to see and hear HIV-prevention messages in many venues. The importance of the communicator was also stressed. Some of the teens in this study said that the HIV-prevention message would be more powerful if delivered by a young woman like themselves who is infected with HIV. This finding is consistent with findings from another study of young, urban women, who also expressed the belief that the HIV-prevention message would be delivered most effectively by HIV-infected women who are demographically similar to themselves (Morrison-Beedy, 1999). Another teen spoke about the importance of parents in HIV prevention. She said that “Parents should be friends to their kids and that way they can open up to them and tell them more instead of just going out there and being sneaky.” Although little recent research could be found on the influence of parents on teen sexual behaviors, the health education literature has been consistent about the importance of parents in sexuality education (Miller, Levin, Whitaker, & Xu, 1998).

An unexpected barrier to condom use was detected. Several young women used the term irritation when discussing condom use. This may be related to increased latex allergy, which has been noted in the general population (Kwittken, Sweinberg, Campbell, & Pawlowski, 1995). It may also be related to
nonoxynol-9, which has recently been found to be associated with increased vaginal lesions and to apparent increased HIV transmission (CDC, 2000).

**Implications for Nursing Practice**

This study has implications for nurses in a variety of settings, especially ambulatory care and school- and community-based sites. First, although at this point in the epidemic it may seem obvious, clarifying and distinguishing for teens the separate issues of pregnancy prevention and disease prevention is critical. Of particular importance, teens who are given a hormonal method of contraception should be counseled about the importance of condom use despite the fact that they are protected from pregnancy. For young women who use OCs, this counseling can, in addition to the issue of disease prevention, include the fact that condoms offer extra protection against pregnancy should she forget to take her pills.

Although most of the young women said that they felt positive about asking their partner to use condoms, the syntax analysis revealed that few teens had actually done this. Responses to questions about the partner’s response were phrased in the subjunctive, for example, “he would . . .” If communication with the partner is perceived as easy, why doesn’t it happen? It is important to create a forum that can increase communication about condoms among sexually active teens, perhaps as part of a group intervention (Roye, 1994).

The issue of partner trust also appears to be crucial to condom use decisions. When a young woman feels that she can trust her partner, that is, that he is faithful, then she is less likely to use a condom. The key teaching point is that current fidelity does not equate to low risk. Young women must understand that only when their partners consistently test negative for HIV and other STDs is current fidelity a more substantial deciding factor in whether to use a condom. Furthermore, because of the apparent ambivalence of some young women about whether their partners are actually monogamous, teens must be helped to discuss this with their partners so that they can be more confident that they can trust their partners or that they need to use condoms.

Increasing the communication skills of parents and other relevant adults is a necessary part of HIV prevention for teens. The young women in this study told us that they want to be able to talk to their parents about sexuality, so “they [teens] can open up to them [parents] and tell them more instead of just going out there and being sneaky.” Clearly, parents are key allies in the fight to promote responsible sexual health in teens, but they are rarely put to use in that capacity (Roye, 1994).

Parent training could be done in the schools or health care facilities using workshops. It might be useful to align such a workshop with other educational programs or inducements that the parents might perceive as relevant, as it is often difficult to get busy parents to come in for a workshop. Future nursing research on HIV prevention should involve interventions for parents as well as teens.

Increasing the salience of prevention messages can be accomplished by having infected peers talk about how they became infected with HIV, as suggested by the young women in this study as a way of influencing them to use condoms. This message can be presented either in person or by use of videos. Nurses should facilitate such programs and then clarify and reinforce the messages.

Finally, condoms must be available to teens. Many teens did not use a condom at previous intercourse simply because they did not have one. Condoms must be widely available for little or no cost in schools and medical offices. Although many school districts ban condom distribution in schools, school nurses are in an ideal position to utilize existing research findings to propose and lobby for condom availability in schools. Research has shown that condom availability leads to more condom use, not to an increase in sexual activity (Guttmacher et al., 1997).

**Conclusion**

HIV prevention in this population is a critical issue to address at this time. There are two trends disproportionately affecting the teens in this study and in any geographic area with high HIV seroprevalence. The first trend is that most new infections are among the young, with the CDC (1998) estimating that half of all new infections are among teens. The second trend is that HIV infection is increasing among women (Wortley & Fleming, 1997). Given the biologic factors detailed in the introduction, this study underscores the
importance of reaching sexually active teens in areas with high HIV seroprevalence, focusing on interventions to promote consistent condom use by teens who use a hormonal method of contraception.

Acknowledgement

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References


Abacavir Sulfate, Lamivudine, and Zidovudine (Trizivir™)

Demetrius Porche, DNS, RN, FNP, CS, CCRN

Treatment Review is intended to inform and update nurses about treatments relevant to HIV/AIDS. Product information presented in this column does not imply endorsement by the Association of Nurses in AIDS Care.

Generic name: Abacavir Sulfate, Lamivudine, and Zidovudine
Trade name: Trizivir™
Medication classification: antiretroviral

Background

Background information on highly active antiretroviral therapy treatment guidelines was presented in an earlier article on abacavir sulfate (Porche, 2000). Trizivir combines three antiretroviral nucleoside analogue medications—abacavir sulfate, lamivudine, and zidovudine—into one single tablet. These medications have demonstrated inhibitory activity against human immunodeficiency virus (HIV).

Indications

Trizivir is indicated for the treatment of HIV-1 infection alone or in combination with other antiretroviral agents. There are no long-term clinical trials demonstrating suppression of HIV RNA or disease progression with abacavir sulfate. There are limited data supporting the use of this triple-combination regimen with HIV RNA viral loads exceeding 100,000 copies/mL (Glaxo Wellcome, 2000).

Contraindications and Precautions

Abacavir sulfate, a component of Trizivir, has been associated with fatal hypersensitivity reactions. The hypersensitivity reaction consists of fever, skin rash, fatigue, gastrointestinal symptoms (nausea, vomiting, diarrhea, or abdominal pain) and respiratory symptoms such as pharyngitis, dyspnea, or cough (Glaxo Wellcome, 2000). The abacavir hypersensitivity reaction registry has been established to collect information on each case. Patients can be registered via telephone by calling 1-800-270-0425.

Abacavir sulfate should not be restarted following any hypersensitivity reactions. In addition, Trizivir is contraindicated with a known hypersensitivity to any of its components.

Trizivir is a pregnancy Category C medication. Trizivir should be used during pregnancy if the potential benefits outweigh the risks. The Centers for Disease Control and Prevention encourages all HIV-infected mothers not to breastfeed their infants. Mothers should be instructed not to breastfeed during Trizivir therapy because of the potential for HIV transmission with breastfeeding. Maternal and fetal outcomes are being monitored through the Antiretroviral Pregnancy Registry. Clients can be registered by calling 1-800-258-4263.

Demetrius Porche, DNS, RN, FNP, CS, CCRN, is an associate professor and acting associate dean for Nursing Research and Evaluation at the Louisiana State University Health Sciences Center, New Orleans.
Pharmacologic Action

Abacavir sulfate is a carbocyclic synthetic nucleoside analogue that is intracellularly converted to the active metabolite carbovir triphosphate. Carbovir triphosphate inhibits the activity of HIV-1 by competing for a substrate. Carbovir triphosphate is incorporated into the viral DNA, terminating its replication.

Lamivudine is a synthetic nucleoside analogue that is intracellularly phosphorylated to 5'-triphosphate. This active metabolite incorporates into the DNA and terminates the DNA chain. Zidovudine is a synthetic nucleoside analogue that is intracellularly phosphorylated to the active metabolite 5'-triphosphate. The mechanism of action for lamivudine and zidovudine are similar.

Pharmokinetics

Abacavir sulfate has synergistic activity in combination with amprenavir, nevirapine, and zidovudine and an additive activity in combination with didanosine, lamivudine, stavudine, and zalcitabine in vitro. Rapid absorption of abacavir sulfate occurs following oral administration. Fifty percent of abacavir sulfate is bound to plasma protein. Abacavir sulfate exhibited cross-resistance to lamivudine, didanosine, and zalcitabine in vitro.

Lamivudine has synergistic antiretroviral activity with zidovudine. Rapid absorption and distribution of lamivudine occurs following oral administration. About 70% of an intravenous dose of lamivudine is recovered unchanged in urine. Cross-resistance between didanosine and zalcitabine exists with clients having lamivudine resistance.

Zidovudine exhibits synergistic activity with delavirdine, didanosine, indinavir, nelfinavir, nevirapine, ritonavir, saquinavir, and zalcitabine and an additive effect with interferon-alpha. Zidovudine is also rapidly absorbed and distributed following oral administration. Zidovudine binding to plasma proteins is minimal. Cross-resistance mutations at codon 151 in combination with mutations at 62, 75, 77, and 116 results in retroviral’s reduced susceptibility to didanosine, lamivudine, stavudine, zalcitabine, and zidovudine. Abacavir sulfate, lamivudine, or zidovudine are not significantly metabolized by the cytochrome P450 enzyme system (Glaxo Wellcome, 2000).

Dosage and Routes of Administration

The recommended adult oral dosage of Trizivir is one tablet twice daily. Trizivir is not recommended for adults or adolescents weighing less than 40 kg. The fixed-dose tablet does not permit dosage adjustments for clients with creatinine clearance < 50 mL/min or those experiencing dose-limiting side effects (Glaxo Wellcome, 2000). Trizivir is not recommended for pediatric usage.

Adverse Reactions

The adverse reactions of Trizivir are complex because of the combined ingredients of abacavir sulfate, lamivudine, and zidovudine. Severe or fatal hypersensitivity reactions to abacavir sulfate can occur within hours and may consist of life-threatening hypotension and death. Zidovudine is associated with hematologic toxicity consisting of neutropenia and severe anemia. Zidovudine is also associated with symptomatic myopathy. Nucleoside analogues (abacavir sulfate, lamivudine, and zidovudine) have been associated with lactic acidosis and severe hematomegaly with steatosis (Glaxo Wellcome, 2000).

Medication and Food Interactions

Abacavir sulfate had no clinically relevant changes in the pharmacokinetic’s properties with the addition of lamivudine or zidovudine or both. Nor did lamivudine and zidovudine demonstrate clinically relevant changes with the administration of abacavir sulfate. There were no clinically relevant alterations in lamivudine or zidovudine pharmacokinetics in asymptomatic HIV-infected clients given a single dosage of zidovudine in combination with multiple doses of lamivudine.

Trizivir can be administered with or without food. The administration of Trizivir with food did not alter
the extent of absorption of abacavir sulfate, lamivudine, and zidovudine as compared to fasting state (Glaxo Wellcome, 2000).

Management of Overdosage

Abacavir sulfate has no known antidote, and the extent to which it can be removed with peritoneal or hemodialysis is unclear. There has been one reported case of lamivudine overdose of 6 grams. It is not clear whether lamivudine can be removed with peritoneal or hemodialysis. Pediatric and adult overdoses with zidovudine have been reported with consistent symptoms of nausea and vomiting. Other findings with zidovudine overdose are headache, dizziness, drowsiness, lethargy, confusion, and transient hematologic changes. Clients recovered from zidovudine overdose. Peritoneal and hemodialysis appear to have a negligible effect on zidovudine overdose (Glaxo Wellcome, 2000).

Nursing Assessment

Nursing assessment should include the following:

1. history of current medications, prescribed and over-the-counter;
2. ability to comply with prescribed regimen;
3. review of clinical symptoms of HIV disease or drug toxicities;
4. review of CD4 and viral load test results; and
5. review blood chemistries and creatinine clearance.

Nursing Instructions

Nurses need to include the following administration instructions during client education:

1. reinforce the importance of taking the medication exactly as prescribed without altering dosage;
2. instruct on potential complications with other medications;
3. instruct on potential hypersensitivity reactions: skin rash, fever, nausea, vomiting, diarrhea, abdominal pain, extreme tiredness, achiness, sore throat, shortness of breath and cough;
4. encourage mother not to breastfeed;
5. inform clients that Trizivir is not a cure for HIV infection and has not been demonstrated to reduce the risk of HIV transmission to others;
6. instruct to never take Trizivir again if an allergic reaction occurs; and
7. instruct that a missed dose should be taken right away with the next dose taken at the usual scheduled time.

Nursing Evaluations

Evaluate patient outcomes during administration of Trizivir:

1. evaluate response to therapy with CD4+ cell count and/or HIV viral RNA analysis;
2. experience of adverse events;
3. monitor complete blood count, creatinine clearance, and liver function.

References

How Does a Peer Review Scholarship?

Nancy C. Sharts-Hopko, PhD, RN, FAAN

Nurses are increasingly involved in peer review of scholarship. Peer review may entail the evaluation of manuscripts submitted for publication, grant applications submitted for funding, abstracts submitted for presentation, or proposals submitted to institutional review boards or to settings where participants may be accessed. Peer review is intended to foster quality in the development and dissemination of nursing scholarship and to prevent ethical breaches. Although peer review has been used in academia and biomedicine for decades, the system is not perfect. Political agendas, scientific biases, and adherence to old knowledge structures may get played out; competitors may be obstructed; and quality may not be appropriately balanced with freedom of expression through misapplication of the peer review process (Laitman & Rikkers, 2000). Nevertheless, science has not been able to come up with a better system for ensuring quality. Because reviewers are the gatekeepers of a science, it is essential that they understand what peer review is intended to accomplish and how it should be done if the discipline is to flourish.

Who Is a Peer?

Peer reviewers are usually volunteers. Journals, funding agencies, and professional associations often recruit reviewers through their publications and at conferences. In addition, editorial or funding agency staff members use their own professional networks to expand their lists of potential reviewers.

Peer review should, ideally, be performed by peers of the authors or investigators. That is, reviewers should be people who understand the scholarly work under consideration from various salient perspectives. In the case of manuscripts submitted for publication and grant applications, peer reviewers are people with relevant clinical and/or research backgrounds or with expertise in a particular research methodology. They need to have demonstrated an understanding of scholarship. When a manuscript or proposal describes research, a majority of the peer reviewers should have a research background.

One common situation that arises is that an author with great expertise and stature submits a manuscript or grant that is reviewed by relative novices in the field. They may lack the vision and experience necessary to appreciate what the author has said; on the other hand, the author may no longer be current. When the author is a known expert in the area, peer reviewers should be selected with care, and the person in charge of assigning reviewers will want to weigh these factors in making editorial or funding decisions. Some investigators believe that senior members of the field are favored by reviewers and editors; others maintain that they have earned this respect through decades of productivity.

When a reviewer believes that evaluating a particular manuscript or grant would constitute a conflict of interest, it is the reviewer’s responsibility to notify the editor or funding agency immediately. Conflicts of interest occur when the reviewer has submitted an application for the same funding, when the reviewer is competing to publish a similar paper first, and when the reviewer has worked on the scholarly project under review or is closely connected to the author in some other way.

Nancy C. Sharts-Hopko, PhD, RN, FAAN, is a professor in the College of Nursing at Villanova University.
**Should a Review Be “Blind”?**

Authors receiving a rejection letter may indeed believe that reviewers are blind! This term actually means that the review of a manuscript or conference presentation is conducted with the author’s and reviewer’s identities concealed from one another—that is, anonymously, or double-blinded. In some instances, and often in the case of funding proposals, reviewers know who the author is, but knowledge of identity is not reciprocal. There is considerable controversy about this practice; some scientists believe that political agendas would be minimized if authors knew who their reviewers were and that, as responsible and mature adults, reviewers should be willing to stand behind their critiques. Others believe that bias against women and minorities or against specific institutions is reduced through double-blind review (Laitman & Rikkers, 2000; Song, Eastwood, Gilbody, Duley, & Sutton, 2000).

**How Should a Review Be Done?**

The way a review is conducted depends on its purpose. In general, reviewers are concerned with the appropriateness of the manuscript or research project, its importance to advancing the science or improving health care outcomes, its quality, and its regard for ethical considerations. Manuscript reviews are usually written in response to a series of questions posed by the journal’s editorial board. Items may be scaled, and a numerical total may be reported along with reviewers’ narrative comments. Grant reviews often place greater emphasis on a numerical score, although narrative comments are usually elicited. The funding agency can then rank grants in priority order and fund from the project with the highest priority score down through the list until the money for that funding cycle is exhausted. Reviews of abstracts for conferences also typically involve a numerical rating on several criteria, and there is usually no mechanism for feedback to the author other than acceptance or rejection. Often a substantial number of submissions are being reviewed and will, in fact, be accepted for presentation. When institutional review boards and agency research committees evaluate projects to determine their suitability, the reviews are more qualitative. An institutional review board seeks confirmation that government regulations related to the protection of human participants are being upheld, whereas an agency seeks to ensure that the project is congruent with its mission and activities and will not tax its resources unreasonably.

Every research textbook includes a detailed list of criteria for the review of research, which can be modified for evaluating manuscripts as well as proposed projects (Burns & Grove, 1999; Polit & Hungler, 1999). General questions include, Is the purpose clear? Is the study significant? Does this study build on a scientific foundation and/or address a gap or controversy in the current knowledge base? Is the study logically congruent? Is the methodology appropriate and well thought out? Is the study feasible? Is the analysis appropriate? Does the discussion relate this set of findings to the broader science and/or to practice or education? Are limitations acknowledged? Is the study ethical?

**What Can Peer Review Accomplish?**

At its best, peer review serves as a mechanism for the improvement of manuscripts and grant proposals and, ultimately, the development of the science or of health outcomes. Helpful peer reviews offer comment on the strengths of a manuscript or grant proposal as well as thoughtful suggestions for its improvement when they are indicated.

Many reviewers convey a negative attitude in their comments that is not only discouraging to young investigators but also fails to provide useful direction. This author and her colleagues have, over the years, received such feedback as, “You should take a writing course,” “This study is unnecessary,” or “This author is unqualified.” More helpful ways to address the concerns would have been, “Please have the document reviewed editorially before resubmitting,” “Consider redirecting the study in the following way . . .” or “Consider adding an individual with these credentials to the project . . .” Blanket negative statements are often reflective of the reviewer’s ego or a lack of understanding of the research process. In addition, a good
review takes time, and experts who are asked to review manuscripts and funding applications are often extremely busy.

Reviewers are helpful when they direct authors' attention to important related work, when they ask questions about issues needing clarification, when they suggest ways for the authors to convey their thoughts more clearly, when they help authors place the current study in a broader context, and when they make suggestions specific to the design and methodology. It is useful for reviewers to distinguish between essential changes versus ideas that the authors might like to consider. This author regards the process of review as not essentially unlike the process of education or mentorship: What will be helpful to the author(s) in improving their work, and what will encourage the author(s) to persevere?

Reviewers often focus on details of grammar and format rather than the substance of the manuscript. It may be because grammar and format are easier to address than the content of the manuscript or grant, or it may reflect distraction from the document’s substance by its poor quality. It is certainly true that authors have a responsibility to follow the editorial guidelines for a manuscript or grant and to write to the best of their ability. This author routinely engages one or more colleagues to review manuscripts before they are submitted and recommends that practice to others, especially novices in publication and grantsmanship. But the need for this level of focus by reviewers depends on the organization of the staff of a particular journal—that is, whether the editorial team members are voluntary and need to undertake all editing themselves or whether a professional editorial staff is employed. Reviewers are selected for their content expertise.

It has been suggested that a quality review of a manuscript takes about 3 hours (Laitman & Rikkers, 2000). It is interesting to note that in one study of reviews for two journals and two conferences, agreement among the reviewers was little greater than would be expected by chance (Rothwell & Martyn, 2000). That is why multiple reviews are sought, with three being a typical number.

Outcomes

Grants are either accepted and funded, accepted and not funded, or rejected. Most funding agencies expect that grants will be resubmitted after revision. Likewise, manuscripts submitted for publication are either accepted, rejected, or returned for revisions—the latter being the largest category (Campion, Curfman, & Drazen, 2000). One study of submissions to a medical journal found that most articles that are returned for revision or rejected do eventually reach publication, often in more specialized outlets, if the authors persevere (Ray, Berkwits, & Davidoff, 2000).

The potential to develop nursing science and to mentor scholars through peer review is great. In addition, there are personal benefits to participation in the peer review process. One’s own ability as a scholar can be strengthened by engaging in critical review, and one’s network of colleagues and knowledge of peers’ scholarship is expanded. If reviewers maintain a vision of the development of their discipline and their own contributions within it and remember that it is a privilege to review one’s peers, their contributions will be truly valuable.

References

The Cochrane HIV/AIDS Review Group and Evidence-Based Practice in Nursing

Glenn B. Urbshott, RN, BScN, BSc, ACRN
Gail Kennedy, MPH
George Rutherford, MD

The nursing profession has long recognized the importance of research and the incorporation of research findings into the clinical environment. The paradigm shift from traditional and intuition-driven practice to evidence-based practice can be witnessed in all areas of health care. Models for change to evidence-based practice help guide nurses and other health care professionals through a systematic process incorporating research findings into the clinical setting. This practice is more likely to occur in environments that value the integration of new knowledge and provide resources to access this information (Rosswurm & Larrabee, 1999).

Nurses, physicians, public health practitioners, policy makers, and consumers are deluged with unmanageable amounts of information about the best approaches to prevention, treatment, and health care delivery. The development of comprehensive HIV/AIDS-care programs has been based and revised on numerous clinically based observations since the outset of the pandemic. With the exponential increases in scientific knowledge about most diseases and HIV/AIDS in particular, many practitioners often turn to journal review articles, which are usually narrative reviews. These articles may be useful reminders of the main issues and published evidence, but they are notoriously prone to bias, with concluding remarks often at odds with the evidence discussed in the article. This is because such review articles are rarely performed in a structured and explicit way (Cook, Sackett, & Spitzer, 1994).

To address this problem, a movement called evidence-based health care has arisen that seeks to have practitioners and consumers make informed decisions based on the best available scientific evidence. These systemic reviews and evidence-based practice have become invaluable tools for nurses and other health care practitioners. The Cochrane Collaboration seeks to provide systematic reviews of all health care interventions since the first randomized controlled trial (RCT) was conducted in 1948. How nurses may contribute to and access this database, specifically the HIV/AIDS Review Group, will be discussed.

Evidence-Based Health Care

Evidence-based health care is defined as “the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996, p. 71). Among the five basic steps that Sackett, Richardson, Rosenberg, & Haynes (1997) laid out for the practice of evidence-based health care are the identification of rigorous, well-

Glenn B. Urbshott, RN, BSN, BS, ACRN, is a pediatric research nurse at the University of California, San Francisco (UCSF) Medical Center and a PhD student at the UCSF School of Nursing, Department of Community Health Systems. Gail Kennedy, MPH, is the coordinator of the Cochrane Collaborative Review Group on HIV Infection and AIDS at the AIDS Research Institute, UCSF. George Rutherford, MD, is Salvatore Pablo Lucia Professor of Preventive Medicine, Epidemiology and Pediatrics, Department of Epidemiology and Biostatistics, UCSF.
designed studies to answer specific clinical and public health questions and a critical appraisal and synthesis of the identified evidence.

What the best evidence is varies by the question being asked. In many clinical situations, the best evidence is provided by properly conducted RCTs. In other situations—and many of the population-level interventions conducted by public health agencies are among these—the most reliable evidence may come from other types of controlled studies, including observational studies (Sackett, 1994). However, no matter what the best evidence is, the overwhelming volume of the relevant public health literature makes keeping fully abreast of the best evidence relating to public health prevention strategies an almost impossible task (Covell, Uman, & Manning, 1985). Among the most prominent advocates of the use of evidence-based health care is the Cochrane Collaboration, whose work in the fields of the prevention and treatment of HIV infection and AIDS we discuss in this article.

Systematic Reviews

To address the health information overload, an approach has been developed to synthesize vast numbers of studies by conducting systematic reviews, which combine detailed and comprehensive search strategies to identify all relevant published and unpublished studies. Systematic reviews use predetermined research questions and methodologies; qualitative reviews of the quality of the relevant studies; and, where appropriate, quantitative estimates of the effects of the same or similar interventions for the same conditions (Cook, Mulrow, & Haynes, 1997; Hunt & McKibbon, 1997; Sackett et al., 1997). Drawing from the methods of meta-analysis (Cook et al., 1994; Dickersin & Berlin, 1992; L’Abbé, Detsky, & O’Rourke, 1987), systematic reviews combine evidence from multiple studies, including pooling data from separate studies if the interventions are sufficiently similar and, as a result, can reduce bias and random error and resolve conflicting findings. There are varied uses for systemic reviews. They can be used by (a) health care providers to answer specific questions about the management of a person with a specific health condition, (b) expert panels as a basis for the formulation of clinical practice guidelines, (c) public health practitioners as a guide to best public health practices, (d) policy makers to prioritize limited resources for interventions to those that provide the greatest proven value, and (e) individuals to inform their search for the most effective treatment of their health condition.

The Cochrane Collaboration

The Cochrane Collaboration is an international network of researchers, health care providers, and individuals interested in different health care conditions whose mission is to prepare, maintain, and disseminate systematic, continuously updated reviews of RCTs and other methodologically rigorous studies of health care and public health interventions (Bero & Rennie, 1995; I. Chalmers, 1993; McPherson, 1994; Sackett, 1994). Named for Professor Archie Cochrane, an early advocate of evidence-based health care, the work of the Cochrane Collaboration is immense and is on the order of magnitude approaching the human genome project (A. L. Chalmers, 1999). A specific long-range goal of the Cochrane Collaboration is to review systematically all health care interventions since the first RCT was published in 1948. The purpose of this is to provide the type of information needed by health care providers and public health agencies to make fully informed decisions about patient care and public health actions in a digestible format and by researchers and policy makers to understand the body of research in areas of health care with which they are concerned.

The Collaboration at present is made up of 50 collaborative review groups organized around medical and health specialties covering diverse aspects of human health such as infectious diseases, drugs and alcohol, stroke, schizophrenia, pregnancy and childbirth, and HIV infection and AIDS. These review groups are charged with producing systematic reviews in their topic areas.

The primary tool for disseminating the results of Cochrane reviews is The Cochrane Library, which is in essence an electronic journal published quarterly and distributed on CD-ROM and via the Internet (http://hivinsite.ucsf.edu/cochrane/) to subscribers. The Cochrane Library consists of five separate parts:
How HIV/AIDS Can Benefit From Systematic Research

In a field evolving as rapidly as HIV infection and AIDS, the best evidence for treatment decisions may not always be clear. The provision of up-to-date and readily accessible systematic reviews assists clinicians in providing state-of-the-art care for their patients. This is especially true outside of the major urban AIDS centers in the developed world and in countries in the developing world where antiretroviral therapy and treatment for opportunistic infections is just now becoming available. Our inclusion of data presented as abstracts in conferences and our access to data from unpublished studies sponsored by pharmaceutical companies provide us with up-to-the-minute information far more quickly than conventional medical journals. Similarly, the quarterly updates published in The Cochrane Library enable us to revise our systematic reviews rapidly as additional evidence becomes available. Because AIDS clinical practice often lends itself to treatment algorithms, systematic reviews can also form the evidence base for clinical practice guidelines development. For consumers, the availability of readily accessible systematic reviews will help guide their approach to the various therapeutic choices they have. The Cochrane Collaboration, and the HIV/AIDS Group in particular, are especially committed to involving consumers at the level of the editorial team and to making the products of the HIV/AIDS Group as accessible to consumers and their advocacy groups as possible.

HIV is a field in which multiple meta-analysis initiatives are ongoing, often with high sophistication, including several groups performing meta-analyses of individual patient data. Leading investigators from many of these groups have joined the Cochrane HIV/AIDS Group and are making their work available to the Cochrane effort, bringing together worldwide experts in the field. For example, at present, a review of interventions to reduce perinatal HIV transmission is being jointly conducted by British, French, and African researchers and clinicians. In addition, whereas there have been movements to review the HIV-infection and AIDS literature systematically, there is a large amount of material that has not been, as yet, systematically reviewed. An additional role of systematic reviews may be to identify gaps in knowledge that should become urgent research priorities. Sometimes, a review based on an important question may not reveal any RCTs. This provides essential information for grant proposals for trials if indeed a strong argument can be made for supporting such a trial, for example, widespread use of a treatment in the absence of evidence. Specific gaps in HIV research include treatment and prophylaxis of common opportunistic infections and malignancies, HIV vaccines, a variety of biomedical preventive interventions (such as vaginal microbicides and postexposure prophylaxis), complementary therapies, and medication adherence. Systematic reviews conducted by the Cochrane HIV/
AIDS Group must not be confined only to research areas with RCTs, for then the work of the group becomes data-driven rather than question-driven. It is imperative that the Cochrane HIV/AIDS Group starts with questions that are important to patients and that it does not limit itself solely to areas where there are many trials.

**Cochrane Review Group on HIV Infection and AIDS**

**Structure and Scope of the Group**

The Cochrane Review Group on HIV Infection and AIDS (HIV/AIDS Group) began in November 1996 and was officially registered with the Cochrane Collaboration in March 1997. The Group has its editorial base at the University of California, San Francisco. The mission of the Group is to conduct systematic reviews of randomized controlled trials and other rigorous controlled studies with clinical, serologic, behavioral, economic, and other outcomes on the prevention and treatment of HIV infection and AIDS and the organization and financing of health care services. A full-time coordinator administers the day-to-day functioning of the Group. Infrastructure support for the Group is provided through a grant from the California HealthCare Foundation.

The HIV/AIDS Group has international and multidisciplinary representation and is an affiliate of the International AIDS Society. In particular, the Group has active members from both developed and developing countries and attempts to address reviews from both the developed and the developing world perspectives. In addition, since its inception, the Group has had active involvement of people infected and affected with HIV through the sponsorship and support from the National Association of People with AIDS and the Global Network of People Infected with HIV. Systematic reviews of prevention interventions include primary and secondary prevention and subsume (a) behavioral, social, and policy interventions for sex- and drug-related risk factors (in conjunction with the Centers for Disease Control and Prevention’s Prevention Research Synthesis project) and the cost-effectiveness of prevention interventions; and (b) biomedical prevention interventions such as community-level sexually transmitted disease control programs, interventions to prevent perinatal transmission (such as antiretroviral therapy, avoidance of breastfeeding, vaginal cleansing, and vitamin A prophylaxis), vaginal microbicides, vaccinations, and postexposure prophylaxis. Reviews of treatment interventions include treatment of HIV infection and AIDS and the opportunistic infections and malignancies associated with HIV infection. Reviews of health services interventions include studies of treatment adherence, alternative and complementary treatments, cost-effectiveness of care, and different models of health care delivery including palliative and supportive care for patients with HIV infection and AIDS. Primary outcomes used in the reviews are incident HIV infection for HIV prevention, progression to clinical AIDS or death for HIV/AIDS treatment, and incident infection or death for opportunistic infection prophylaxis and treatment. Different surrogate endpoints are utilized depending on the topic under review; for instance, prevention reviews use sexual and drug use behavior change or other sexually and parenterally transmitted infections (such as hepatitis B and C, gonorrhea, or syphilis) as surrogate endpoints. Reviews of antiretroviral therapy utilize HIV plasma viral load, CD4+ lymphocyte counts, or even adverse drug reactions as endpoints. In addition, with the wide interest that currently exists in managing HIV infection on the basis of predictive and surrogate information, reviews and meta-analyses are being conducted in the areas of diagnostic testing and prognostic and surrogate markers. Finally, in some instances such as the effectiveness of condoms, data gathered from individual patient records produce higher quality, more thorough reviews of the evidence, and we encourage reviewers to pursue these types of projects.

Included in the appendix are the topics presently under review. A total of 41 topics are under review; 6 of these are completed and already available on The Cochrane Library, and 16 have been approved as protocols (outlines of proposed reviews). For the remaining 19 topics, authors are preparing protocols of review topics. Protocols and completed reviews are peer reviewed by referees external to the Group for content and methodology.
**International Registries of HIV/AIDS Studies**

Having complete ascertainment of the universe of relevant and eligible studies on which to base systematic reviews is a key first step in the preparation of Cochrane HIV/AIDS reviews. To this end, the Group, along with its collaborators, is developing a series of international HIV/AIDS registries of RCTs and other types of controlled intervention studies of prevention, treatment, and health services. The international HIV/AIDS-prevention registry was created by merging the Centers for Disease Control and Prevention–sponsored Prevention Research Synthesis Project and the University of London’s Centre for the Evaluation of Health Promotion and Social Interventions’ registry for the Cochrane Field of Health Promotion, Sexual Health Subset. At present, 450 studies have been identified. This database will be supplemented with biomedical prevention studies.

An international HIV/AIDS treatment registry is being created by merging AIDSTRIALS—a database of open and closed clinical trials sponsored by the National Institutes of Health and pharmaceutical companies—with information about ongoing and completed international clinical trials through a grant from the National Library of Medicine.

Each of these registries has strict scope and selection criteria, inclusion and exclusion criteria, and search strategies. Searches of bibliographic databases (such as Medline, EMBase, Scisearch, and The Cochrane Library itself) identify the large majority of, but not all, relevant studies. Many studies not published in journals are abstracted in these databases. Database searches are supplemented with manual, page-by-page hand searching of the literature back to 1985 to identify all the relevant trials. This includes hand searching of the “gray” literature, including journals that are not widely available, and records of proceedings of conferences and meeting abstracts (Mulrow & Oxman, 1999). Non-English-language publications are also hand searched and translated. In addition, the Cochrane HIV/AIDS Group attempts to identify data from unpublished studies as well as data from ongoing studies for inclusion in reviews.

As these registries are developed, they will be accessible to the members of the Group through the Cochrane HIV/AIDS Web site. In the near future, individuals will be able to search the registries and download relevant information. Also, study references found in the registries will be available shortly in the Cochrane Controlled Trials Register in The Cochrane Library.

**Contributing to the Cochrane HIV/AIDS Group**

Individuals can become involved with the HIV/AIDS Group in a variety of ways. Individuals can volunteer to prepare or assist with the preparation of a systematic review. Guidance and resources are available for reviewers so that prior experience is not needed. A less time-consuming commitment is to volunteer to peer referee a protocol or a completed review. No prior experience is needed to carry out this task, only an interest in the topic area. Hand searches of journals and conference proceeding are needed, particularly those not listed in MEDLINE and those published in languages other than English. Technical and methodological expertise is needed in the areas of review preparation and meta-analysis. Finally, information about the Cochrane HIV/AIDS Group is primarily disseminated through word of mouth; therefore, it is very important for individuals to share information about the activities of the Group with colleagues.

**The Benefits of Cochrane Reviews**

The Cochrane Collaboration in general and the Cochrane HIV/AIDS group in particular place a large premium on identifying and including all relevant studies in reviews. For instance, every attempt is made to identify published as well as unpublished data including data presented as abstracts in conferences and data from research in which the results are never published. This broad, inclusionary approach allows the synthesis of all available evidence, thus minimizing bias.

Timing is similarly an issue. One of the great advantages of Cochrane reviews published in The Cochrane Library over reviews published in conventional health care literature is that Cochrane reviews can be, and are expected to be, updated as new evidence becomes
Thus, reviews are more current and contain more up-to-the-minute information than reviews published in print medical journals.

Cochrane reviews can also identify gaps in evidence and suggest new research priorities. Sometimes, a review based on an important question may not reveal any rigorous, well-designed studies. This provides essential information for granting agencies and policy makers, who can use this information to identify priority areas for the allocation of research funds to support necessary studies, especially in areas where there is widespread use of an intervention in the absence of evidence (Mulrow & Oxman, 1999). Examples of gaps in rigorous evidence for prevention and treatment of HIV infection and AIDS include a variety of biomedical prevention interventions (such as vaginal microbicides and postexposure prophylaxis), complementary therapies, and medication adherence.

### Conclusion

In summary, in order for researchers, health practitioners, and policy makers to make sense of the vast quantities of HIV/AIDS research, techniques of synthesizing and rating the quality of the research have been developed. The Cochrane Review Group on HIV Infection and AIDS aims to become the best source of unbiased external evidence for summarizing the effects of HIV/AIDS prevention and treatment. Nurses currently are active on a number of established and potential reviews. Those interested in initiating new reviews, contributing to the HIV/AIDS Review Group, or receiving more information are invited to contact

Gail Kennedy, MPH  
Coordinator, Cochrane Collaborative Review Group on HIV Infection and AIDS  
AIDS Research Institute  
University of California, San Francisco  
74 New Montgomery, Suite 600  
San Francisco, CA 94105  
Phone: (415) 597-9373  
Fax: (415) 597-9125-9213  
E-mail: gkennedy@psg.ucsf.edu

The Cochrane Collaborative Review Group on HIV Infection and AIDS is an affiliate of the International AIDS Society.

### Appendix

#### Topics Under Review Within the Cochrane Review Group on HIV Infection and AIDS

**Behavioral, social, and policy prevention**

- **Drug-related risk reduction**
  - Interventions to modify drug-related risk behaviors for preventing HIV infection in drug users
  - Syringe exchange and pharmacy sales of sterile injection equipment

- **Sex-related risk reduction**
  - Interventions for improving condom use in people at risk for sexually transmitted infections including HIV
  - Interventions for preventing HIV infection in heterosexual people
  - Interventions to modify sexual risk behaviors for preventing HIV infection in drug users
  - Interventions to modify sexual risk behaviors for preventing HIV infection in MSMs
  - Interventions to modify sexual risk behaviors for preventing HIV infection in developed countries

- **Specific intervention types and those targeting specific populations**
  - Counseling and testing for preventing HIV infection
  - Interventions for preventing HIV infection in street youth
  - Interventions for preventing HIV infection in young people
  - Interventions to promote health among gay and other homosexually active men
  - Peer education interventions for preventing HIV infection in young people
  - Theory-driven interventions versus interventions lacking an explicit theory base for preventing HIV infection

- **Cost-effectiveness of intervention**
  - Behavioral interventions for preventing HIV infection: a cost-effectiveness analysis

- **Biomedical prevention**
  - Condoms for preventing HIV infection among heterosexuals
Interventions for reducing mother-to-infant transmission of HIV infection
Methadone maintenance treatment to modify drug-related HIV risk behavior among drug users
Population-based interventions for reducing sexually transmitted diseases, including HIV infection
Post-exposure prophylaxis to decrease HIV seroconversion in occupationally exposed needlestick injuries
Vaginal microbicides for preventing sexually transmitted infections, including HIV

Therapeutics, diagnostics, and prognostics
Antiretrovirals and protease inhibitors
Immediate versus delayed zidovudine (AZT) in asymptomatic or mildly symptomatic HIV-infected adults
AZT versus AZT plus didanosine versus AZT plus zalcitabine in HIV-infected adults
Hydroxyurea for the treatment of HIV
Treatments for adverse drug reactions in HIV infection
Three- or four- versus two-drug antiretroviral regimens for maintenance therapy for HIV infection
Prophylaxis and treatment of opportunistic infections and malignancies
Anabolic steroids for the treatment of weight loss in HIV-infected persons
Antimicrobials for preventing and treating oropharyngeal infections in persons infected with HIV
Broad-based antibiotics for preventing and treatment of opportunistic infections in people with HIV
Drugs for preventing tuberculosis in HIV-infected persons
Influenza immunizations in people with HIV/AIDS
Interventions for cytomegalovirus retinitis in people with AIDS
Pneumococcal vaccine in HIV-infected persons
Pneumocystis carinii pneumonia prophylaxis in HIV-infected adults
Pneumocystis carinii pneumonia prophylaxis in HIV-infected infants and children
Treatment of HIV-related leishmaniasis
Prognostics
Effects of chemokine and chemokine receptor genotypes on HIV disease
Prognostic implications of antiretroviral resistance for disease progression in adults
Health services delivery and quality of life
Aerobic exercise interventions for people with HIV/AIDS
Complementary treatments for people with HIV/AIDS
Highly active antiretroviral therapy and quality of life for HIV-infected individuals
Interventions for self-care management of HIV/AIDS symptoms
Interventions to improve adherence to HIV/AIDS medications in children and adolescents with HIV/AIDS
Patient support and education for promoting adherence to highly active antiretroviral therapy
Provider training and education for clinicians treating people with HIV/AIDS

b. Protocols in progress.
d. Completed review available at http://hivinsite.ucsf.edu/cochrane/.

References


**GeneEd and UCSF Introduce Free HIV E-Learning Seminar**

GeneEd, Inc. and the HIV InSite Program at the University of California, San Francisco (UCSF) have partnered to distribute an anti-HIV therapy e-learning seminar at no cost to Internet users worldwide. This electronic seminar, developed by GeneEd, provides an animated audiovisual presentation offering a broad overview of the lifecycle of HIV, how the virus causes AIDS, and how the disease can be treated.

This multimedia seminar is intended to help HIV patients, their families, and their health care teams in understanding how HIV works in the body, what treatments are currently available, and the scientific rationale for adhering to the therapeutic regimens. According to Dr. Sunil Maulik, CEO of GeneEd, the seminar was developed to take the most current information available on HIV/AIDS and its treatment and provide an online seminar that informs and educates in a way that ensures maximum retention.

The electronic seminar is available via the Internet from GeneEd at www.GeneEd.com and on UCSF’s HIV InSite Program Web site at www.hivinsite.ucsf.edu. The seminar is also available on CD-ROM.

**Viracept® Combination Therapy as Initial HAART Demonstrates Long-Term Response**

Agouron Pharmaceuticals, Inc. reported in July 2001 that Viracept® provided durable and potent HIV viral load suppression as well as an increase in CD4 cells in patients receiving Viracept® (nelfinavir mesylate) combination therapy as initial highly active antiretroviral therapy (HAART). These findings were based on a retrospective chart review of 1,309 people living with HIV who received such initial therapy. Viracept® is the most prescribed HIV protease inhibitor (PI), a class of drugs associated with a significant drop in mortality and opportunistic infections among people living with HIV.

The study, presented at the 1st International AIDS Society Conference on HIV Pathogenesis and Treatment in July 2001 in Buenos Aires, Argentina, consisted of a sample of 1,309 people living with HIV—24% women and 76% men—who had received more than 24 months of continuous therapy with Viracept® as a single PI with dual nucleoside reverse transcriptase inhibitors as first-ever HAART. At baseline, individuals had a median plasma HIV RNA of 13,350 copies/mL (range <60–3,863,300) and a mean CD4 cell count of 300 cells/mm³ (range 0–1,656). The mean number of years since HIV diagnosis at baseline was 6.4; the mean time spent on Viracept® was 36.3 months, with 88.2% remaining on Viracept®-based HAART at time of analysis. The study showed a mean increase of 230 CD4 cells/mm³ and a mean decrease in HIV RNA of 1.41 log₁₀; two thirds of patients had a viral load of <400 copies/mL at 36 months.

“This observational data reaffirms the effectiveness of PI–based first-line HAART therapy. In our report, Viracept®-based regimens provided substantial and durable increases in CD4 cells and decreases in plasma HIV RNA.
viral loads for the vast majority of first-time HAART recipients, regardless of their baseline viral load,” said Frank Palella, MD, an assistant professor in the Division of Infectious Diseases at Northwestern University Medical School. “This benefit was noted to persist for at least 2 years, with most patients remaining on such therapy at the time of our report.”

Viracept® in combination with other antiretroviral agents is indicated for the treatment of HIV infection. Coadministration of Viracept® with certain drugs is contraindicated. For a listing of these drugs and for information regarding the side effects of this medication therapy, please consult the Agouron Pharmaceuticals, Inc. Web site at www.agouron.com or obtain this information by calling 1-888-VIRACEPT.

**Study Demonstrates Durable Viral Load Suppression With Combination Regimen Containing Sustiva™ in Heavily Pretreated Patients**

A four-drug regimen containing Sustiva™ (efavirenz), a nonnucleoside reverse transcriptase inhibitor (NNRTI), nelfinavir, and two nucleoside reverse transcriptase inhibitors (NRTIs), provides greater and more durable viral load suppression compared to a triple combination of nelfinavir or Sustiva™ when combined alone with NRTIs in extensively nucleoside-experienced HIV-infected individuals. This finding is the result of a study released in August 2001 and funded by the National Institute of Allergy and Infectious Diseases.

The study was a Phase II, randomized, multicenter, partially double-blinded three-arm trial that compared Sustiva™, nelfinavir, or Sustiva™ plus nelfinavir, in combination with open label NRTIs. The quadruple therapy arm demonstrated the highest rates of response through 48 weeks of treatment and achieved superior HIV-RNA suppression compared to the nelfinavir arm by both standard (HIV-RNA < 500 copies/mL) and ultrasensitive assays (HIV-RNA < 50 copies/mL) ($p = .001$ and $p = .001$, respectively). Similarly, the three-drug arm containing Sustiva™ conferred significantly greater viral load reductions compared to the nelfinavir arm by the standard ($p = .004$) and ultrasensitive ($p = .008$) assays (this was the first blinded head-to-head comparison of efavirenz with nelfinavir). The quadruple arm achieved superior virologic suppression compared to the three-drug arm containing Sustiva™ only in the ultrasensitive analysis ($p = .008$).

Based on the intent-to-treat approach, 74% ($n = 63$) in the quadruple therapy arm had plasma HIV-RNA levels less than 500 copies/mL through 48 weeks compared to 60% ($n = 65$) in the arm containing Sustiva™ and 35% ($n = 66$) in the nelfinavir arm. Furthermore, through 48 weeks, 67% in the quadruple arm had a viral load less than 50 copies/mL compared to 44% in the arm containing Sustiva™ and 22% in the nelfinavir arm.

“The data suggest pretreated individuals with NRTIs have an excellent chance of benefiting from a new regimen that includes both Sustiva™ and nelfinavir with new NRTIs,” said Laura Bessen, MD, Executive Medical Director, Worldwide Medical Affairs, DuPont Pharmaceuticals Company. “People who need a potent regimen to help reduce viral load now have another proven option.”

Durability of response, as determined by time from baseline to virologic failure (confirmed HIV-RNA ≥ 200 copies/mL), was longer in the quadruple therapy
arm (79% of patients were still responding through 48 weeks) compared to 36% in the nelfinavir arm ($p < .001$). Additionally, 58% in the arm containing Sustiva™ were still responding through 48 weeks ($p = .01$). The median CD4 cell increase over this period was 94 cells/mm$^3$ (pooled arms, $p < .001$).

A total of 195 NNRTI- and protease inhibitor–naive patients were recruited from 24 AIDS clinical trial units and five Regional National Hemophilia Foundation Units in the United States and Puerto Rico for this study and were subsequently randomized in the double-blind fashion. A full report of this study was published in the August 9, 2001, issue of the New England Journal of Medicine (Vol. 345, No. 6, pp. 398-407).

Sustiva™ is indicated for use in first-line combination with NRTIs for the treatment of HIV infection. Coadministration of Sustiva™ with certain drugs is contraindicated. For a listing of these drugs and for information regarding the side effects of this medication therapy, please consult the DuPont Pharmaceuticals Web site for Sustiva™ at www.sustiva.com or obtain this information by calling 1-800-4PHARMA.
2001 Peer Review Panel

The editor and the editorial staff would like to thank the following professionals who provided peer review for JANAC manuscripts in 2001:

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Save the Date

November 8–11, 2001
The 11th conference of the European Association of Nurses in AIDS Care will be held in Rotterdam, the Netherlands, on November 8-11, 2001. For more information on this conference, please send inquiries to the following e-mail address: n.langebeek@rijnstate.nl.

November 11–14, 2001
The 14th annual conference of the Association of Nurses in AIDS Care will be held November 11-14, 2001 at the Minneapolis Hilton and Towers in Minneapolis, MN. This conference is themed “Lighting the Future of HIV/AIDS Nursing” and calls on ANAC and its members to lead the way in finding creative ways to manage the complexities and challenges of HIV/AIDS care. For more information on this conference, please consult the ANAC Web site at www.anacnet.org or call 1-800-260-6780.

December 2–5, 2001
The National AIDS Treatment Advocates Forum 2001 will be held December 2-5 at the Sheraton Vancouver Wall Centre Hotel in Vancouver, Canada. This forum is open to anyone interested in broadening their knowledge of HIV/AIDS research and treatment issues and learning to use this knowledge to advocate on behalf of everyone living with HIV/AIDS. For more information on this forum, please visit the forum Web site at www.nmac.org/nataf/2001/welcome.htm, or contact Paul Woods at 202-483-6622.

December 11–14, 2001
The Fifth International Conference on Home and Community Care for Persons Living With HIV/AIDS will be held December 11-14, 2001, in Chiang Mai, Thailand. This conference was organized to maximize the commitment, leadership, participation capacity, and experiences of communities and leaders from across the globe and to harness the power of humanity to address the challenges of the HIV/AIDS epidemic. For more information on this conference, please visit the conference Web site at www.hiv2001.com. Pre-registration deadline for this conference was September 30, 2001.

May 23–24, 2002
The International Association for Human Caring will hold its 23rd Annual Conference, themed “Creating Caring Environments,” on May 23-24, 2002, in Boston. For more information on this conference, please contact the association’s Web site at www.humancaring.org.

July 2002
The 14th International Conference on AIDS will be held in Barcelona, Spain, in July 2002. For information on this event, please consult the event Web site at www.aids2002.com.

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Information for Authors

The Journal of the Association of Nurses in AIDS Care (JANAC) is the official journal of the Association of Nurses in AIDS Care. JANAC’s mission is to support nursing practice, research, and education through the scholarly dissemination of knowledge and practice standards. JANAC’s aim is to increase the understanding of the complex physical and psychosocial issues associated with HIV disease and the quality of nursing care provided to persons with or at risk for HIV infection. To that end, JANAC provides a forum for the interdisciplinary discussion of practice, education, research, and public policy issues related to all aspects of the HIV/AIDS epidemic.

JANAC is a peer-reviewed journal for nurses involved in all areas of HIV/AIDS care—the delivery of care, the development and implementation of programs, the formulation of policies, and the pursuit and analysis of research. JANAC invites original articles from other disciplines such as social work, public health, and medicine that focus on clinical practice, health services, education, research, law, ethics, and social-medical issues.

Submission of Manuscripts

JANAC reviews manuscripts for publication with the understanding that they have not been previously published and are not being reviewed or considered for publication elsewhere. JANAC invites contributions in the form of regular articles (maximum 25 pages), letters to the editor (maximum 2 pages), and book reviews (maximum 2 pages).

Five copies of the manuscript and a cover letter should be submitted to the following address:

Richard L. Sowell, PhD, RN, FAAN
Editor, JANAC
4840 Forest Drive, PMB #356
Columbia, SC 29206

Inquiries regarding manuscript status should be directed to the editorial assistant, Lee Pearson, via e-mail at JournalofANAC@prodigy.net. All other inquiries should be directed to the editor, Dr. Richard L. Sowell, by calling 770-423-6062 or via e-mail at RSowell@Kennesaw.edu.

Peer Review

Manuscripts are acknowledged on receipt. All manuscripts are initially reviewed by the editor or assistant editor. After the editor’s review, the manuscript will be submitted for review by at least two peer reviewers. Manuscripts are evaluated according to their relevance and significance to HIV/AIDS care, the degree to which they advance nursing knowledge, scholarly presentation, integrity of research methodology and/or clinical content, and appropriateness of nursing implications. Accepted manuscripts may be revised to conform with the standards and editorial style of JANAC.

Manuscript Preparation

Manuscripts must be typed on one side only of 8½" by 11" paper, double-spaced, with 1-inch margins on all sides. Text pages should be numbered consecutively in the upper right corner. Each manuscript should have the following components: title page, abstract, key words, manuscript body, and references. Other components such as tables, figures, and photographs are encouraged if they enhance or amplify the text. Manuscripts should be written in accordance with APA style.

Title page. The title page should include the following information: title of the article, all authors’ full names, academic degrees, affiliations, titles, home and work addresses, telephone and fax numbers, and e-mail addresses. Names of authors should not appear on
Abstract. All manuscripts, except letters to the editor and columns, require an abstract of 75 to 150 words. No references should be cited in the abstract. Double space the abstract and place it on a separate page.

Key words. All manuscripts, except letters to the editor and columns, must have 3 to 4 key words identified for indexing. Key words may be typed on the abstract page or may be placed on a separate page.

Manuscript body. JANAC is committed to publishing manuscripts that advance HIV/AIDS knowledge and are clinically relevant. Authors are encouraged to submit manuscripts that increase or improve HIV/AIDS literature. The authors are free to develop manuscripts in a manner that fulfills the mission of JANAC. All manuscripts should include a section titled “Nursing Implications” or another appropriate title that addresses the manuscript’s implications for nursing practice.

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