The medical trend to consider HIV infection as a “chronic but manageable” condition is predicated on early treatment with antiviral drugs. This trend also acknowledges the need for new drug and vaccine development to complement the currently available class of anti-HIV drugs, that is, the nucleoside analogues zidovudine (ZDV; AZT), didanosine (dDI), and zalcitabine (ddC).

People with HIV disease and their providers anticipate the international conference each year hoping for breakthroughs in HIV treatment. At this year’s conference researchers presented several studies that have dampened these expectations and led to a variety of reactions ranging from anger to despair, and a more complicated environment in which to make treatment decisions. This article offers medical and mental health providers the four ingredients they will need to help patients make these decisions: an overview of the key ZDV and combination therapy reports, including the Concorde study; a catalogue of some of the possible client responses to this information; a review of the treatment options that follow from the new data; and an approach for helping patients make treatment decisions.

The Concorde Study

Researchers presented results from this large English/French collaborative study that looked at immediate versus deferred treatment with ZDV alone in people with asymptomatic HIV infection (WS-B24-5).* After three years of study involving 1,749 people, there was no difference in the survival or risk for progression to AIDS between the group randomized to ZDV and the group receiving placebo. Of note, there were significant increases in T-helper cell counts in the ZDV-treated group that did not translate into increased life-expectancy or prolonged good health. In addition, while ZDV delayed progression to AIDS—defined as the onset of opportunistic conditions—in the first 12 months of study, this effect disappeared at the three-year analysis.

Criticism of the study centered on the fact that the dose of ZDV used was 250 milligrams four times a day, two times higher than the standard dosage in the United States. Concorde investigators responded, however, that there were very few side effects from this dose. Likewise, critics suggested that the validity of the study was compromised when, after a year, researchers offered participants the opportunity to drop out. In response to data from AIDS Clinical Trials Group (ACTG) study 019 (see below), which found a benefit from ZDV among people with T-helper cell counts of less than 500, 37 percent of participants dropped out of the Concorde study.

Although Concorde researchers have yet to publish their data in a peer-reviewed journal, these results suggest strongly that the beneficial effects of ZDV may be transient. Likewise, the study calls into question the common practice of using T-helper cell counts—rather than rates of onset of new infections or death rates—as indicators of drug effectiveness.†

AIDS Clinical Trials Group Studies

Results from this U.S. study of ZDV versus placebo in people with asymptomatic HIV disease mirrored the Concorde study findings. As noted above, researchers partially halted ACTG 019 in 1989 after an interim analysis showed a significant decrease in progression to
AIDS in people with T-helper cell counts of less than 500 who were on 600 milligrams a day of ZDV. However, the most recent data, presented in Berlin after 30 months of study, found no difference in the death rates between those treated before and those treated after the onset of symptoms (WS-B24-6). Likewise, the Berlin analysis showed that the difference in rates of progression to AIDS had also disappeared.

A "sub-analysis" found that people who enrolled with T-helper cell counts of 300 to 500 still benefited from early treatment with ZDV. But, since this sub-analysis was not built into the original study design, its statistical validity is questionable. In any case, this continued analysis again highlights the transient duration of benefit from ZDV for persons with HIV infection, but without symptoms.

ACTG 155 looked at 991 people who had been on ZDV alone for a mean period of 18 months, and who either were symptomatic and had T-helper cell counts of less than 300 or were asymptomatic and had T-helper cell counts of less than 200 (WS-B25-1). Researchers randomized participants into three groups: to continue ZDV alone, to switch to ddC, or to take ZDV and ddC in combination. Overall, they found no difference among the groups in terms of survival or risk for deterioration, defined by the occurrence of new opportunistic infections. When participants were stratified based on their entry T-helper cell count, however, subjects with T-helper cell counts ranging from 150 to 300 who were switched from ZDV to the combination of ZDV and ddC showed significantly lower rate of progression.

It was people with T-helper cell counts lower than 150 who showed no apparent benefit regardless of the regimen they received. The researchers concluded that while there is value in combination therapy for people with less advanced HIV disease, the study supports the trend in thinking that there are few options for people with more advanced disease after 18 months of ZDV therapy.

All of these studies raise questions about recommendations for asymptomatic patients. What should asymptomatic patients, who may have started taking ZDV years ago, do? Should they stop therapy and watch for disease progression? Should patients considering treatment options for the first time start ZDV as early as they had been? These questions were not part of the design of these studies and remain unanswered.

**Data Summary**

In response to these questions and others the National Institute of Allergy and Infectious Diseases (NIAID) issued in June new recommendations on the use of ZDV, ddI, and ddC, focusing in particular on early intervention. Relying on a consensus panel of 18 medical experts, who heard testimony from 30 researchers and clinicians and who considered the conference results, NIAID softened their previous guidelines, which had absolutely recommended ZDV monotherapy for everyone with T-helper cell counts below 500.

NIAID now suggests two equally valid options for asymptomatic people with T-helper cell counts between 200 and 500 and no history of antiviral therapy. These include initiation of antiviral therapy with ZDV alone, or continued observation and monitoring for clinical or laboratory evidence for deterioration followed by initiation of antiviral therapy. The panel did not suggest that asymptomatic patients who have started therapy based on the previous guidelines discontinue it now. Finally, for people with T-helper cell counts of less than 200, NIAID continues to recommend monotherapy with ZDV, although they added that combination therapy "may be considered."

**Emotional Response to the Studies**

The Berlin data ushers in a new period in HIV-related treatment. Confirmation of the limits of the nucleoside analogues and of the painstaking effort required by antiviral research has left resignation where only two years ago there were high hopes. For mental health and medical practitioners alike, the first task may be dealing with the emotional responses of clients to this information.

People with advanced HIV infection, who have been undergoing antiviral therapy and have developed side effects to these medications, may feel a sense of hopelessness over the failure to see new treatment options emerge. They may also feel anger towards their health care providers because they experienced side effects and spent time trying antivirals that these studies suggest are ineffective in people with advanced HIV disease. Discussions about stopping antiviral treatment may raise fears about diminishing quality of life, death and dying, and "giving into the disease."

HIV-infected people without symptoms must balance scientific evidence that viral activity warrants early intervention with the new studies suggesting the limited efficacy of antivirals. They may respond
with confusion and concern over their newly limited options. The conference results are also confusing for people already on these medications, sometimes for five to seven years without symptoms. The data threatens their convictions that, despite the risks and costs of drugs, they have been actively fighting infection. Some will ignore these results, responding that “While these medications do not work for everyone, in my case, they do.” For others, particularly those ambivalent about the medications, the data may evoke a renewed sense of hopelessness and loss of control over the course of infection.

Again, some of these feelings may translate into anger at health care providers or the health care system that promised benefits that appear to be undeliverable. They may also result in patients feeling the need to “take control” by stopping current therapy without waiting for the interpretation of these results, their publication and review, and results of ongoing studies that may shed additional useful interpretation on their own situation. Patients may also try “alternative therapies” without consulting their health care providers.

Making Treatment Decisions

In order to deal with these feelings and at the same time move patients toward making the treatment decisions with which they can be most comfortable, providers should consider the following three steps. First, both medical and mental health providers need to be aware of the most recent treatment possibilities and recommendations. Having a firm grasp on the best available knowledge, however limited, allows providers to feel confident of the validity of whatever decisions patients make. Failure to maintain this knowledge leaves practitioners, particularly mental health providers, unable to provide an informed sounding board for resolving patient concerns and leads to the danger that therapists may inadvertently contradict the advice patients receive from their physicians. Understand-ing the range of factors involved in treatment decisions also makes it easier to support these decisions once they are made.

Second, providers need to appreciate that patients will be facing treatment decisions with incomplete, and in some cases, conflicting information. This situation is a metaphor for living with HIV disease: the uncertainty that surrounds antiviral treatment decisions is not unlike the uncertainty associated with the progression of the illness. By pointing this out, providers can help patients recognize this familiar situation and appreciate the limits of available knowledge.

Despite this uncertainty, providers need to explain treatment issues and controversies before making treatment recommendations. This will communicate two important principles: that patients should be active partners in treatment decisions, and that patients can and should understand the rationale that governs medical recommendations. Physicians who take this approach are likely to avoid having patients who feel angry or betrayed when they later discover new or apparently contradictory information.

Third, it is important for providers to empathize with the dilemma of making such important treatment decisions in the context of inconsistent information. Providers should communicate to patients that their decisions do not need to be made immediately, that they should take as much time as they need to decide, and that they should discuss their options with friends and loved ones.

Providers should remind patients that they can change their minds: for example, after beginning ZDV treatment, they can always stop at a later point in time; and after stopping treatment, they can begin again. A decision about antiviral treatment does not have to be a crisis. It can be made over a period of several office visits, and setting aside time at each visit to approach the issue communicates to patients that the option is always available.

In response to the Berlin studies, providers should openly empathize with patients who feel hopeless or angry about the disappointing data. At the same time, providers should hold out to their patients the hope of new treatments and reinforce the idea that prevention—in the form of working together over time to identify and treat new symptoms—can protect patients from opportunistic conditions and ensure that patients start antiviral treatment when it is likely to be most effective.

Treatmen Options

It is also useful to consider more specifically the range of patients who may respond to the new treatment information
and their specific treatment options. For individuals who are confident about their current treatment approach or who leave the treatment recommendations up to their providers, simply raising the issue may suffice to ensure that patients remain comfortable about their care.

Raising the issue with less assured patients, will give them permission to question the validity of current treatment programs. This is consistent with the “new” NIAID guidelines, which suggest continued dialogue between patients and providers regarding HIV treatment strategies. Similarly, for those patients with advanced HIV disease and side effects to therapy, raising the issue gives them a chance to rethink the continued use of medications that may be causing them pain or medical problems.

For those tolerating antiviral medications—despite low T-helper cell counts (often below 50)—there is no evidence that these drugs speed disease progression, and continuation of therapy seems to be in order. Asymptomatic patients taking ZDV alone or in combination may also question the value of continuing therapy. In the absence of laboratory tests that assess the status of viral activity and as long as therapy is well-tolerated, it remains prudent to continue previous treatment strategies.

For people still contemplating initiation of antiviral therapy, providers need to define separately the issue for those with and without symptoms. Providers should encourage those with symptoms of HIV disease, even mild ones such as oral hairy leukoplasia or oral or vaginal candidiasis, to consider antiviral therapy. Neither ACTG 019 nor the Concorde study enrolled participants who fit this description, and so the results of these studies do not pertain to this situation.

Providers need to make asymptomatic patients aware of the results of these studies and encourage them to pursue standard “lifestyle” recommendations—regarding, for example, good nutrition, reduced stress, and avoidance of other sexually transmitted diseases—that may help preserve their “good health.” They should offer these patients close monitoring of physical condition and T-helper cell count and consider antiviral therapy when counts drop to levels that both patient and provider agree are significant.

Conclusion

Despite the lack of encouraging results from Berlin, optimism about the state of HIV therapy is justified. There are a variety of new drugs in development, and some, such as interleukin-II, the protease inhibitors, and the non-nucleoside reverse transcriptase inhibitors, are entering clinical trials to assess efficacy. The philosophical approach of “buying time” with currently available nucleoside analogues is still valid for many people with HIV disease, and this strategy can extend good health by as much as three years.

The Berlin results simply remove the wool from the eyes of those patients and providers who thought that the science of HIV therapy was settled. The new NIAID guidelines emphasize what has always been true: the progress of science, especially HIV-related science, is disorderly, and physician and patient must work in partnership to negotiate the chaos. No one—neither patients, providers, nor mental health practitioners—should underestimate the psychological effects of either apparent successes or failures in this process. All of us must continue to lend our support to the efforts to find effective treatments.

Clearinghouse: AIDS Conference

Conference-Specific Publications

A limited number of the two-volume set of conference abstracts can be purchased for DM90 plus shipping and handling. Call or write before ordering to confirm availability: Institute for Clinical and Experimental Virology, Free University of Berlin, Hindenburg-damm 27, D-1000 Berlin 45, Germany; 01-49-30-798-3687 or 01-49-30-798-3696 (fax: 01-49-30-834-3061). Audiotapes of conference presentations are available for DM20 each. For ordering information, write: Intrec, PO Box 85015, 3500AA, Utrecht, The Netherlands, call 01-31-30-340-619, or fax 01-31-30-340-334.

Journals and Newsletters

AIDS Treatment News devotes several issues to the conference. Number 175 (May 21) previewed some of the conference topics. Number 178 (July 9) discussed the latest advances in AIDS treatments. Among the other topics slated for discussion are immune-based therapies, nutrition, diagnosis, markers of progression, treatment information specific to women, and international organizations. Individual issues cost $2. To order, write: P.O. Box 411256, San Francisco, CA 94141, or call (415) 255-0588 or (800) 873-2812.

AIDS Weekly covers the conference in its June 7 and June 14 issues, and continues to report findings. Individual issues are available for $12. To order, write: P.O. Box 830409, Birmingham, AL 35283, or call (800) 633-4931.
Surviving the AIDS Conference
Diane K. Haas

I attended the Ninth International Conference on AIDS in Berlin as a participant, an HIV/AIDS educator and trainer, and a person living with AIDS, eager to gain information that would satisfy all of these interests. This was my first time traveling to Europe and my first opportunity to attend an International AIDS Conference.

I arrived with a lot of grief and fear and left with renewed hope, commitment, and a sense of belonging to a global effort of people working for the care, treatment, and prevention of HIV disease. In this article I offer my impressions of the conference from the perspective of a person with HIV disease.

Connecting

When I arrived at the conference, I felt overwhelmed and insecure. In an effort to feel connected to other HIV-infected participants and combat my sense of alienation, I set out to find the PWA lounge. Because it wasn’t clear where the lounge was, I realized I would have to ask a staff person and out myself as being HIV infected. All of this made me feel even more insecure and fearful, but I was determined to make connection with other HIV-infected people. After the ordeal of asking not one but three people, I was finally pointed in the right direction.

Why did I feel so uneasy about being out as a person living with HIV disease at an AIDS Conference? Being the object of so much discussion was very off-putting. It was the feeling of being “other than,” of being a Patient in a sea of Doctors. I felt like everyone was talking about me and I was the only one who knew it.

I understood the irony of this feeling when I asked a pharmaceutical sales representative about rifabutin (a drug being studied to prevent Mycobacterium avium complex). He immediately lost interest in my question when it became clear that I was interested in using it myself rather than selling it to patients. I realized that the reason I felt so uncomfortable coming out as a person with HIV disease was because I felt like an impostor. The AIDS conference is geared towards the “experts,” not towards people with the experience of living with HIV disease.

On the other hand, I was moved by what I experienced as immense compassion and dedication toward people living with AIDS. I felt a sense of community with other participants, whether or not they were infected. I felt my grief lift as I walked through the exhibition halls and saw the international effort of activism, research, and creative prevention programs. It was the voices of camaraderie that helped to inspire me and revive my spirit.

These voices, particularly those of people with HIV disease, came from all over the world. Their stories put my life into perspective. There was the woman from Malawi who had lost her own children and most of the young people in her village to AIDS. She said that HIV antibody testing is done in all public hospitals and that the results of the tests are not disclosed to patients. She said that government hospitals studied to prevent Mycobacterium avium were interested in using it myself rather than selling it to patients. I realized that my question when it became clear that I was interested in using it myself rather than selling it to patients. I realized that the reason I felt so uncomfortable coming out as a person with HIV disease was because I felt like an impostor. The AIDS conference is geared towards the “experts,” not towards people with the experience of living with HIV disease.

These voices, particularly those of people with HIV disease, came from all over the world. Their stories put my life into perspective. There was the woman from Malawi who had lost her own children and most of the young people in her village to AIDS. She said that HIV antibody testing is done in all public hospitals and that the results of the tests are not disclosed to patients. She said that government hospi-
tals will deny malaria treatment to people who test HIV antibody positive, even though malaria is treatable. She told me about her battle to win back her government job after being dismissed because she was HIV infected. I was struck by how she described in such a matter-of-fact way a life full of sadness, loss, and triumph.

Her story and others like it broke my heart and filled me with rage. But they also inspired me and gave me strength to continue to fight in this epidemic. They gave me strength because I realized I wasn’t alone; I was joined in my struggle with AIDS by people from every pocket of the earth.

Disappointments
The politics of AIDS was omnipresent at this conference. The inequity of financial resources was glaringly obvious in the exhibition halls and workshops, and in the underrepresentation of people from developing nations. I was also struck by the absence of presentations on HIV infection in women—aside from those covering women as vectors of transmission to male sex partners and fetuses—and the lack of participation of people with HIV disease. In a “Meet the Experts” workshop on women and HIV infection, there were no HIV-infected women on the panel. We’re too far along in this epidemic not to know that the true experts are those of us who are living with the disease.

While exhibit space for community-based organizations was so tight that two or more agencies often crammed themselves into an 8-by-10-foot booth, pharmaceutical companies, like Burroughs Wellcome (the makers of AZT) spread themselves over spaces 10 times as large. I couldn’t help juxtaposing the promise of the Burroughs Wellcome exhibit, with its scenic landscapes and catchy phrases—like “Helping people with HIV to live longer and healthier lives”—with my own experience of taking AZT: headaches, nausea, muscle atrophy, leg pain, premenopausal symptoms, and no lasting improvement in my condition.

Long-Term Survival
The highlight of the conference for me was participating in the Long-Term Survivors roundtable. This was one of the few workshops that included people with HIV disease. There were three of us: a gay man from New York City, a heterosexual woman from Trinidad, and myself, a lesbian, and recovering addict from San Francisco. Also on the panel were three researchers from New York, Puerto Rico, and Zaire.

We discussed whether long-term survival is related to characteristics of the virus, genetic differences in people with HIV infection, or something that survivors are doing. The panelists agreed that, while much remains unclear, positive attitude, nutritious diet, safer sex, increased exercise, aggressive treatment of opportunistic infections, love, active spirituality, setting goals, abundant laughter, and available psychosocial support play a role in long-term survival. I realized that one of the paradoxes of being a long-term survivor is wondering whether each year increases the likelihood of your survival or the probability of your death.

At the time of the conference, a decline in my health and a recent AIDS diagnosis had left me feeling frightened and hopeless. As a result of participating in this panel, I left Berlin with a new attitude that enabled me to focus on living and believe in myself and my treatment choices. While physical, social, and spiritual activities may not prevent me from dying, I’m at least feeling active and am setting my goals for the future. One participant said that while it is crucial for us to look for ways to survive AIDS, we should never view death as failure, for there are many “survivors” who have passed on.

Conclusion
Overall, the conference was a wonderful experience. I was honored to be a part of an event that represented, on such a large scale and on so many levels, the worldwide fight against AIDS. The politics did not keep me from getting the inspiration and support I need to continue my commitment to living and struggling with HIV disease.

Authors
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The topic was sexuality, and the ultimate focus was HIV prevention. The approach was an ongoing “roundtable” discussion that took place at three sessions over three days: the first session reviewed theories of sexuality; the second session described the prevention dilemmas raised by these theories; and the third session presented interventions. The “Sexuality and AIDS” roundtable of the International Conference on AIDS was designed to go beyond presentations, and each session offered more than an hour of audience discussion during which participants and presenters clarified, challenged, confronted, and came to agreements.

This design was in sharp contrast to the usual scheme for conference workshops, and the roundtable format was meant to allow for more spontaneous discussion. In most workshops, presenters—sharing neither language, approach, nor the ability to connect—occupy only a common venue and communicate in formal ways data from their particular studies. This narrow focus is ironic, because it is at international conferences, where diversity of culture is likely to result in diversity of approach, that a freer exchange of ideas might lead to breakthroughs. With only a little more time, the sexuality roundtable might have achieved these breakthroughs.

**Sexuality across Cultures**

Presentation after presentation focused on different cultures, and despite vastly different expressions and concepts of sexuality, it was clear that archetypal sexual practices and prevention dilemmas exist. Three ethnographies in particular demonstrate this principle.

Gary Dowsett studied the culture of working-class gay men in Australia.* He found that men in this community identify more with popular culture than with gay culture, and that they live with and near their families and not in gay ghettos associated with expensive lifestyles. They prize intimacy above eroticism, reject HIV educational messages that are defined only in terms of erotic images, and see sexuality as being private. Dowsett emphasized that these men are neither prudish nor closeted; they simply live their lives with different constraints and expectations, and despite these differences, they comprise an “authentic gay culture,” untouched by current HIV prevention campaigns.

In the United States, HIV-related risk classifications have reduced “homosexual activity” to sex among gay men, bisexual men, and “men who have sex with men.” While some AIDS educators have started to go beyond these labels to identify subgroups, such as gay youth, African-American gay men, and rural gay men, rarely do they produce careful studies like Dowsett’s identifying clear differences among gay men that might very well determine the success or failure of prevention campaigns. In addition, it is important not to confuse these “authentic gay cultures” with the all-encompassing men-who-have-sex-with-men category, whose key characteristic is avoidance of gay identity. But as one roundtable participant noted, prevention messages might be more successful if they focused on all anal eroticism—including anal sex among gay, bisexual, and other men, and between men and women. HIV educators will have to seek to reconcile these two perspectives.

In Papua New Guinea, sex roles are clearly defined, according to Carol Jenkins who completed an ethnographic survey of this recently modernized nation. While female sexuality is constricted, male sexuality has no limits, often extending to group sexuality, a practice through which men bond. During this practice, as many as 10 men may have sex with one woman. Jenkins said that 50 percent to 60 percent of the time, men rape women and that women gain social status by being raped.

East Indian women are expected to be ignorant about their sexuality and sex education is unavailable to them, according to a study by Purnima Mane. During sex, women cover their eyes. As Mane puts it, these characteristics “are not conducive to the sexual negotiation” required to prevent HIV transmission. For Indian women “sex equals pain,” and Indian wives appreciate it when their husbands go outside marriage for sex. At the same time, they acknowledge that sex is a useful bargaining tool within the marriage. Mane concludes that the utility of AIDS education is limited until the Indian philosophy of sexuality changes.

The attitudes of these last two cultures speak of the silence and shame that char-
Managing Desire

To believe that it is only intellectual assumptions such as these that influence sexual activity, however, is to reduce complex biology to popular culture. Evolution and instinct play a huge role in determining sexual behavior. We turn to cognitive and psychological processes over which we have some control only because influencing behavior on the more fundamental plane of biology seems impossible.

Nonetheless, a participant at one workshop raised the issue of managing desire, that is, actually mediating an instinctive response. Is this anything different from what the church has failed to accomplish in 2,000 years? Or is it something more complicated, relating to the role of sexuality in the life of each individual?

A room full of skeptical participants dismissed the question, and one responded with the glib phrase: safe sex is management of desire. But safe sex guidelines do not manage desire; they manage risk. The roundtable never fully explored the question: would managing desire, that is, the root of sexuality, be an efficient and effective way of avoiding unsafe sex? On one level—the level of the "out" gay male community in the United States—the idea seems ridiculous. The psychological health of gay men in a society that stigmatizes homosexuality is grounded in the positive role of sexual desire. Is it possible to manage desire and not invalidate this perspective?

The workshop never defined the components of desire, but a participant did raise a point that is gaining more attention in the HIV prevention world: to what extent is dangerousness a central element to the sexual expression of some people? To what extent does the fact that unsafe sex is dangerous and forbidden make it all the more desirable to people despite sexual orientation, gender, class, or ethnicity? How does this complicate the management of desire?

Is it possible to manage an instinctive response? People manage desire all the time, especially once they identify a desire-driven activity as leading to an undesirable situation. The best example of this, specifically because, like sex, it represents a basic need, is eating.

Are there strategies that would effectively manage sexual desire without exacerbating the already dangerously negative perceptions of sexuality in the United States and other societies? While the roundtable did not answer questions like this, more than any other workshop, it allowed participants to define the most important questions facing the HIV prevention effort today.

Conclusion

The key to the roundtable process is the idea that we can learn as effectively from our differences as we can from our commonalities. It suggests that the old AIDS adage—interventions must be developed by people who are members of targeted populations—needs to be updated. By all means, never formulate interventions without community members at the center of the process. But consider what can be learned only from people living in different contexts.

Our cultural differences may be important tools in discovering new ways of dealing with archetypal responses—everything from safe sex to multiple loss. Cultural exchange must happen. It is at events like the sexuality roundtable that it can.

Next Month

HIV-related treatments in development offer an alternative to standard antivirals. It is crucial that clinical trials for these drugs represent all populations, but not all patients have equal access to them. In the October issue of FOCUS, Patricia J. Kelly, FNP, MPH, until recently the Director of Women’s HIV Research at Downstate Medical Center in New York, discusses how and why researchers and medical and mental health practitioners can help get women into HIV-related clinical trials. She also looks at the psychological benefits of these trials.

Also in the October issue, Terry McGovern, JD, Director of the HIV Law Project, examines the legal approaches used to broaden access to trials and explores how women can benefit from direct participation in this process.
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