HIV/AIDS Antiretroviral Medications: Train the Trainer Curriculum for Nurses in Low Resource Countries

HIV/AIDS Bureau
Health Resources & Services Administration
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- The HAB, HRSA Adherence Curriculum authored by Linda Frank, RN, PhD and Helen Miramontes, MSN, RN, FAAN. Dr. Frank is Director of the Pennsylvania/Mid-Atlantic AIDS Education and Training Center and Helen Miramontes, Clinical Professor Emeritus of University of California, San Francisco is a consultant/author of the Antiretroviral curriculum.
- The HIV/AIDS Fact Sheets for Nurses and Midwives developed by the International Council of Nurses, the World Health Organization, and the United Nations Program on AIDS (ICN/WHO/UNAIDS).
- The Guidelines for Antiretroviral Agents in HIV Infected Adults and Adolescents developed and published by the USDHHS.
- The Guidelines for Use of Antiretroviral Treatments in Adults with Particular Reference to Resource Limited Settings developed and published by WHO.

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Helen M. Miramontes, MSN, RN, FAAN

NURSES TRAINING WORKSHOP

February 13 – 15, 2002

DAY ONE (9AM – 5PM)

9:00am – 10:00am	Introductions (each participant – background, expectations) (3 minutes each)
10:00am – 10:30am	Overview of Project – D. Parham, Raul Romaguera
10:30am – 10:45am	**BREAK**
	Orientation to working in Africa –Briefings
10:45am – 11:00am	Office of Global Health Affairs
11:00am – 11:15am	HRSA – International Health
11:15am – 11:45am	HAB teams sent to Zambia & Ethiopia (how to deal with local politics, multiple partners, structure of HIV/AIDS & health programs
11:45am – 12:15pm	Jeanne Raisler (John Cohn's wife) – Training in Africa
12:15pm - 12:30pm	Overview of Needs Assessment (Botswana)
12:30pm – 1:30pm	**LUNCH**
1:30pm – 1:45pm	Overview of Current Training
1:45pm – 3:15pm	Overview of Curriculum (including Resource Materials, Slides/Transparencies, Technical Assistance) • Module One – Pathogenesis & Immunology (30 minutes) • Module Two – ARV Medications (30 minutes) • Module Three – Adherence (30 minutes)
3:15pm – 3:30pm	**BREAK**
3:30pm – 5:00pm	Continue Review of Curriculum • Module Four – Cultural Issues (30 minutes) • Module Five – Nursing Care Issues (one hour)

DAY TWO (9AM – 5PM)

9:00am – 10:30am	Discussion of Adult Learning Principles and Train the Trainer Principles • Experiential vs. Passive Listening • Knowledge acquirement vs. Skills Development • Climate Setting • Role of Facilitator • Demonstrations (Exercises) • Example: Introspection Exercise
10:30am – 10:45am	**BREAK**
10:45am – 12:30pm	Discussion of Cultural Issues • Assumptions • Exercises
12:30pm – 1:30pm	**LUNCH**
1:30pm – 5:00pm	Team Assignments – Will be assigned by the facilitator- Microteaches (5 teams to develop comprehensive teaching/learning plan for presentation on third day – using curriculum, slides/transparencies, adult learning, train the trainer techniques – evaluation by participants/facilitator with discussion) Presentation of Microteaches (on 3rd day) – with comprehensive discussion of techniques, strategies (each presentation will be 40 minutes with 20 minutes discussion) Topics: Pathogenesis/Immunology; ARV Medications; Adherence; Cultural Issues; Nursing Care Issues Work on presentations

DAY THREE (9am – 4pm)

9:00am – 9:40am	Microteach One – Pathogenesis & Immunology
9:40am – 10:00am	Discussion of Microteach One (with written evaluation)
10:00am – 10:40am	Microteach Two – ARV Medications
10:40am – 11:00am	Discussion of Microteach Two (written evaluation)
11:00am – 11:15am	**BREAK**
11:15am – 11:55am	Microteach Three – Adherence
11:55am – 12:15pm	Discussion of Microteach Three (written evaluation)
12:15pm – 1:15pm	**LUNCH**
1:15pm – 1:55pm	Microteach Four – Culture
1:55pm – 2:15pm	Discussion of Microteach Four
2:15pm – 2:55pm	Microteach Five – Nursing Care Issues
2:55pm – 3:15pm	Discussion of Microteach Five
3:15pm – 3:30pm	Written Evaluation of the Training
3:30pm – 4:00pm	Discussion of Training - Closure

OBJECTIVES OF THE NURSES TRAINING:

Upon completion of the three (3) day nurses' train the trainer workshop, the nurses will be able to:

- define train the trainer concepts,
- list adult learning principles,
- identify teaching/training strategies that can be used in regions with low resources and reflecting different cultures,
- describe some cultural differences that may impact HIV/AIDS nursing care in low resource settings,
- develop a 40 minute teaching presentation using curriculum materials and incorporating adult learning and experiential strategies,
- verbalize an increased comfort level for training nurses in ARV care in low resource settings.

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Introduction to the Curriculum

Global HIV/AIDS Pandemic

According to the estimates of the UNAIDS Program, by the end of the year, 2001, sixty five (65) million people had been infected with HIV, twenty five (25) million infected people had died from AIDS; and, currently, forty (40) million people are living with HIV/AIDS. Approximately one-third (1/3) of those living with this disease are between the ages of 15-24 years. In developing countries the primary route of viral transmission is through heterosexual activity, and women are equally infected. HIV/AIDS is the fourth leading cause of death worldwide, but the first cause of death in sub-Saharan Africa.

Of the 40 million people living with HIV/AIDS, 28.1 million (88%) are living in sub-Saharan Africa and 55% of infected people are women. Of the 5 million new infections in 2001, 95% occurred in developing countries, and of these, 3.4 million (68%) occurred in sub-Saharan Africa. It is estimated that 2.4 million African children, under the age of 15 years, are living with HIV/AIDS. HIV/AIDS in sub-Saharan Africa has disseminated communities and families, created economic disasters, exacerbated health conditions, overwhelmed health facilities and systems, significantly impaired educational progress, decreased life expectancy by 1-2 decades, negatively impacted food productivity, and destabilized political systems.

In South and Southeast Asia, the pandemic is rapidly expanding in India, China, Myanmar (Burma), and Thailand with 6.1 million people living with HIV/AIDS who were infected through heterosexual activity and injection drug use (IDU). In Eastern Europe and Central Asia, also a region of rapid expansion of the pandemic with approximately one (1) million people living with HIV/AIDS infected primarily through injection drug use. In Latin America and the Caribbean, almost 2 million people are living With HIV/AIDS. And in North America new infections are on the rise.

Antiretroviral medication therapies have been available in North America and Europe since 1987, but not available in developing countries. Since 1987, therapies have become more effective, disease progression has slowed, infected people are living longer with fewer opportunistic infections (OIs), and the death rate has decreased. In regions without antiretroviral therapies, HIV/AIDS continues it's relentless expansion with fairly rapid disease progression, development of OIs, and death. During the past year or two, more pressure has been brought to

bear on the developed countries with significant resources, pharmaceutical corporations, and public institutions to make antiretroviral (ARV) therapies available and accessible in lows resource countries. During the past few months in low resource countries, there have been major efforts to increase the availability and accessibility to some of the ARV medications. In anticipation of this increase in availability and accessibility of ARV treatment, this curriculum has been developed to train nurses in low resource countries to train other providers about the use of ARV therapies in order to enhance the quality of infected peoples' lives and slow disease progression.

Use of This Curriculum

This curriculum has a limited scope and does not attempt to address all the complex issues of the HIV/AIDS pandemic. The HIV/AIDS Bureau at HRSA, encourages the development and use of both basic HIV/AIDS curricula and also advanced curricula. This curriculum is primarily a Train the Trainer project and should be built upon basic HIV/AIDS knowledge. The goal of this curriculum is to increase knowledge about ARV therapies and enhance nursing skills in providing HIV/AIDS ARV therapies training to other care personnel.

It is anticipated that when HAB, HRSA, receives a request for assistance in preparing HIV/AIDS for using ARV therapies, in partnership with the requesting country, this curriculum will be adapted to reflect the culture and training needs of the specific country. The current curriculum reflects a more Western cultural perspective and can be used as a guide to operationalize a specific country/region cultural viewpoint training program.

When planning a specific country program, significant thought should be given to the sustainability of the training program, as well as the availability and provision of technical support as needed. Routine intermittent training needs to be a component of the training program in order to maintain a viable core of trained HIV/AIDS providers with updated knowledge and skills.

Trainer Expectations

Trainers will be expected to be able to plan and conduct training programs for other providers/personnel on HIV/AIDS issues, including the use of ARV therapies utilizing the most current knowledge and skills available.

Within a training setting, trainers are responsible for:

- creating an effecting learning environment,
- modeling and facilitating the learning activities,
- being sensitive and responsive to learner's needs,

- protecting the learners so that everyone feels safe but not forced to participate,
- appropriately addressing the challenges of problem learners,
- explaining the adult learning principles underlying the training strategies,
- modeling sensitivity, understanding, tolerance and the ability to recognize issues or topics that make you and others uncomfortable.

Training Concepts

1. Use adult learning principles (need to know; experiential; participatory in learning activities; variety of training/learning strategies; use-friendly materials/tools; small group activities aimed at preparing trainers to teach).

2. Three (3) day workshop. Day 1 and 2 focus on transfer of knowledge and information. Day 3 focuses on "putting it altogether."[using tools and knowledge from first 2 days to demonstrate readiness to train other nurses (micro-teaches; critical incidents; development of training plans; role plays demonstrating skills)].

3. Keep initial trainings small in order to provide in depth training and guidance (25-30 participants).

4. Provide follow-up technical support. Co-train (observe) with new trainers. Provide materials/tools for trainers' classes/courses. Provide follow-up/update trainings for trainers.

5. Build evaluation component into the training for both 1st and 2nd generations of trainers/learners.

6. Provide training setting conducive to learning and meeting personal physical needs.

7. Provide time off for potential trainers in order to participate fully in the training. Commitment of potential trainer's supervisor to support the trainer post workshop.

Learning Objectives

a. Upon completion of the workshop, the participant will demonstrate increased knowledge of the:
   i. pathophysiology of HIV/AIDS,
   ii. ARV treatment of HIV/AIDS,
   iii. critical issues of treatment regimen adherence,

iv. cultural issues that may either impede or facilitate adherence to the treatment regimen,
v. nursing care activities essential to providing appropriate and competent care to people living with HIV/AIDS

through a pre/post test, case studies, and other training activities during the workshop.

b. Upon completion of the workshop, the participant will be able to demonstrate increased skills in providing training for other health care providers by:
   i. workshop activities, such as micro teaches, designed to demonstrate training behaviors
   ii. development of a training plan for the participant's work setting

SAMPLE TRAINING AGENDA

Day One

8:30am – 9:15am - Introductions (each participant – 1-2 min. – background, course expectations)

9:15am – 9:30am - Overview of the Workshop (build in Train the Trainer concepts, adult learning concepts)

9:30am – 10:30am - Review of epidemiology and pathophysiology of HIV/AIDS

(Prepare country specific epidemiological materials, both written and verbal). These can be obtained from the UNAIDS web site before training begins.

10:30am – 11:00am - Tea Break

11:00am - 11:45am - Continue review of epidemiology and pathophysiology

11:45am – 12:30pm – Case Studies – epi & pathophysiology

12:30pm - 1:30pm - Lunch

1:30pm - 3:30pm - ARV Treatment

3:30pm - 4:00pm - Break

	4:00pm - 5:00pm - ARV Treatment Case Studies (Critical Incidents)
Day Two	8:30am - 9:00am - Review of Key Concepts on ARV Treatment
	9:00am - 10:30am - Issues of Adherence
	10:30am - 11:00am - Tea Break
	11:00am - 12:00pm - Case Studies on Treatment & Adherence
	12:00pm - 1:00pm - Lunch
	1:00pm - 2:00pm - Cultural Issues
	2:00pm - 3:00pm - Cultural Activities & Case Studies
	3:00pm - 3:30pm - Tea Break
	3:30pm - 5:00pm - Mental Health Issues – 30minutes Case Studies
	5:00pm - 5:30pm - Assignment of Micro Teaches
Day Three	8:30am - 9:00am - Review of Key Concepts from Day Two (culture, adherence, mental health)
	9:00am - 10:00am - Group work on micro teach
	10:00am - 10:30am - Tea Break
	10:30am - 12:00pm - Presentation of 3 Micro Teaches (20 minutes each – present for 10 minutes – large group feedback for 10 minutes)
	12:00pm - 1:00pm - Lunch
	1:00pm - 2:00pm - Presentation of 2 Micro Teaches and 20 minutes of discussion about this teaching technique and others

2:00pm - 3:00pm - Critical Incidents (incorporating all the key concepts discussed in the previous 2 days)

3:00pm - 3:30pm - Tea Break

3:30pm - 4:45pm - Development of Teaching Plans (individual, small group, and large group work)

4:45pm - 5:00pm - Closing (Summary)

Nursing Care Issues will be built into the case studies, the critical incident presentations, and the micro teaches

Slides can be used for lecture content – if we had a video on infection control that would be good also - the important idea to remember is to use a variety of teaching strategies.

Adult Learning

Andragogy vs. Pedagogy Adult education is a complex phenomenon that incorporates many subjects, settings, and learner purposes. These purposes may include personal growth, skill development, professional growth and/or enjoyment. The term for modern adult education theory is andragogy, the science of assisting adults to learn as contrasted with pedagogy, the science of teaching children. Malcolm Knowles, considered the leader in theory research and development of adult learning principles, has been writing and articulating andragogy for over 30 years.

The following general assumptions are offered about the Differences between adult learners and non-adult learners:

- adult learners are assumed to be self-directed,
- adult learners bring rich resources in experiences to the learning setting,
- adult learners are motivated by the need to solve a particular problem or the need to develop a particular skill,
- adult learners can be identified by their maturity, independence, and self-discipline,
- have diversity of life experiences and interests,
- may need to give structure to new experiences,
- perceive that their time is valuable,
- believe that there is usually no answer that is

totally correct,
- may view new situations in relation to past experiences, traditional cultural, religious, and/or institutional values.

In pedagogical learning, the assumptions are different. Some of these assumptions are:

- the focus of pedagogical learning is on subjects of a curriculum/course,
- the focus is on long term goals, such as college and/or preparing for a career,
- pedagogical learning involves external motivational rewards or punishments.

Principles of Adult Learning

Malcolm Knowles (Informal Adult Education, 1950, Association Press, New York) and Ron and Susan Zemke (30 Things we Know For Sure About Adult Learning, Training, the Magazine of Human Resources Development, June, 1981) have identified some principles of adult learning. These principles are founded on the assumptions about adult learners emphasizing the importance of participation by the learner. These principles support the establishment of an informal contract between the learner and the instructor. The learner identifies what he/she wishes to accomplish, and the instructor assists the learner in meeting his/her goals. In this setting, the instructor is a **Facilitator** rather than a teacher.

Some of these **Principles of Adult Learning** are:

- the learner's life experiences are a resource of knowledge that can be incorporated into new learning situations,
- identifying specific educational needs enhances motivation to learn,
- planning, identification of needs, and setting of goals should involve the participation of the learners,
- learning is self-directed requiring facilitation of learning rather than "spoon-feeding" information,
- learners seek out learning experiences to cope with specific life events,
- learning orientation is associated with specific problems or needs,
- in order to use and retain the new information it must be integrated into previous knowledge base,
- adult learning is competency driven rather than content-driven. Competency outcomes should

drive the content and methods,

- establishment of a safe, supportive environment is essential for learning,
- the physical environment needs to be comfortable and pleasant,
- participatory, experiential learning activities and strategies should replace traditional, lecture-based methods,
- learner should have feelings of accomplishment.

Role of the Facilitator

The instructor's role is to facilitate the learning experience for the self-directed adult learner. The concept is to create a win-win situation in which both the instructor and the participant learner accomplish their goals. Part of the facilitator's role is to identify and use the learner's experiences to enhance the learning experience. The facilitator is also responsible for establishing the pace of content delivery based upon the learners' comprehension and acknowledging individual variances. The facilitator accepts each learner as a person of worth, seeks to build relationships of mutual trust and respect, and contributes to the group learning as a co-learner and member of the group. The facilitator validates expressions of learners' thoughts and feelings, and brings to the setting a sense of humor and enthusiasm about the topic and the teaching/earning strategies.

Climate Setting

In order to create an environment that is safe, comfortable, and supportive in which participants feel respected and valued, the facilitator must pay particular attention to several details of the learning experience and the setting. Establishing ground rules for respecting each other even when disagreeing and establishing the parameters of confidentiality. It is important that the facilitator model the desired behavior. Encouraging spontaneous questions, comments, and rebuttals facilitates participation and enhances learning from various perspectives. Three strategies conducive to positive climate setting are:

- design seating to encourage eye contact and dialogue (round or oval tables with 4-5 people),
- carefully plan the first 20 minutes of the learning experience in order to create a comfortable setting (use exercises, i.e. introductions, introspection exercise),
- articulate the ground rules at the beginning of the session (confidentiality, etc).

Introspection Exercise
[45 minutes]

This climate setting exercise allows you to explore and share your concerns associated with training other health care personnel about the use of ARV therapies to treat HIV/AIDS patients in low resource countries.

Individual
[10 minutes]

Record your responses to the following questions/statements on the index card given to you at the beginning of this session.

1. Fill in the blank: When I think about ARV therapies being used in low resource countries, I'm concerned about_____ _____.
2. What issues around HIV/AIDS care in low resource settings is most difficult for you to handle?
3. What are your concerns about training/facilitating nurses in low resource countries about ARV therapies?
4. List three (3) strategies that you use to take care of yourself.
5. List five (5) personal strengths that you believe make a good facilitator for ARV treatment training.

Small Group
[20 minutes]

Based upon your experiences, knowledge and the climate setting exercise, discuss in your small groups:

1. Your concerns associated with ARV therapies for HIV/AIDS patients in low resource settings.
2. Your concerns, fears associated with training in other cultures/countries.
3. What you do to relieve stress/tension.
4. Your personal strengths.

Large Group
[15 minutes]

Based upon the discussions in the small groups, consider the following:

1. The similarities in concerns and expectations expressed by the participants.
2. How the climate setting exercise demonstrates the principles of adult learning.

3. Creative ways to establish a supportive environment for Training.

(The previous sections on Adult Learning, the Role of the Facilitator, and Climate Setting were adapted from the California Nurses Association's AIDS Train the Trainer Program for Health Care Providers funded by the State of California, Department of Health Services, Office of AIDS, Sacramento, California, 1986-1995).

References

United Nations Programme on HIV/AIDS (UNAIDS). AIDS Epidemic Update, December, 2001. http://www.unaids.org/epidemic_update/report_doc01/index.html

California Nurses Association. AIDS Train the Trainer Program For Health Care Providers. San Francisco, 1986-1995.

Pathophysiology of HIV/AIDS

Overview

Since the virus that causes AIDS was identified in 1983-84, there has been extensive research to understand the pathophysiology of HIV, the normal immune system functions, and the mechanisms for the interactions between the virus and the immune system. The search for answers continues to focus on basic science research to provide us with more knowledge about this simple organism. The more we learn about HIV the more successful we will be in the development of effective ARV agents and preventive vaccines.

There has been some controversy about the relationship of HIV and AIDS. A few scientists and a few activists continue to deny that HIV causes AIDS. Numerous scientists have researched the etiology of AIDS, and the evidence is overwhelming that HIV causes AIDS. Sensitive testing procedures demonstrate that the virus is present in infected individuals, and antibodies to HIV are present in more then 90% of people with AIDS. Hopefully, we can move on from this controversy to focus on the overwhelming needs of providing care and treatment for those already infected and developing options to prevent infection and stop this pandemic.

In order to provide the appropriate ARV treatment therapies and assist patients to adhere to their treatment regimens, we need to understand the pathophysiology of HIV, normal immune system functioning, and the interaction of the two. This module is designed to provide a brief review of both HIV pathophysiology and the functions of the normal immune system. The epidemiology of HIV/AIDS (transmission routes, co-infections, O.I.s, and classification of HIV) will be briefly reviewed also.

Objectives

Upon completion of the training on this module, the learner will demonstrate increased knowledge of:

- the normal immune system
- the pathophysiology of HIV/AIDS
- the classification system of HIV and AIDS
- the O.I.s and co-infections

by increasing scores on posttests and analyzing case studies.

Immune System

The immune system includes all the cells, organs, and processes that protect the individual from substances foreign to his/her body. These substances can be organisms, like viruses or bacteria, pollen, animal hair, chemicals, and other foreign agents. The

process of providing protection is called immunity and is either natural (innate) or acquired. Natural or innate immunity, available quickly, is nonspecific and includes the white blood cells, the skin and mucous membranes, the body's pH, inflammation, phagocytosis, interferon, and other mechanisms and agents that the body mobilizes to protect itself from invasion and harm. Natural immunity does not require the action of an antigen that is a characteristic of acquired immunity.

Acquired immunity is developed through exposure to an antigen (infectious agent). The initial response to a foreign substance (a longer process than the innate response) triggers a process of developing protection, such as antibodies, against the agent. The response is specific and occurs through the action of antibody cells (humoral - B cells) or lymphoid cells (cell mediated immunity –T cells). Each antigen triggers a specific protective response. Acquired immunity can be either passive (antibodies from someone else, such as an infant that receiving antibodies from the mother through breast feeding) or active (immune host stimulation by an antigen triggering the release of antibodies). Passive immunity is short term and active is long term. Any exposure to the same foreign substance after the initial exposure triggers a much faster protective reaction. Immunization can also be acquired through vaccination.

Leukocytes [white blood cells (WBCs)] synthesized in the bone marrow are components of the immune system. The leukocytes are categorized as:

* Polymorphonuclear (PMN) cells include mast cells, basophils, eosinophils, and neutrophils. They make up about 50-70% of the WBCs, are short-lived and their primary function is phagocytosis in bacterial infections
* Lymphocytes, about 25-35% of WBCs, are categorized by surface markers as:
  * T Cells (70%) synthesized in bone marrow from the bone stem cell and matured in the thymus gland
  * B Cells (25%) synthesized in the bone marrow from the stem cell and via plasma cells become antibodies (immunoglobulins)
  * Natural Killer (NK) cells (5%) fight off viral infections, kill leukemia and lymphoma cells
* Monocytes (3-8%) are synthesized in three (3) days and are quickly circulating in the blood and become macrophages

Lymphocytes Only about 1-2% of lymphocytes are in the circulating blood at any one time. The rest are in the lymph system/tissue (resting – inactive). Lymphocytes (CD4 T-cells) are infected by HIV early in the infection phase, probably about the time of the acute HIV infection when the virus replication bursts forth and "seeds" the cells in the resting stage. This pool of infected cells can persist for years. T-cell lymphocytes are activated via presentation of antigen by macrophages. Activated T-cells become differentiated into subpopulations in the thymus gland. All T-cells have CD3 markers, but through a differentiation process, cells express either CD4 or CD8 receptor sites. The CD4 T-cell is the very cell that is the target of HIV invasion. The CD4 T-cell is the helper cell (helps other cells), and it functions in helping B cells produce antibodies, CD8 cells to mature, and assists the cells that activate macrophages. CD8 cells mature into cytotoxic cells. The normal ratio of CD4 to CD8 is 2:1, but about 2% of the population has a flipped ratio. The CD8 T-cell blocks replication of HIV and the decrease in activity of CD8 cells over time may be related to progression to AIDS of HIV infected individuals.

Pathophysiology of HIV

HIV, a member of the Lentivirus (long acting) genus of the retroviral family, is the only Lentivirus that is known to infect humans. There are two (2) HIVs, HIV-1 and HIV-2. HIV-1 is the most prevalent in the world and HIV-2 is primarily localized in West Africa. HIV, like other viruses, requires a host's cell for replication. A retrovirus, such as HIV, carries genetic material (nine genes) in the form of ribonucleic acid (RNA) and uses an enzyme, reverse transcriptase, to convert the RNA to deoxyribonucleic acid (DNA). RNA occurs in a single strand of genetic material and DNA is a double strand of genetic material. The synthesis of HIV DNA from HIV RNA must occur in the cytoplasm of the CD4 cell before the virus' genetic material (DNA) can be inserted into the cell's DNA.

HIV can infect any cell carrying a CD4 receptor site. Most of the CD4 cells are T-cells, but HIV also infects monocytes, macrophages and dendritic cells, as well as other organs in the body. HIV attaches to CD4 receptors on human cells and a co-receptor, fusion, helps HIV to enter and infect CD4 cells and a second co-receptor, CC-CKR5, helps HIV to enter and infect

macrophages. Only 3-4% of the virus is circulating in the blood. The rest of the virus in located in the cells.

HIV uses two other enzymes, protease and integrase, to facilitate infection of human CD4 cells. HIV attaches to the CD4 cell by modifying a glycoprotein precursor (gp160). The gp160 is in a non-functional form, and in order for HIV to attach to the CD4 cell, gp160 must be clipped into two (2) molecules, gp41 and gp120 by the protease enzyme. The gp120 attaches to the CD4 receptor site and the gp41 harpoons the cell assisting HIV to fuse with the cell. HIV integrase functions within the CD4 cell nucleus to clip the cell's DNA so that the HIV DNA can insert itself into the cell's genetic code thereby ensuring active replication of virus whenever the cell becomes active. Recent studies have shown that there is an additional process that enhances the insertion of HIV DNA into the cell nucleus. After the HIV RNA synthesizes the HIV DNA in the cytoplasm, and prior to its integration into the cell nucleus the HIV DNA stimulates the production of viral proteins. These proteins activate the cell out of its dormant state enabling the HIV DNA to insert itself more easily into the cell nucleus.

Activation of the Immune System

The immune system in HIV infection is activated by an antigen, HIV, which triggers the immune system to respond with vigor. A massive response occurs with the synthesis of antibodies (B cells) and a cell mediated response (T cells). HIV infected macrophages travel to the germinal centers in lymph nodes where dendritic cells and CD4 T-cells become infected early.

It is thought that HIV crosses the blood-brain barrier sequestered in macrophages. HIV continues to replicate in macrophages, and is relentless in viral replication. Research studies reveal that 10 billion HIV virions are reproduced (replication takes place in HIV infected activated CD4 cells) and cleared by the immune system each day in an infected individual. The virus replication is error prone and easily produces viral mutations. A steady state is maintained between viral production and destruction by the body's immune responses for some time, but eventually the immune system is overwhelmed and the infected individual becomes symptomatic with disease, progresses along the continuum of disease with increase morbidity, and eventually, dies.

Epidemiology of HIV

<u>Transmission</u> HIV is transmitted through exposure to infected body fluids. These fluids are:

* Blood – exposure can occur through a variety of methods, including used syringes, needle sticks, transfusions of contaminated blood, mucocutaneous exposure to blood or other infected body fluids.
* Semen – male to female and male to male – HIV has been found in semen even after treatment with HIV antiretroviral agents.
* Vaginal Fluid – vaginal fluid is the least infectious of body fluids because there are fewer CD4 cells in vaginal fluid. There is still a chance of contracting HIV from vaginal fluids but the risk is lower then through blood and semen.
* Breast Milk – HIV can be transmitted through breast milk. Current recommendation is not to breast feed if you are HIV infected, or to breast feed only for the first six (6) months after birth.
* Urine, feces, saliva, tears – are NOT infectious unless they contain visible blood. HIV is also present in other body fluids but represents a very low risk of transmission unless they contain visible blood.

HIV Clades – As previously mentioned there are two (2) HIVs. HIV-1 and HIV-2. Clade is the term used to identify the various HIV-1 subtypes. These subtypes or clades (determined by divergence of nucleotide sequencing) are sufficiently similar to each other to be classified within the larger category of HIV-1, but dissimilar enough to be designated as a separate subtype (clade). A HIV infected person may have several strains of HIV in his/her blood, but these strains are mutations of the person's original viral infection, not multiple infections with different strains. Genetically these strains are very similar to each other. Clades (subtypes) have more genetic diversity than HIV strains. Currently, it is not known what impact clade diversity has or will have on antiretroviral (ARV) medication efficacy and upon vaccine development. Preliminary findings with ARV medications that have been developed and tested in the United States and Europe, indicate that the medications are effective against other clades. The current vaccine research paradigm reflects that there may be a need to develop vaccines specific to the dominant clade within a country or region. Currently, HIV-1 has nine (9) clades (subtypes) around the world.

- Clade B is the dominant subtype in the United States, also found in Asia and South America,
- Clade A is in central Africa,
- Clade C is in southern Africa and India,

- Clade D is found in Africa,
- Clade E in Asia and Africa,
- Clade F in Africa, Asia, and eastern Europe,
- Clade G in Africa and Asia,
- Clade H in Africa,
- Clade O in Africa.

Clade C is the primary subtype of new infections, especially in southern Africa.. The greatest diversity of subtypes is found in west Africa, especially in Cameroon; an area believed to be the site of where HIV first jumped species from animal primates to humans.

Risk Factors – a few of the risk factors are listed below:

* unprotected sex – receptive anal/vaginal intercourse without a condom
* substance use/abuse – especially sharing injection needles. Use of alcohol may impair thinking leading to increase in risk behaviors.
* other sexually transmitted infections (STIs) - especially STIs that cause genital ulcerations that interrupt the normal mucosal barriers.
* poverty – health problems, inadequate access to health care, poor diet, higher incidence of violence and victimization.
* Trauma, abuse – power imbalances between men and women, civil strife, discrimination, violence.

HIV Disease Progression

The following stages of HIV Progression do not take into account any antiretroviral (ARV) treatment that can slow disease progression, decrease morbidity, and prolong life.

Asymptomatic Infection – During the initial stage (primary infection) viral replication is rapid and viral load is high. Seeding of virus into cells of the bone marrow, central nervous system, and lymphoid tissue occurs rapidly (within 10 days). A person may experience flu-like symptoms especially at the time of seroconversion (detectable antibodies in the plasma). Second phase of this stage is the clinical latency, with a significant drop in viral load as the immune system mounts a massive response. This phase may last for years, but the individual remains infectious to others if engaging in risky behaviors. During this clinical latency phase HIV infected people may not have clinical signs and symptoms of clinical disease, but may be dealing with emotional issues, such as depression, anxiety, and fear, associated with a HIV diagnosis. Nurses

are skilled in providing the appropriate emotional support and psychosocial interventions to alleviate some of these issues and assist patients in coping with the stressors of an HIV diagnosis.

Early symptomatic – The rate of viral replication remains relative constant, however the immune system's decreasing ability to control the virus results in increase viral load. As the immune system weakens, the infected individual begins to develop symptoms of opportunistic infections (O.I.s). Candida (thrush), herpes (shingles), lymphadenopathy (swollen lymph nodes), weight loss, and fatigue – signs of disease progress from mild to moderate and may begin to interfere with activities of daily living (ADL). The CD4 drops, may be 200 to 500/ml, and viral load increases. There may be an increase in the occurances of O.I.s also. Nurses need to assist patients in dealing with the psychological issues associated with impairment of functioning status, as well as the clinical problems associated with progressive HIV disease.

Advanced Disease – Increase in morbidity. The immune mechanisms continue to fail, resulting in higher viral loads and a decrease in CD4 count, usually below 200/ml. Clinical manifestations may include loss of lean body mass and wasting syndrome. May have an increase in viral infections, neurological impairment and cancers (lymphomas) eventually leading to death. Nurses are key to the provision of palliative care and relief of suffering. Support of the patient and family are essential in ensuring a caring, dignified end-of-life experience.

HIV/AIDS Classification Systems

The Centers for Disease Control and Prevention (CDC) in the United States Department of Health and Human Services (USDHHS), and the World Health Organization (WHO) have developed classification systems to categorize different stages of HIV/AIDS disease. Both systems contain laboratory criteria and clinical criteria. The CDC first published their system in 1986, and it has been revised twice (1993, 1999). The WHO published their system in 1990.

(CDC documents are listed in the references at the end of this module. A copy of the WHO staging system is located at the end of this module).

Diagnosis Without A Classification System

Patients in areas where CD4 T-cell count tests are not available, can be diagnosed clinically (presumptive diagnosis) using a list of major and minor symptoms. Two (2) major signs or symptoms and at least one (1) minor sign or symptom identifies symptomatic HIV infection.

Major Signs or Symptoms

- Weight loss greater than 10% of body weight
- Chronic diarrhea for more than one (1) month
- Prolonged fever for more then one (1) month
- Tuberculosis

Minor Signs or Symptoms

- Persistent cough for more than one (1) month
- Generalized itching skin rash
- History of herpes in last two (2) years
- Fungal infections of mouth and/or throat
- Chronic progressive or generalized herpes simplex infection
- Generalized enlarged lymph nodes (lymphadenopathy)

In many low resource countries, laboratory testing, such as HIV antibody testing, CD4 counts, and viral loads has not been available. The need to be able to categorize signs and symptoms reflecting probable HIV disease triggered the development of the above classification system.

Common HIV Tests

The routine laboratory tests for HIV do not actually test for the virus, but for the antibodies to HIV that are produced by the individual's immune system in response to exposure and infection with HIV. Although the tests are very sensitive and accurate, there is a "window period" of several weeks after initial infection with the virus and before the appearance of detectable antibodies. The HIV antibody is primarily used for three (3) purposes:

- diagnosis of HIV infection in an individual,
- screening of blood,
- epidemiological surveillance.

Enzyme Linked ImmunoSorbent Assay (ELISA) has in the past been the first test used. If the results are positive for HIV antibodies, then a Western Blot Assay was done as a confirmatory test. Confirmatory tests were done because the ELISA, being a very sensitive test, sometimes yields a false positive finding.

Test results were not available immediately, and in the United States at most of the anonymous testing sites, a person had to wait for two (2) weeks to obtain the results. Many people did not return for their tests results. To use ELISA tests, WHO states that there are several essential requirements for tests to be performed accurately:

- Appropriate laboratory equipment must be

available, including ELISA readers.

- A constant supply of electricity and routine maintenance of equipment
- Skilled technicians
- Accurate storage and testing temperatures

Recent advances in testing technology has provided easier and quicker methodologies, including an oral test, such as, kits that do not require reagents, equipment, technicians, or special storage and temperatures. These tests can be done at anytime, are as accurate as the ELISA test and yield results quickly.

Opportunistic Infections

Opportunistic Infections (O.I.s) are conditions that develop as the immune system of a HIV infected person deteriorates and the person progresses along the continuum of disease. The immune system is severely compromised by HIV over time allowing the growth of infections that had been held in check by a competent immune system. In the United States and other Western countries, HIV infected patients have been treated prophylactically to prevent outbreaks of O.I.s. O.I.s are determining factors in the classification systems of HIV/AIDS, and are specific to the different categories and/or stages of disease. Patients with HIV disease may have acute outbreaks of O.I.s as well. Discussion of O.I.s and their treatment is beyond the scope of this curriculum.

Co-Infections

For some time there has been discussions, among clinicians and researchers, about the possibility of several infectious diseases being identified as co-infections, rather than O.I.s, due to some preliminary evidence that when individuals are infected with both diseases there appears to be a more rapid progression of either the HIV disease or the other infectious disease. The diseases considered as potential co-infections are genital herpes (HSV-2), tuberculosis (TB), hepatitis C (HCV), hepatitis B (HBV), and malaria.

Genital Herpes(HSV-2) The presence of persistent genital herpes in HIV infected individuals has been noted for a long time. It is the most common sexually transmitted disease (STD) among HIV positive people. There has been some speculation over time about the possibility of HSV-2 accelerating the progression of HIV disease. A researcher at the University of Minnesota who has been studying HSV-2 for more than a decade, says that their findings are suggesting a biological interaction between HIV and HSV-2 that appears to enhance sexual transmission of HIV and increases the

replication rate of HIV. The mechanisms of this interaction are not identified and remain unclear, but the researchers suggest that the herpes lesions provide a more efficient port of entry for HIV. Other research studies have also supported the theory that the presence of STDs, especially STDs that cause ulcerative lesions facilitates the transmission of HIV. Researchers have also found that herpes appears to hasten the progression of HIV disease. Tracking is difficult because only about 20% of cases of herpes are identified in the United States (US). Routine screening is not done, and frequently, HSV-2 infected individuals are clincally asymptomatic; and yet 80% of herpes infected people shed virus during their asymptomatic phase. It is unknown whether or not treatment with antiviral agents impacts transmission of herpes. Currently, the only effective transmission intervention method is the use of condoms to prevent, or at least, minimize HSV-2 transmission.

Tuberculosis (TB) is a airborne transmitted disease that is seen in HIV negative people, as well as in HIV positive people, but it is especially dangerous for people that are HIV infected. Worldwide, it is the leading cause of death for persons with HIV/AIDS. According to the CDC, the person living with AIDS (PLWA), has a much greater risk of developing active TB disease and becoming infectious to others.

According to UNAIDS:

* Two (2) billion people worldwide (1/3 of the world's population) are infected with the organism that causes TB.
* TB is the cause of death for one (1) out of every three (3) people,
* One-third (1/3) of the increase in TB during the past 5 years is due to HIV infection.

We are also seeing an increase in the number of cases of multi-drug resistant (MDR) TB. MDR TB is very difficult to treat, prevention of MDR TB requires adherence to TB treatment regimens. In some countries/communities, a protocol called Directly Observed Therapy (DOT) has proven highly effective in assisting people to follow their regimens of TB medications and prevent MDR TB. TB medications are effective in HIV infected people, but some of the agents in the TB drug regimens are contraindicated when the person is on ARV drugs for HIV disease treatment complicating an already complicated situation. Some health authorities are suggesting that persons with HIV disease and at high risk of developing active TB be treated prophylactically with one of the anti-TB agents, isoniazid (INH). WHO/UNAIDS

recommend contacting the specific country's Ministry of Health or District Health Management for guidelines on TB treatment.

Malaria is a severe disease endemic in countries where we are seeing rapidly increasing prevalence of HIV infection (Africa, Southeast Asia, India, South America). Malaria kills more than a million people a year worldwide. Malaria, as most of you know, is not a transmittable disease from person to person, but is caused by a parasite (*Plasmodium falciparum)* found in anopheline mosquitoes and transmitted to humans through mosquito bites. Malaria, like HIV, can be transmitted by contaminated blood, and does not appear to be a typical O.I. associated with HIV disease, but there is some evidence of a malaria connection or intersection in HIV infected women. The malaria parasite infects the red blood cells (RBCs) in humans causing anemia by rupturing the blood cells and exacerbating the commonly occurring anemia of pregnancy. Malarial episodes during pregnancy have been associated with low birth weight, fetal distress, premature labor, and increases in stillbirths, miscarriages, and neonatal deaths. Placental malaria may increase mother-to-child transmission of HIV. Frequently, malaria is asymptomatic during pregnancy and not easily diagnosed, but studies have shown that even subacute malaria can contribute to anemia and placental infection. Clinical trials in Kenya using two (2) doses of sulfadoxine-pyrimethamine (SP) for all pregnant women in endemic malarial areas reduced the incidence of anemia in first-time mothers by 39%. The use of SP prophylactically in areas of malarial risk is becoming the standard of care. The immune system responses to the malaria parasite is not fully understood, but does involve both the cell mediated and humoral mechanisms, including various T-cell subsets. Researchers have proposed various theories for a potential interaction of immune responses to HIV and the malarial parasite. Certainly much research still needs to be done, but in the mean time, awareness of the effects in pregnant HIV infected women and the possibility of other associations between these to common diseases is important in caring for HIV infected people.

Hepatitis C (HCV) is transmitted primarily through repeated injections of contaminated blood. Therefore, in the U.S., co-infection with HCV and HIV is common among HIV infected injection drug users (50-90%), and among hemophiliacs who received clotting factors before the clotting concentrates were effectively treated for both viruses (before 1987). The risk for acquiring HCV through perinatal or sexual transmission is much lower than it is for HIV. For individuals infected with HIV through sexual transmission, the chance of being co-infected with

HCV is the same as in the general population (3-5%). Chronic HCV infection develops in 75-85% of HCV infected people and leads to chronic liver disease in 70% of cases. Co-infection with HIV leads to more rapid progression of HCV disease. HCV is considered an O.I. in HIV infected individuals, but is not an AIDS defining illness. With the extensive use of HAART regimens and prophylactic treatment of O.I.s prolonging life and slowing HIV disease progression, HCV related liver disease has become a major cause of increased morbidity and mortality in HIV infected persons. A vaccine for HCV is not yet available. Treatment of HCV with alpha interferon monotherapy or with alpha interferon and ribavirin in HIV infected people being treated with ARV agents is being studied. The recommendation is to use combination therapy with caution until more data are available.

Hepatitis B (HBV) is a disease that has been known for decades and is endemic in many parts of the world. A vaccine was developed in the mid 1980's and there has been and continues to be extensive efforts to distribute the vaccine worldwide. The Gates Foundation, founded by Bill Gates of Microsoft fame, has provided massive funds to distribute the vaccine, and numerous countries' public health systems have done much work to track and treat HBV. In spite of these efforts, in endemic countries, two (2) billion people still carry markers of HBV infection; of these, 350 million are chronic carriers of HBV, and 25% will eventually die of the disease at a rate of one (1) million annually. One of the major problems in vaccine distribution is the cost of providing the vaccine to low/limited resource or "have-not" countries. Most of these countries are in sub-Saharan Africa.

HBV is transmitted by the same routes as HIV transmission, sexually, contaminated blood (injection drug users, hemophiliacs, transfusions), and perinatally. Co-infection with HIV and HBV has been well documented since the early identification of HIV in the 1980's. In the early 1980's, before the routine testing of blood for HIV, co-infection with HIV and HBV, was found in 80% of the gay men with AIDS in San Francisco, California, U.S.A. Studies seem to suggest that for HIV infected individuals there is an impact upon the development of HBV antibodies and that HIV infected persons become chronic carriers of HBV more often than HIV negative individuals.

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Key Concepts

* HIV stimulates the infected individual's immune system to mount a massive response to fight the virus.
* Both arms of the immune system are involved in the response to the virus.
* The CD4 T-cells of the cell mediated arm of the immune system are key cells in the battle against HIV, but are the very cells attacked by the virus.
* The CD8 T-cells are cytotoxic and are important in the fight against HIV.
* The decrease in CD8 function over time may contribute to the progression to AIDS of HIV infected people.
* HIV can infect any cell carrying a CD4 receptor site.
* A co-receptor, fusion, facilitates the infusion of HIV into the human cell.
* CCC-CKR5 is a co-receptor that facilitates the insertion of HIV into macrophages.
* In a retrovirus, genetic material is carried in a single strand of RNA, and requires an enzyme, reverse transcriptase, to convert the RNA into a double strand of DNA.
* The conversion of RNA into DNA occurs in the cell cytoplasm and must occur before the HIV DNA can be inserted into the DNA in the cell's nucleus.
* Two (2) other enzymes of HIV (protease and integrase) are used at two (2) other sites in the infusion/insertion process.
* HIV gp160 is a precursor (non-functional form) to gp120 and gp41, both needed for attachment of HIV to the cell and fusion of the virus into the cell. Protease enzyme clips gp160 into gp 41 and gp 120.
* Integrase is needed to clip the cell DNA in the nucleus so that the HIV DNA can be inserted into the cell DNA.
* Activation of the immune system by infection with HIV elicits a massive response which holds the replicating virus in check for a significant time.
* Ten (10) billion HIV virions are produced and cleared each day by the immune system.
* Eventually, the immune system is overwhelmed and symptomatic disease develops.
* Transmission of HIV occurs with exposure to infected body fluids (blood, semen, vaginal fluids, breast milk).
* Currently, there are two (2) HIV viruses, and nine (9) Clades of HIV-1 worldwide, while HIV-2 is localized in West Africa.
* HIV disease progresses from asymptomatic to early symptomatic to advanced disease and is defined by CD4 T-cell counts, viral load, and presence of specific O.I.s.
* HIV/AIDS classification systems use CD4 counts, viral

loads, and specific O.I.s to determine stage of disease.

* Most common tests are to determine if antibodies to HIV are present.
* The "window period" refers to the time period after initial exposure and infection and before the presence of antibodies in the infected individual.
* O.I.s are conditions that develop as the immune system of an infected person deteriorates and the person progresses along the disease continuum.
* Co-infections refers to other infectious diseases which may impact HIV/AIDS progression.
* The diseases most often considered as potential co-infections are genital herpes, tuberculosis, hepatitis C, hepatitis B, and malaria.

Nursing Implications

Understanding the pathophysiology of HIV and how the immune system responds to the virus enhances the nurse's ability and self confidence to work with the patient and the patient's family in providing the appropriate care and treatment by maximizing the patient's coping abilities in responding to the disease, improving clinical outcomes, slowing disease progression, prolonging life, and enhancing his/her quality of life by:

- Integrating secondary prevention teaching into the care plan to protect the patient and others, not only from primary HIV infection, but also to prevent patient related infections (co-infections) that may exacerbate the patient's HIV status.
- Knowing the continuum of HIV disease allows the anticipatory planning to delay or slow deterioration by routine monitoring for signs and symptoms of additional immune system compromises and implementation of targeted interventions. Early recognition of co-infections, such as malaria and TB, and initiating prophylactic treatment decreases patient morbidity and aids in preventing transmission of TB to others.
- Educating the patient and the family about the disease, and how to manage the disease (side effects from medications, O.I.s symptoms, psychosocial issues, available resources, etc.) can significantly decrease anxiety and fear, encourage family care giving, support and enhance feelings of self-worth and empowerment, and validate the patient's dignity.

* Advocating in the care setting and in the community for acceptance and tolerance of people with HIV disease can decrease the fear, stigma, and isolation so often associated with the HIV/AIDS pandemic. Educating the community about the disease, encouraging tolerance and sympathy for individuals afflicted with HIV/AIDS, and seeking support for family care givers can increase community involvement in meeting the needs of infected and affected families, and strengthening the community's ability to cope with the devastation caused by AIDS to the social structure of the community.
* Role modeling for other health care personnel in providing empathetic and knowledgeable quality care for HIV infected patients and their families, as well as modeling the advocacy role in the community for both professional providers and community members.

Review Questions

1) Describe the specific cells and function of the immune system.
2) Discuss the virus (HIIV) and how it interacts with the immune system.
3) What activates the immune system to respond to HIV?
4) Explain the process of the virus' function to integrate into the human cell nucleus.
5) What is "fusion?". Explain the function.
6) Explain the function of the protease enzyme.
7) Identify the transmission routes of HIV.
8) What are clades?
9) Describe the stages of HIV disease progression.
10) What are the common HIV tests?
11) Describe the classification systems for case definition of HIV/AIDS.
12) What are O.I.s?
13) What are co-infections?

Case Studies

1) Rebecca is a 20 year old female who has been married for 3 years. She is 4 months pregnant and has 18 month old son. Rebecca lives in a rural village approximately 250 kilometers from the region's largest city. Rebecca's husband is 10 years older then Rebecca and works in the city. He stays in the city for months at a time, and only comes home a few times a year. Rebecca was sexually active with her husband before they were married. She presents at the primary care clinic today with a complaint of intermittent diarrhea for 2 months, white patches in her mouth, a productive cough of yellow sputum, and intermittent afternoon fever. Suspecting HIV infection, the clinic nurse counsels her about HIV and encourages testing (just recently available). Test results reveal that Rebecca is HIV+. CD4 counts and viral load testing are not available.

2) William is a 24 year old male living and working in the region's largest city. His family of parents and 7 younger siblings live about 150 kilometers from the city in his home village. William is not married and is helping to support his family, especially in sending his siblings to school. He has been sexually active since he was 16 years of age, and never uses condoms. He lives in a small two (2) room apartment with 2 other men. William has a 17 year old girl friend in his home village that he sees several times a year. He also has a girl friend in the city. He is sexually active with both women. His girl friend in the city sometimes earns extra money by selling sex. William has been treated for sexually transmitted infections STIs three times in the past two (2) years. He recently presented at the STD clinic with genital ulcerated lesions. He also has had a 8 kilogram weight loss in the past 6 months and some congestion in his
head. The clinic medical officer diagnoses the genital lesions as herpes, and encourages William, after counseling, to be tested for HIV. The test results are positive.

<u>Questions to Consider with Each Case Study</u>

1) What are the specific issues in each case study?
2) Using the WHO Staging System, what is the clinical stage of infection?
3) Would each case meet the criteria for AIDS using major and minor signs or symptoms?
4) What are the risk factors in each case?

5) What are the key issues that need to be addressed by the provider? (clinical as well as psychosocial)
6) What would be the appropriate interventions?
7) Assuming that ARV agents are available, what would be the appropriate clinical interventions?
8) What would be the recommendations for testing others?

Table 1. WHO Staging System for HIV Infection and Disease: Clinical Classification

Clinical Stage 1	
*	Asymptomatic
*	Persistent generalized lympadenopathy
*	Performance Scale 1: asymptomatic, normal activity
Clinical Stage 2	
*	Weight loss less than 10% of body weight
*	Minor mucocutaneous manifestations (i.e., sebhorreic dermatitis, fungal nail infections, recurrent oral ulcerations)
*	Herpes Zoster, within the last 5 years
*	Recurrent upper respiratory infections (i.e., bacterial sinusitis)
*	And/or performance scale 2: symptomatic, normal activity
Clinical Stage 3	
*	Weight loss greater than 10% of body weight
*	Unexplained chronic diarrhea for more than 1month
*	Unexplained prolonged fever for more than one (1) month
*	Oral candidiasis (thrush)
*	Oral hairy leukoplakia
*	Pulmonary tuberculosis
*	Severe bacterial infections (i.e., pneumonia)
*	And/or performance scale 3: bed-ridden less than 50% of the day during past month
Clinical Stage 4	
*	HIV wasting syndrome (weight loss greater than 10%, and unexplained chronic diarrhea for more than 1 month or chronic weakness or unexplained prolonged fever for more than 1 month)
*	Pneumocystis carinii pneumonia
*	Toxoplasmosis of the brain
*	Cryptosporidosis with diarrhea for more than 1month
*	Cryptococcosis extrapulmonary
*	Cytomegalovirus (CMV) disease of an organ other than liver, spleen, or lymph nodes
*	Herpes simplex (HSV) infection (mucocutaneous greater than 1 month)
*	Progressive multifocal leukonenphalopathy (PML)
*	Any disseminated mycosis (histoplasmosis)
*	Candidiasis of the esophagus, trachea, bronchi, or lungs
*	Atypical mycobacteriosis (disseminated)
*	Non-typhoid Salmonella septicemia
*	Extrapulmonary tuberculosis
*	Lymphoma
*	Kaposi's Sarcoma (KS)
*	HIV encephalopathy [clinical manifestations of disabling cognitive and/or motor dysfunction interfering with activities of daily living (ADL) progressive over time without a condition that explains the dysfunction)
*	And/or performance scale 4: bed-ridden more than 50% of the day during the past month

(Adapted from the Baylor University, HIV Nursing Curriculum (2001), Baylor College of Medicine: Houston.

Antiretroviral Treatment of HIV/AIDS

Overview

Total eradiation of HIV cannot currently be accomplished with antiretroviral (ARV) treatment due to the pool of infected latent (inactive) CD4 T cells. These cells were infected early during the acute phase of HIV infection and are known to have a very long half-life. The steady development of antiretroviral (ARV) medications used in multiple drug regimens to treat HIV disease has significantly slowed disease progression and prolonged lives, but this increase availability of numerous drugs and the variety of potential combinations of medications has contributed to the complexity of care that clinicians are providing. Appropriate follow-up and monitoring is essential to determining the correct drug regimen for the individual patient. Knowing when to initiate therapy or modify the regimen based upon sophisticated laboratory tests and clinical signs is part of the standard routine of care in the United States. Additionally, treating the opportunistic infections (O.I.s) frequently seen in HIV/AIDS disease may become more difficult due to the potential drug interactions of the ARV regimen and the prophylactic medications used to prevent O.I.s and/or treat acute onsets of O.I.s. The clinician's knowledge about the current standards of care and ARV treatment is critical to the welfare of the patient.

This module is designed to provide information about current ARV treatment, guidelines for using multiple ARV medications, the goals of therapy, considerations for therapy, side effects and interactions of ARV drugs, monitoring of regimens, and adverse clinical events associated with ARV. The module also includes a list of ARV medications. Key concepts, review questions, and case studies are included to facilitate learning. A short reference list is provided.

Objectives

Upon completion of the module, the learner will demonstrate increased knowledge of:

- ARV drugs and treatment regimens
- When to initiate or change drug therapy
- The side effects and drug interactions of HIV/AIDS medications
- Adverse effects associated with ARV
- Potential treatment regimens as described in case studies

Goals of Therapy

The goals of ARV therapy are:

- maximum suppression of HIV (viral load)
- sustainability of maintaining the suppression of the viral load over time
- restoration and/or improvement of the function of the immune system
- improvement of the patient's quality of life
- reduction in HIV-related morbidity and mortality

ARV drug treatment regimens of at least three (3) ARV medications from two (2) classifications of ARV are frequently designated as Highly Active Antiretroviral Treatment (HAART). Use of HAART regimens may produce a rise in CD4 cell counts and/or a significant suppression of virus (viral load) dependent upon a variety of factors. These factors include the stage of infection and/or disease progression in the individual, whether or not the patient had been on other ARV therapy prior to the initiation of HAART, the presence of resistant strains of the virus, the degree of immune destruction, the patient's unique response to HAART, and the degree of the patient's adherence to the HAART regimen.

Considerations For Therapy

Acute HIV Infection Syndrome Acute primary HIV infection syndrome is estimated to occur in patients 50-90% of the time. Acute infection has been identified as the time of seroconversion in a newly HIV infected person. That is, after infection with HIV, an individual's laboratory tests would show antibodies to HIV and a high viral load [approximately three (3) weeks to three (3) months – usually less than 3 months]. The associated signs and symptoms of Acute HIV Infection Syndrome can be missed and not diagnosed because the signs and symptoms are similar to the signs and symptoms of the flu syndrome. These signs and symptoms are:

- fever (96%)
- lymphadenopathy (74%)
- pharyngitis (70%)
- rash (70%)
- myalgia or arthralgia (54%)
- diarrhea (32%)
- headache (32%)
- nausea and vomiting (27%)
- hepatosplenomegaly 14%)
- weight loss (13%)
- thrush (12%)
- neurologic symptoms (12%)

Some studies suggest that ARV treatment at this time could be beneficial as demonstrated in laboratory disease markers and clinical outcomes. The questions about the duration of ARV therapy for primary infection have yet to be answered. It is assumed that ongoing clinical trials will answer these questions in the future.
(Discussion of Acute HIV Infection signs and symptoms can be reviewed in the Treatment Guidelines, including Table 22. Acute Retroviral Syndrome). http://www.hiv/atis.org/

Post Exposure Prophylaxis (PEP) for Occupational Exposures
The Centers for Disease Control and Prevention within the Public Health System of the United States, has been disseminating recommendations and updated guidelines on the prevention of occupational exposures to bloodborne pathogens since the early 1980's. The latest updated guidelines were released on June 29, 2001. The guidelines provide appropriate intervention information and recommendations for the management of occupational exposures to Hepatitis B (HBV), Hepatitis C (HCV), and HIV. Of course, avoidance of occupational exposures is the primary way to prevent exposures, but accidents do happen in the best of practices.

For exposure to HBV, the recommendations include HBV vaccine series for the unvaccinated provider and postexposure prophylaxis (PEP) with HBV immune globulin after determination of HBV surface antigen of the source patient and the vaccine-response of the exposed provider. Immune globulin and ARV agents are not recommended for providers exposed to HCV. The recommendations for HIV PEP include a basic four (4) week regimen of two (2) drugs: zidovudine (ZDU, AZT) and lamivudine (3TC); or 3TC and stavudine (d4T); or didanosine (ddI) and d4T. The PEP regimen is expanded to three (3) drugs if the exposure poses a greater risk of transmission. If the source patient's virus is resistant to some of the above medications, the choice of ARV drugs will probably differ from those previously recommended.

It is vital that exposures to bloodborne pathogens be promptly reported and assessment made as to the extent of the injury and specificity of the exposure so that appropriate interventions may be initiated.
(A more comprehensive discussion of occupational exposures can be found in the Updated U.S. Public Health Service Guidelines for the Management of Occupational Exposures to HBV, HCV, and HIV and Recommendations for Postexposure

Prophylaxis, Morbidity and Mortality Weekly Report
http://www.cdc.gov/hiv/pubs/mmwr.htm

Management of Nonoccupational Exposure to HIV Several years ago some health care providers proposed offering ARV drugs to unanticipated nonoccupational exposures to bloodborne pathogens to prevent transmission. However, no data existed to determine efficacy. CDC developed guidelines for the procedures, but considered the procedures an unproven clinical intervention. **(The guidelines for nonoccupational exposures, Management of Possible Sexual, Injecting-Drug-Use, or Other Nonoccupational Exposure to HIV, Including Considerations Related to Antiretroviral Therapy, September 25, 1998 can be viewed on the web: http://www.hivatis.**

Patients with Asymptomatic HIV Infection The optimal time to initiate ARV therapy is not known. Although there is a theoretical benefit of ARV for patients with CD4 T cell counts greater than 200, no research studies have been done that demonstrate immediate versus delayed use of ARV therapy in these patients. A major problem is that the ARV/HAART regimens currently available are complex, associated with some significant side effects and/or interactions, and pose difficulties with adherence to the regimens. There are several risks to delaying therapy also; such as, irreversible damage to the immune system and difficulty later on in attempting to suppress viral replication.

Currently, there is increased recognition of the risks associated with initiation of ARV therapy and clinicians are using a more conservative approach to treatment. Generally speaking, patients with less than 350 CD4 T cells should be offered ARV therapy. Disease progression in this category is related to blood levels of HIV RNA. In patients with levels below 20,000 copies, the risk for progression is low (See the DHHS Guidelines for a more extensive discussion). Other factors, such as drug toxicity and problems with regimen adherence, needs to be considered in asymptomatic patients.

Initiating Therapy

Therapy in the Asymptomatic Patient The regimen chosen for the patient that is ARV naïve (hasn't been on ARV therapy) should be one that produces the greatest sustained viral suppression with positive clinical outcomes. Consideration should be given to the factors of the regimen, such as number of pills, the ease of taking pills, the symptomatology caused by side effects and drug interactions, and the patient's readiness to follow a drug regimen.

Guidelines for Starting ARV Therapy The Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents was developed and disseminated by the Department of Health and Human Services (DHHS). A panel of experts in HIV/AIDS care and treatment is convened on a regular basis to review and update the guidelines that were initially published several years ago. These guidelines are used by clinicians to guide their practice in providing ARV treatment and care (available at www.hivatis.org).

Current Guidelines for Offering Therapy are:

- All patients with the acute HIV syndrome
- Patients within six (6) months of HIV seroconversion
- All patients with symptoms ascribed to HIV infection
- In general, treatment should be offered to asymptomatic patients with fewer than 350 CD4 cells or plasma HIV RNA levels exceeding 30,000 copies/ml (bDNA) or 55,000 copies/ml (RT-PCR assay)

The measurement of virus (viral load) is done by measuring the level of HIV RNA using one of two (2) laboratory tests (bDNA or RT-PCR assay).

Current ARV Medications There are currently three (3) classifications of licensed ARV medications being used for treatment of HIV/AIDS disease. The nucleoside analog drugs and the non-nucleoside analog drugs interfere with HIV's reverse transcriptase enzyme and the protease drugs interfere with the virus' protease enzyme.

Reverse Transcriptase Inhibitors (RTIs):

Nucleoside Analogs (NRITs "nukes")

zidovudine	(ZDV,AZT)	(Retrovir)
didanosine	(ddI)	(Videx)
zalcitabine	(ddC)	(Hivid)
lamivudine	(3TC)	(Epivir)
stavudine	(d4T)	(Zerit)
abacavir	(ABC)	(Ziagen)
Combivir	(ZDV + 3TC)	
Trizivir	(AZT + 3TC + abacavir)	

Nucleotide Reverse Transcriptase

tenofovir DF

Reverse Transcriptase Inhibitors (RTIs)

Non-Nucleoside Analogs (NNRTIs, "non-nukes")

delavirdine	(Rescriptor)
nevirapine	(Viramune)
efavirenz	(Sustiva)

Protease Inhibitors (PIs)

saquinavir	(Fortavase)
indinavir	(Crixivan)
ritonavir	(Norvir)
nelfinavir	(Viracept)
amprenavir	(Agenerase)
lopinavir/ritonavir	(Kaletra)

(See Table 1. at the end of this module to review the recommended ARV regimens. Recommendations can also be reviewed in the DHHS, Guidelines for Use of ARV Agents in HIV-Infected Adults and Adolescents. See also WHO Initiative on HIV/AIDS and Sexually Transmitted Infections, Use of Antiretroviral Treatment in Adults).

Initiating Therapy in Advanced HIV Disease According to the Treatment Guidelines, all patients with advanced disease (AIDS) should be treated with ARV regimens regardless of viral load levels. The presence of symptomatic disease and/or O.I.s requires aggressive drug treatment. Patients symptomatic without an AIDS diagnosis should also be treated with ARV regimens. Patients with advanced disease are often treated with very complicated regimens of both ARV agents and medications used for treatment of O.I.s. Concern about potential drug interactions and side effects must be a major focus of the provider. The provider should also be aware of any over the counter drugs, vitamins, and other remedies, such as herbal preparations, that a patient may be using. Drug interactions and side effects can be a major problem. The ARV medications are quite toxic and care must be taken to ensure that treatment is appropriate and effective.

(See Table 2. at the end of this module to review each ARV medication, dosages, side effects, drug interactions, and special instructions)

Changing Therapy

Considerations for Changing Therapy Several factors must be carefully considered if a provider is thinking about changing a patient's ARV drug regimen. The DHHS Guidelines emphasize that these factors are complex and must be evaluated holistically. These factors include recent clinical history and examination; plasma HIV RNA levels (viral load); CD4 T cell counts and changes in the counts; assessment of patient's adherence to the current ARV regimen; what other treatment options are feasible; prior history of resistance to ARV agents; and the impact of a new

and different ARV drug regimen upon the patient, both emotionally and physically.

There are several reasons that regimen failure occurs, including the presence of resistant virus, altered metabolism or altered absorption of the ARV drug, patient problems with adhering to the regimen, interactions of other medications interfering with maintenance of appropriate therapeutic blood levels of the ARV drugs, and toxicity from the drug. Correct assessment of the reasons for ARV treatment failure is vital to resolving the failure issue.

The **Criteria for Changing Therapy**, based upon laboratory findings and clinical deterioration is defined in the **Treatment Guidelines (pages 24-25)** and the **Therapeutic Options When Changing Antiretroviral Therapy (pages 25-26)** are outlined in **Table 21 of the Guidelines.**
(A copy of the Guidelines can be located on the web. Also review the WHO Treatment Guidelines can be located on the web).

Resistance Drug resistance commonly occurs in the presence of living organisms. We have seen this process with antibiotics over the prior several decades. Viruses, as evolving organisms, demonstrate the same mechanisms. Retroviruses, like HIV, have a very rapid turnover, are produced in exceedingly large numbers, and undergo nucleic acid replication by processes that are prone to mutations. When these mutations occur in the presence of less than optimal levels of the ARV medications, resistant strains of the virus emerge and the wild type of virus is suppressed. Careful and consistent adherence to an effective ARV regimen can decrease viral replication and thereby, minimize the occurrence of resistant strains of the virus.

Genotype and Phenotype Resistance is monitored by several parameters: 1) viral load, with the onset of rising viral loads, resistant strains must be considered particularly if the viral load has been undetectable or low and the levels have previously been stable; 2) laboratory tests which measure the virus **genotype and phenotype**. **Genotype** refers to the genetic makeup of the HIV strain. The genes of the virus are examined and the actual DNA sequences are studied. Mutations are identified along the genetic chains of nucleotides. Certain mutations are associated with resistance to specific medications. **Phenotype** refers to the action of HIV in the presence of a particular ARV drug. Phenotypic resistance is when one or more mutations decrease sensitivity of

HIV to a specific drug. **Cross-resistance** occurs when the viral mutation causes resistance to more than one drug. **Cross-resistance** routinely develops within classifications of ARV medications.

Monitoring for ARV Resistance According to the World Health Organization (WHO) monitoring for drug resistance is rarely undertaken in low and middle-income countries. Laboratory monitoring is largely dependent upon financial resources. Although the technology is too costly for many countries, it is acknowledged that surveillance for ARV drug resistance is essential to minimizing the development of resistant strains of HIV. There are several examples of low-income countries finding innovative methods for getting laboratory studies done. Uganda treatment centers, accredited to the UNAIDS HIV Drug Access Initiative, have been able to have the testing done through the collaboration and aid of a donor funded research laboratory. The Ivory Coast and Senegal have also developed collaborative relationships with international laboratories to monitor for ARV drug resistance. It is important that national leadership within low-income and middle-income countries be committed to addressing the HIV/AIDS pandemic and in so doing, explore innovative ways of striking a balance between resource limitations and good public health practice.

(For a more comprehensive discussion of the issues of ARV treatment in resource limited settings, review WHO Initiative on HIV/AIDS and Sexually Transmitted Infections, Safe and Effective Use of Antiretroviral Treatments in Adults with Particular Reference to Resource Limited Settings. A copy can be found on the web, http://www.who.org).

Interruption Of Therapy

According to the Treatment Guidelines, there are multiple reasons for temporarily or permanently discontinuing ARV treatment. Providers and patients should be aware of the theoretical need to stop all ARV medications at the same time rather than continuing to take one or two drugs, in order to minimize the emergence of resistant strains of HIV.

There has been some interest in what has been labeled as **Structured or Supervised Treatment Interruption (STI) or Structured Intermittent Therapy (SIT).** The rationale underlying STI (SIT) is that stopping ARV therapy will allow the re-emergence of HIV that is susceptible to ARV treatment. STI (SIT) can also give a patient a rest from the daily pill burden. STI (SIT) is usually done for very short periods of time (one-two

weeks). Studies have shown a decrease in CD4 T cells and an increase in viral load indicating a probable increase in wild type virus, which may be susceptible to ARV therapy, but resistant strains of HIV persisted in CD4 T cells. At a recent meeting of a panel of 50 experts on HIV/AIDS treatment and care, a report on studies of STI (SIT) concluded that the approach does not work and that people have gotten sick again. Currently, the Treatment Guidelines are not recommending STI (SIT).

ARV (HAART)-Associated Adverse Clinical Events

Lactic Acidosis/Hepatic Steatosis According to the Treatment Guidelines, occurrence of this condition during use of NRTIs is rare but has a high fatality rate. Lactic acidosis is an increase in acidity of the blood due to the accumulation of lactic acid that is produced when there is inadequate oxygenation of the blood. Risk factors appear to be female gender, obesity, and prolonged use of NRTIs. Clinical signs are variable and may be nonspecific (fatigue, abdominal pain, vomiting, hepatitis, and weight loss). Sometimes the condition is resolved with stopping the NRTIs; and some patients have tolerated the re-challenge with NRTIs, but the data is insufficient at this time. Current recommendation is to discontinue ARV treatment if clinical signs and laboratory evidence demonstrate occurrence of this condition.

Hyperglycemia/Diabetes Mellitus Exacerbation of pre-existing diabetes or new onset of diabetes has been reported in patients receiving HAART. According to the Treatment Guidelines, this condition is strongly associated with the use of PIs. The pathogenesis of the condition is unknown, but dysfunction of the beta cells of the pancreas (insulin synthesis) and peripheral insulin resistance appear to be involved in the hyperglycemia. The condition seems to emerge about 60 days after initiation of treatment. Some expert clinicians recommend that routine fasting blood glucose levels be drawn every 3-4 months for the first year of ARV therapy with PIs. Most experts recommend that the ARV therapy be continued unless severe diabetes worsens.

Fat Maldistribution Fat maldistribution is sometimes called "lipodystrophy syndrome" or "pseudo-Cushing's syndrome" and has been documented in 6-80% of patients on an HAART regimen. This condition occurs gradually over several months. Currently, there is no case definition of the condition and other variables are poorly understood which probably accounts for the wide variation in identifying the condition. Fat accumulation occurs centrally and may also appear on the back of the neck like a "buffalo hump." In some patients hyperlipidemia and insulin resistance occur frequently in conjunction with the fat maldistribution.

Lipodystrophy seems to be associated with the use of PIs, but has also been observed in patients on NRTI therapy. Some clinicians may choose to change ARV drugs, but there are insufficient data to support any specific intervention for this condition.

Hyperlipidemia Hyperlipidemia (increases cholesterol and/or triglycerides) is another condition observed within a short time (one month) after the initiation of HAART. Studies have found that all PIs are involved, but there are greater increases with the use of ritonavir. The mechanism triggering this condition is not yet known. So far, controlled studies have not found a corresponding increase in cardiovascular problems, but ongoing studies are needed to accurately assess for cardiac events. So far, the studies are not clear as to the use of cholesterol lowering medications. For some patients, after discontinuation of PIs, the condition has resolved.

There are three (3) other conditions related to the use of ARV (HAART) treatment regimens. These are **Increased Bleeding Episodes in Patients with Hemophilia, Osteopenia and Osteoporosis, and Rash.** Again the use of PIs were involved with the bleeding episodes and osteopenia and osteoporosis. Rash is fairly common during the use of NNRTIs.
(For further discussion, review the Treatment Guidelines A copy can be located on the web).

Considerations For Therapy in Women

Pregnant Women Considerations for ARV therapy in pregnant women are based upon the concept that therapies that benefit women should not be withheld during pregnancy unless the adverse outcomes may outweigh the positive benefits to the woman.

(For a comprehensive discussion of the protocols for ARV treatment in pregnant women, see:

- **Public Health Service Task Force Recommendations For the Use of Antiretroviral Drugs in Pregnant HIV-1 Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV-1 Transmission in the United States. It can be downloaded from web at: http://www.hivatis.org/tglns.html**

- **Review Guidelines for ARV Treatment and Breast Feeding on the WHO web site: http://www.who.org**

- **Read the ICN/WHO/UNAIDS Fact Sheet #10. Women and HIV and mother-to-child transmission Located on the web at: http://www.who.org**

ARV Therapy in Women There are data from some studies that suggest there is a difference between men and women as to viral and immunologic parameters. Further study is essential regarding these differences. The Treatment Guidelines proposed that these differences are hormonally based and there is some evidence to support that proposal, but additional studies are certainly warranted. There also appears to be some evidence that pharmacokinetic parameters may vary over the ovulatory cycle.

(For comprehensive discussion on clinical care for women, see A Guide to the Clinical Care of Women with HIV, edited by Jean Anderson, MD and published by United States Department of Health and Human Services (USDHHS), Health Resources and Services Administration (HRSA), HIV/AIDS Bureau HAB). A copy can also be located on the web at: http://www.hab.hrsa.gov/

Pediatric ARV Treatment

The USDHHS released comprehensive Treatment Guidelines for ARV regimens in children. Discussion of pediatric therapy is beyond the scope of this curriculum. The guidelines were developed by a large panel of experts in Pediatric HIV/AIDS and addresses the specific issues of infants and children. The guidelines are routinely reviewed and updated.

(A copy of the Pediatric Guidelines can be found on the web. The title of the guidelines is: Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection, August 8, 2001.The web address is: http://www.hivatis/tglns.html

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Key Concepts

* ARV therapy does not totally eliminate HIV in the body.
* ARV therapy does delay disease progression and prolong lives.
* ARV regimens are significantly complex with numerous potential combinations.
* It is essential that with ARV regimens there be regular follow- up and monitoring, including clinical assessment and laboratory tests.
* ARV agents have the potential to be toxic.
* Multiple medications increases the potential for drug interactions.
* Treating O.I.s, in addition to ARV therapy, increases the complexity of treatment.
* The increase complexity of treatment and care requires increased knowledge and expertise of the provider.
* Recommendation for an ARV (HAART) regimen is at least three (3) drugs from two (2) classifications of ARV.
* Acute HIV Infection Syndrome occurs in 50-90% of HIV infected people.
* Seroconversion (antibodies present in the serum) usually occurs within three (3) weeks to three (3) months (usually less then three (3) months).
* Signs and symptoms of the Acute HIV Infection Syndrome are "flu like."
* ARV therapy for occupational exposures is two (2) drugs, which is expanded to three (3) drugs if there is a higher risk of transmission.
* Criteria for <u>offering ARV therapy</u> is: CD4 T cell count of less than 350 and a viral load of greater than 20,000 copies.
* Criteria for <u>starting ARV therapy</u> is: acute HIV infection; seroconversion within the past six (6) months; symptoms of HIV disease; CD4 T cell count less than 350; and a viral load greater than 30,000 copies.
* There are three (3) classifications of ARV: NRTIs, NNRTIs, and PIs.
* In advanced HIV disease (AIDS) ARV therapy is given to all patients (if possible).
* Changing ARV therapy requires careful monitoring of both clinical and laboratory findings.
* Genotype of HIV is the actual genetic structure of the virus.
* Phenotype refers to the action of HIV in the presence of a specific ARV drug.
* Resistance can develop if ARV drug levels are less than optimal.
* STI/SIT is not recommended at this time as a therapeutic intervention.

* Adverse effects associated with HAART therapy are: lactic acidosis/hepatic steatosis; hyperglycemia/diabetes mellitus; fat maldistribution; hyperlipidemia; excessive bleeding in hemophiliacs; osteopenia/osteoporosis; rash.
* There are some preliminary findings that there are sex –based differences in responses to ARV therapy, but additional research is necessary.

Nursing Implications

Nurses have unique opportunities, as well as challenges, to not only provide care for individual patients, but to impact the systems in which care is given in order to ensure the delivery of the best health care possible. As ARV drugs become more widely available in low and middle-income countries, it is critical that health care systems be reviewed and evaluated to facilitate the successful implementation of an ARV Treatment Program. In order to establish a successful program, the ICN, WHO and UNAIDS are recommending that there are minimum requirements that need to be in place for an ARV therapy to succeed. These components include:

- the availability of inexpensive, reliable diagnostic tests,
- mechanisms for voluntary and confidential counseling and testing,
- long term, consistent supply of quality medications,
- laboratory facilities to monitor essential testing (CD4, viral load),
- capacity to diagnose and treat OIs,
- Access to affordable health care services,
- Social services systems/networks to support patients and families,
- Appropriate training for health care providers to ensure safe and effective ARV therapy.

Nurses, as part of the community's health care system, are uniquely positioned to evaluate current conditions and recommend and advocate changes to medical officers and ministries of health to implement modifications that will facilitate successful primary care and ARV treatment initiatives.

(For more discussion on strategies for implementing ARV treatment programs in limited resource settings, review WHO/UNAIDS/IAS documents and ICN/WHO/UNAIDS, Fact Sheets for Nurses located in Appendix E).

Nursing implications for providing care and support to individual patients starting ARV therapy will be discussed in the **Adherence Module**.

Review Questions

1) Identify the classification of ARV therapy medications and describe the actions of each classification.
2) List the criteria for offering ARV treatment to asymptomatic HIV infected persons.
3) List the criteria for initiating therapy in symptomatic HIV infected people.
4) Define Acute HIV Infection Syndrome and list the signs and symptoms of the syndrome.
5) Define the criteria for changing ARV therapy.
6) Define resistance, genotype, and phenotype. How are they measured?
7) What is the rationale for treating occupational exposures? And what is the recommended treatment?
8) What are four major adverse effects of HAART therapy? Describe them.
9) Explain sex-based differences in responses to ARV medications..
10) Identify the reasons for treatment failure.

Case Studies

1) Naomi is a 17 year old girl who came into the local community clinic two weeks ago with complaints of vaginal itching and pain, irregular periods, and occasional vaginal discharge. Naomi lives at home in the village and is a teacher's helper in the local school. She is sexually active with a man 10 years her senior who is a truck driver hauling produce into a neighboring city. They rarely use condoms. After appropriate counseling, a HIV test was done. Test results reveal that Naomi is HIV positive. Additional laboratory tests are drawn after discussion with the social services worker. Naomi returns in a week and is told that her viral load test is 40,000 copies of HIB-RNA and her CD4 T cell count is 350. Test results are explained and treatment options are discussed with her.

2) Jonathan is a 26 year old man who works in construction in the city. He is married and has 4 children. His wife and children live in his home village, which is several hundred kilometers from the city. He lives in the city sharing two rooms with 3 other men. Jonathan goes home to his village several times a year at planting time and for holidays. He is sexually active with his wife and he also has a some time girl friend in the city. He doesn't use condoms with either woman. He comes into the local clinic near the city hospital with complaints of weight loss, fatigue, a dry cough, aches in his arm pits and swelling in

his groin.. After counseling, he agreed to an HIV test. Test results are: HIV positive, CD4 T cell count is 198 and is viral load is 90,000. Treatment options are discussed.

Questions to Consider:

1) Identify the stage of infection in each case study.
2) What would be the treatment options for each person?
3) What would be some of the major counseling concepts in each case study?
4) What would be some of the psychosocial problems in each case study?
5) Who else needs to be tested?

Table 1. Recommended ARV for Initial Treatment of Established HIV Infection

(Antiretroviral drug regimens are comprised of one choice each from Columns A and B. Drugs are listed in alphabetical, not priority, order).

Strongly Recommended

Column A	**Column B**
Efavirenz	Didanosine + Lamivudine
Indinavir	Stavudine + Didanosine
Nelfinavir	Stavudine + Lamivudine
Ritonavir + Indinavir	Zidovudine + Didanosine
Ritonavir + Lopinavir	Zidovudine + Lamivudine
Ritonavir + Saquinavir (SGC or HGC)	

Recommended as Alternatives

Column A	**Column B**
Abacavir	Zidovudine + Zalcitabine
Amprenavir	
Delavirdine	
Nelfinavir + Saquinavir (SGC)	
Nevirapine	
Ritonavir	
Saquinavir (SGC)	

No Recommendation: Insufficient Data

Hydroxyurea in combination with ARV drugs
Ritonavir + Amprenavir
Ritonavir + Nelfinavir
Tenofovir

Not Recommended: Should Not Be Offered

All monotherapies, whether from Column A or B

Column A	**Column B**
Saquinavir-HGC	Stavudine + Zidovudine
	Zalcitabine + Didanosine
	Zalcitabine + Lamivudine
	Zalcitabine + Stavudine

DHHS. Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents. February 4, 2002.

(see next page for additional information on ARV drugs)

Table I. Recommended ARV for Initial Treatment of Established HIV l Infection.
(Table 12. Recommended Antiretroviral Agents for Initial Treatment of Established HIV Infection, page 43. DHHS. Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents. February 4, 2002 available on www.hivatis.org)

This table provides recommendations for ARV treatment regimens for individuals with no prior or limited experience on HIV therapy.

In accordance with the established goals of therapy, priority is given to regimens in which clinical trials data suggest the following:

- sustained suppression of HIV plasma RNA (particularly in patients with high baseline viral loads)
- sustained increase in CD4 T cell counts (in most cases over 48 weeks)
- favorable clinical outcomes (delayed disease progression to AIDS and death).

Particular emphasis is given to regimens that have been compared directly with other regimens that perform sufficiently well with regard to these parameters to be included in the "Strongly Recommended" category.

It is important to note that all antiretroviral agents, including those in "Strongly Recommended" category, have potentially serious toxic and adverse events associated with their use.

Ritonavir, as a sole PI, is considered an alternative agent because many patients have difficulty tolerating the standard doses; but the use of this drug to increase plasma concentrations of other PIs is rapidly becoming a widespread practice. (Treatment Guidelines, August 13, 2001.).

See the available guidelines for more comprehensive information about the appropriateness of different ARV regimens.

Table 2. Antiretroviral Medications

NUCLEOSIDE REVERSE TRANSCRIPTASE INHIBITORS (NRTIs)

Drug Name	Dosage	Side Effects	Drug Interactions
Zidovudine (ZDV, AZT) (Retrovir)	300 mg bid	Bone marrow suppression (anemia, neutropenia) G.I. intolerance insomnia, headaches	additive/synergistic with ddI, ddC, alpha interferon

Special Instructions: See health care provider regularly. Some side effects (bone suppression) can only be detected with blood tests

Didanosine (ddI) (Videx)	200 mg bid (wt>60kg) 100 mg bid (wt<60kg) 400mg qd	neuropathy, pancreatitis G.I. intolerance, diarrhea hepatitis	other drugs that cause neuropathy avoid alcohol methadone decreases levels of ddI by 41%

Special Instructions: (Take ½ hour before meal or 2 hours after meal)
Drugs that require gastric acidity for absorption give 2 hrs before or 2 hrs after (dapsone, indinavir, ritonavir, delavirdine, ketoconazole, tetracyclines fluoroquinolones)

Zalcitabine (ddC) (HIVID)	0.75 mg tid	peripheral neuropathy stomatitis, esophageal ulcers pancreatitis	avoid: ddI, ethambutol, disulfiram, ethionamide, INH, phenytoin

Special Instructions: Avoid alcohol and caffeine

Stavudine (d4T) (Zerit)	40 mg bid (>60 kg) 30 mg bid (<60 kg)	peripheral neuropathy G.I. intolerance, diarrhea	ddI and ddC (overlapping toxicity) methadone decreases D4T by 41%

Special Instructions: Avoid alcohol & caffeine – may increase risk for pancreatitis

Lamivudine (3TC) (Epivir)	150 mg bid	minimal toxicity, infrequent G.I. problems	TMP-SMX (1DS daily) increases levels of 3TC, no adjustment necessary
(Combivir) (1 tablet bid)	ZDV + 3TC	anemia, neutropenia	

Special Instructions: None

Abacavir (ABC) (Ziagen)	300 mg bid	nausea, vomiting hypersensitivity reaction (can be fatal – rash, fever, flue-like symptoms)	

Special Instructions: Monitor closely for hypersensitivity reaction especially the first month
Avoid alcohol – may increase ABC levels

Table 2. **Antiretroviral Medications**

NUCLEOSIDE REVERSE TRANSCRIPTASE INHIBITORS (NRTIs) continued

Drug Name	Dosage	Side Effects	Drug Interactions
Trizivir (AZT + 3TC + abacavir)	1 tablet q 12 h combination tablet (300 mg AZT, 150 mg 3TC, & 300 abacavir)	(see individual agents)	(see individual agents)

NUCLEOTIDE REVERSE TRANSCRIPTASE INHIBITOR

Tenofovir (Viread)	300 mg qd	nausea, vomiting

Special Instructions: Take after a meal.

Table 2. **Antiretoviral Medications**

NON-NUCLEOSIDE REVERSE TRANSCRIPTASE INHIBITORS (NNRTIs)

Drug Name	Dosage	Side Effects	Drug Interaction
Nevirapine (NVP) (Viramune)	200 mg qd X 14 days, then 200 mg bid	skin rash, headaches abnormal LFTs	ketoconazole, Rifampin, (not recommended) Rifabutin, Clarithromycin (no dose adjustment)
Special Instructions: Report any skin rashes to health care provider			
Delavirdine DLV) (Rescriptor)	400 mg tid	allergic reactions are common (rash)	**not use concurrently:** Terfenadine (Seldane), phenobarbitol, carbamazepine, phenytoin, amphetamines, rifampin, rifabutin, nifedipine, ergot derivatives, astemizole, cisapride, midazolam, triazolam, alprazolam. **Potential toxicity:** Clarithromycin, dapsone, Quinidine, wafarin
Special Instructions: report rash			
Efavirenz (EFV) (Sustiva)	600 mg qhs	dizziness trouble sleeping vivid dreams nightmares rash	Rifampin (no dose adjust.) Rifabutin (increase dose of Rifabutin) Clarithromycin (use alternative)
Special Instructions: Avoid taking with high fat foods. Report any skin rashes to provider.			

Table 2. Antiretroviral Medications

PROTEASE INHIBITORS (PIs)

Drug Name	Dosage	Side Effects	Drug Interactions
Indinavir (IDV) (Crixivan) Special Instructions: 1) Take one (1) hr before eating or two (2) hours after eating or a meal. 2) Drink six (6) large glasses of water every day. 3) If taken with **Ritonavir** can take with food. 4) Separate dosing with **ddI** by two (2) hours.	800 mg q8hr	G.I. intolerance (diarrhea, N/V, pain,), kidney stones hyperglycemia, lipid abnormalities,	with NNRTIs, **Don't give concurrently:** Rifampin, astemizole, cisapride, ergot alkaloids, midazolam, terfenadine, triazolam **Reduce dose:** Rifabutin & increase indinavir
Saquinavir (Hard gel capsule) (SQV) (Invirase) **Special Instructions:** Invirase not recommended without Ritonavir	400 mg bid with **Ritonavir**	G.I. intolerances, N/V, diarrhea, headache, hyperglycemia, lipid abnormalities, fat maldistribution,	**Contraindicated with:** Rifampin (unless using Ritonavir) rifabutin, clarithromycin, anticonvulsants
Saquinavir (Soft gel capsule) (Fortovase)	1200 mg tid 400 mg bid **Special Instructions**: Take with large meal	(see above)	(see above)
Ritonavir (RTV) (Norvir) **Special Instructions:** 1) Take with food. 2) Separate dosing with **ddI** by 2 hours. 3) Refrigerate capsules. 4) Do NOT refrigerate oral solution. 5) G.I. intolerances may be severe. 6) Being used to "boost" levels of other ARV drugs.	600 mg q 12 hours	G.I. problems (N/V, diarrhea) hepatitis, pancreatitis, weakness, tingling & numbness, change in taste, hyperglycemia, lipid abnormalities,	**Contraindicated with**: amiodarone, astemizole, cisapride, clorazepate, clozapine, diazepam, encainide, estrazolam, flurazepam, flecainide, meperidine, midazolam, propoxyphene, quinidine, rifabutin, terfenadine, triazolam, zolpidem.
Nelfinavir (NFV) (Viracept) **Special Instructions**: Take with meal or snacks	750 mg tid or 1250 mg bid	diarrhea hyperglycemia, fat abnormalities	**Contraindicated with**: rifampin, ergot alkaloids, cisapride, astemizole, midazolam, triazolam, St. John's Wort

Table 2. **Antiretroviral Medications**

PROTEASE INHIBITORS (PIs) continued:

Drug Name	Dosage	Side Effects	Drug Interactions
Amprenavir (APV) (Agenerase)	>50 kg: 1200 mg (capsules) >50 kg: 1400 mg (oral solution) <50 kg: 20 mg/kg bid (capsules) max. 2400 mg/daily <50 kg.1.5 mg/kg bid (oral solution) max. 2800 mg/daily	G.I. intolerances (N/V, diarrhea, oral paresthesias increase in LFTs fat maldistribution hyperglycemia	rifampin (avoid concomitant use) increases rifabutin levels (lower rifabutin dose)

Special Instructions:
Can take with food, but avoid high fat foods

Lopinavir + Ritonavir (LPV) (Kaletra)	400 mg lopinavir + 100 mg ritonavir bid	G.I. intolerances (N/V, diarrhea) hyperglycemia lipid abnormalities fat maldistribution	rifampin (avoid concomitant use) lower rifabutin dose (see above) oral contraceptives

Special Instructions:

1) Take with food (moderate fat content)
2) Refrigerated capsules stable until date on label.
3) If stored at room temperature, stable for 2 months.

Adherence to Antiretroviral Treatment Regimens

Overview

The evolution of ARV/HAART drug treatments for HIV/AIDS has brought to the forefront of clinical practice concerns about the issues of adherence (compliance) to the prescribed regimens. Adherence to prescribed therapeutic medications has always created some problems for both the patient and the provider, but it hasn't been an area of practice that has received much attention. But with the advent of ARV/HAART therapy that has changed. Significant concerns about the potential for emerging drug resistance when therapy is unintentionally incomplete have been triggered due to the complexity of the prescribed regimens (pill burden, frequency of dosage routines) and the severe toxic side effects of the ARV agents as factors that can interfere with a patient's desire or ability to adhere to the regimen. Extensive research has been done during the past few years in an attempt to understand and identify the critical factors that influence adherence. Pharmaceutical companies have also spent significant resources to evaluate the issues impacting adherence to prescribed medications. It is an essential skill that health care providers become proficient in the issues of adherence also. Adherence strategies are as vital to an ARV Treatment Program as the prescribing and/or dispensing of ARV therapeutic medications.

This module is designed to provide information about adherence issues and strategies that providers can use to facilitate positive outcomes for patients on ARV therapy. Key concepts, review concepts, and case studies are included to facilitate learning. References are also provided.

Objectives

Upon completion of the training on this module, the learner will demonstrate increased knowledge of:

* factors that impact a patient's adherence to ARV drugs
* strategies to support patient adherence behaviors
* assessment, planning, and evaluation skills to monitor adherence behaviors

Definition of Adherence

Several decades ago, the term for following physician's orders was compliance. The word implies a passive patient role without any input into the decision making process. The assumption was that the physician knew best and the patient's responsibility was to follow the physician's orders. With the advent of HIV/AIDS, we have seen a more shared decision- making process develop. In the United States, we saw this process begin early in the epidemic.

HIV/AIDS was a new disease and no one, including health care providers, had the answers to what constituted the right way (the correct practices) to treat patients with this disease. It was not unusual to find that some patients were as knowledgeable about what was known about HIV as their provider. In fact, some patients sometimes knew more than their provider. In this type of climate, the evolution of the patient-provider relationship changed. Currently, many physicians, and other providers, encourage and support a more equitable partnership with a shared decision-making process. With the changing environment the term used to describe the process changed from compliance to adherence. A working definition of adherence developed by the authors of a national adherence curriculum (with input from other nursing research experts in adherence) incorporates the shared decision making process concept into its definition. The term adherence also refers to more than just taking medications, and encompasses the total health care plan, including appointments, laboratory work, nutrition, etc.; in other words, all decisions made about the patient's care and treatment.

Findings from Studies

The significance of adherence to ARV therapy became very apparent with the development and availability of protease inhibitors (PIs) in 1995-96 that significantly added to the complexity of the ARV regimens. During the International AIDS Conference in Vancouver, Canada, in 1996, use of PIs was the major topic of discussion, but soon after the conference the issue of adherence became a major focus of concern stimulating research of adherence issues and establishment of numerous multi-disciplinary discussion groups to explore the issues of adherence.

It soon became obvious that adherence had always been a problem even before the use of PIs became part of the ARV regimens. Additionally when reviewing the literature before the onset of the HIV/AIDS pandemic, "pill taking" and compliance were significant issues. Research on taking antibiotics demonstrated that at least 20% of patients were not compliant; and studies of chronic illnesses, such as hypertension, as much as 40% of patients were not compliant to prescribed medication.

In studies of compliance to ARV drugs before the advent of PIs, over 70% of patients omitted drug doses; and when the researchers looked at clinical drug trials, one-third (1/3) or more of the participants dropped out before reaching study end-points. The reasons for non-compliance/adherence varied. Factors such as, number of pills per day, the length of time to take the pills (acute

vs. chronic), the cost of the drugs, the difficulty of taking the meds, the side effects of the drugs, were some of the reasons given.

Several studies of HIV/AIDS patients in San Francisco in the late 1990's, found that 12% of the patients had skipped doses the day before, 11% had skipped doses two days before, and that 13% of the patients had skipped doses three days before. The reasons given were:

- simply forgot to take their meds – 40%
- slept through the dose – 37%
- away from home without their pills – 34%
- a change in routine – 27%
- busy with other things – 22%
- the side effects of the drugs – 10%
- depressed – 9%

Study data found that patients couldn't remember beyond three (3) days with any accuracy whether or not they had taken their medications as prescribed.

Studies cited in the Treatment Guidelines, found that one-third (1/3) of the patients missed doses within three (3) days of the survey. Another study in an urban center found that one-fifth (1/5) of the patients never filled their drug prescriptions.

Significance of Adherence

Clinical There are many reasons why adherence is important within the clinical setting. Clinicians involved in prescribing ARV therapy need to consider the impact of adherence on the efficacy of treatment and the ability of the drug regimen to reduce viral load. Several studies have shown that 90-95% of doses must be taken for optimal suppression of the virus. Lesser degrees of adherence are correlated with virologic failure. If patients are having difficulty adhering to the regimens, providers need this information in order to make informed decisions about changing and/or modifying the drug regimens.

Patient's Perspective From the patient's perspective, adherence to the ARV regimen can improve quality of life, slow disease progression, prevent OIs, and prolong life. Inadequate adherence to the regimen allows the emergence of resistant strains of the virus. Resistant strains of HIV can be transmitted to others and decreases intervention options for the newly infected, as well as less treatment options for the patient that has had non-adherence to the prescribed regimen.

Factors Predictive of Adherence

Many factors have been identified as predictors of adherence to therapeutic regimens. These factors fall within the domains of the provider-patient relationship, the drug regimen itself, characteristics of the patient or the patient's environment, and the health care delivery system. These factors/characteristics can either facilitate or impede the patient's ability to adhere to the health care plan for treatment. Factors not predictive of adherence have also been identified.

Factors not Predictive Many providers make assumptions about which patients will be able to adhere to treatment regimens. Studies about adherence and predictors of adherence indicate that age, socioeconomic status, and race/ethnicity are **NOT** predictors of adherence.

Factors Predictive of Inadequate Adherence The Treatment Guidelines cites research findings on factors that predict negative influences on adherence. Some of these factors are: poor patient-provider relationships, active drug and alcohol use, acute/chronic mental illness, depression, lack of patient education, and lack of access to primary medical care and treatment. Domestic violence and discrimination are also cited as negative influences potentially impeding adherence to a therapeutic regimen.

Factors Predictive of Appropriate Adherence The availability of support, both emotional and practical, the ability of patients to fit the drug regimens into their lives, patient knowledge about the importance of taking their meds as prescribed, and not feeling the need to hide their condition from people (taking their medications in front of people) are characteristics of positive influences enhancing adherent behaviors.

Patient Factors Contributing to Adherence

There are a variety of patient factors that can contribute to appropriate adherence behavior. First, a patient must be ready to initiate and maintain an ARV treatment regimen. In the past few years with the advent of HAART, we have seen some providers pressure patients into initiating ARV (HAART) therapy without assessing the patient's readiness to start and maintain a drug treatment program. Because the patient isn't ready, he/she has difficulty managing the regimen, misses doses of medications, may have problems with the side effects, and sometimes stops taking the medications. In order to maintain a regimen, the patient needs knowledge about the medications, understanding about the critical need for adherence and the skills and resources to plan and implement a treatment program in collaboration with his/her provider. Family/caregiver support is

essential to maintaining positive attitudes and contributes significantly to good adherence outcomes. The patient's individual beliefs about health, his/her trust in the effectiveness of the treatment regimen, and the person's perspective on the cultural relevancy of treatment are all factors that can positive impact on the patient's ability to manage the treatment regimen plan. The patient's perception that his/her self-care behaviors will be able to control the side effects of the medications also influences adherence behaviors.

Patient Factors Contributing to Non-adherence

There are numerous factors contributing to imperfect or non-adherence behaviors, in addition to not being ready to start an ARV therapy program, missing doses of medications is not the only non-adherent behavior. Incorrect dosages taken at the wrong time and/or frequency, failure to follow food/water associated recommendations, and missing follow-up appointments also constitutes non-adherent behavior.

Anticipatory fear or actual occurrence of side effects has a significant impact on adherence. Providers must be skilled at disclosing information to patients about possible side effects and approaches to dealing with them in advance of their occurrence. Skepticism about the effectiveness of the treatment, fears about disclosure, and the association of "pill-taking" as a constant reminder of infection, illness, and possible death are other factors that can contribute to inadequate adherence to treatment.

Cognitive impairment from mental illness and/or substance use/abuse clearly effect coping efficacy and has direct impact upon the patient's ability to manage ARV regimens. The decision that the provider needs to address is not to decide whether or not the patient should be given ARV medications, but how to clinically and psychosocially intervene so that the impairment is minimized. With the appropriate interventions and support, the patient can have successful ARV therapy.

Provider Factors Contributing to Adherence

The provider-patient relationship is a major factor in determining the success of any care and treatment program. The building of a professional relationship occurs over time requiring commitment from both the provider and the patient. It is important that the patient interface consistently with an empathetic provider in order to develop a collaborative, supportive relationship in which effective communication mechanisms are established, and the patient achieves satisfaction in the treatment experience. Trust within this relationship can enhance the likelihood that the patient can optimally adhere to the treatment regimen. The provider's

expertise in care and treatment, belief in the treatment regimen, and cultural sensitivity are also factors that can influence adherence behaviors. Creating an environment in which "shared decision-making" happens increases patient satisfaction and thereby, impacts adherence and improves clinical outcomes.

Regimen Factors Contributing to Adherence

There are ARV regimen factors that can significantly influence adherence behaviors. Basically, the more complex the regimen, the more difficult it is for patients to adhere. The complexity refers not only to the number of pills the patient may be forced to take, but also to the frequency of the dosing, and the special instructions (such as specific types of food) that may be required. The duration of therapy is theoretically lifelong. Studies have shown that the longer the duration of drug therapy, the less likely a patient will adhere over time. Some adherence surveys have identified that patients may take drug holidays without informing their providers in order to "forget" about having a potentially fatal disease. Daily "pill taking" of numerous medications can become a major burden.

The inconvenience of "pill taking", concerns about disclosure and confidentiality, and the side effects are factors that impede appropriate adherence behaviors. Many patients have stopped their drugs because of the side effects. Working with patients to treat the side effects is critical to assisting the patient to maintain consistency in the therapy plan. The complexity of the treatment regimens may require significant changes on the part of the patient. Too often we expect patients to "fit their lives around the activities of the regimen" instead of **fitting the regimen into the lives of the patients.** Simplifying the treatment regimen, if possible, may ease the pill burden and improve adherence.

Environmental Factors Contributing to Adherence

Characteristics of the care/treatment system environment can significantly impact patients' ability to adhere to the prescribed treatment plan. Factors that can influence adherence behaviors:

- the distance to the clinic/treatment center,
- the degree of confidentiality within the setting,
- the duration of time that the clinic setting is open,
- the establishment of a supportive milieu,
- the availability of sufficient knowledgeable, committed providers and sufficient time to provide care,
- the accessibility to a consistent supply of high quality medications,

- the effectiveness of the follow-up and monitoring protocols, including laboratory testing,
- the availability and accessibility to an effective case management (care coordination) system that works collaboratively with patients and families to:
  1) identify needs,
  2) develop plans of care and treatment,
  3) assist providers, patients, and families to implement the treatment plans,
- ongoing evaluation to ensure continuity of a high quality of care.

Measurement of Adherence

There is no specific perfect methodology to measure adherence. Various measurement strategies, such as:

1) Directly observed therapy (DOT),
2) Biochemical measures (laboratory tests),
3) Pill counts of unused medications,
4) Tallies of refills,
5) Electronic monitors,
6) Self report records/diaries, and
7) Patient Interviews

have all been used in practice, as well as in research projects in an attempt to identify the best measurement methodology. The studies have demonstrated some success with each method, but all methods have some limitations as well. Self report surveys have some weak predictive findings of adherence, but a patient's estimation of non-adherence has a strong predictive value and should be seriously considered. Findings from other studies suggested that using two or more measurement methodologies for comparison provided better results. In areas of limited resources, providers may chose to use low technological measurement methods, such as pill counts; self report dairies, and interviews.

Adherence Process & Skills

Adherence to ARV treatment is difficult and complicated. It is a process, not an event, and requires skill development on the part of both the provider and the patient. It is a skill that can be taught and learned. The provider, in turn, needs to learn as much as possible about adherence, as well as strategies for teaching the patient and the family. Behavior change and/or the acquiring of new behaviors take time, support, and encouragement. In many cases, change occurs in successive approximations ultimately leading to optimal adherence behaviors. **Encouragement and support of the patient efforts to adhere facilitates the continuation of adherence behaviors.**

Strategies to Improve Adherence

The basic foundation of a successful ARV treatment regimen is the development of a plan through a shared decision-making process in which the patient, the patient's family, and the provider together work out the specific details. (In cultures, other then the United States, the focus of care is the family unit, not only the individual patient). Recruitment of family members into the planning is worthwhile and should be encouraged. Involving the family provides opportunities for education about the regimen and offers options for enlisting support from the family for the patient's activities in achieving adherence in managing his/her therapy regimen.. As part of the treatment plan, the following strategies are suggested:

Clarify the Regimen A study in San Francisco found that 10% of patients leaving the clinic after seeing the nurse and receiving their medication did not understand what they were to do about taking their medications. Providers need to do more then "talk at" their patients. Patients need the opportunity to reflect back to the provider their understanding of the individual medications and how they are to be taken. More then verbal communication should be involved in the process. Patients may need to have their own med cards prepared by both the provider and the patient together containing information about the dosage, when to take the meds, and special instructions about taking the drugs. Side effects of the meds could also be on the med card, especially the more serious side effects that must be reported quickly to the provider. Provider/clinic contact information could also be included on the med cards. If literacy is an issue, simple sketches of the meds can be drawn on the med cards.

Tailor the ARV Regimen to the Patient's Life Activities
Adherence is easier if the "pill taking" is fitted into the patient's activities of daily living (ADL), not changing the patient's activities of daily living to fit around the "pill taking." During the initial assessment phase of developing the treatment plan, identifying the patient's ADL provides opportunities to determine those activities/behaviors that could be used as triggers or cues to remind the patient to "take my pills." Identify those behaviors that are always performed. The "pill taking" behavior would be done before the behavior/activity is performed. As an example, if the first behavior in the morning is to use the toilet, then take the pills before using the toilet.

Assist the Patient in Developing a Medication Diary A diary can be simply a chart with a check off list of the drugs of the daily regimen. It can be individual med cards as previously mentioned.

It can be a simple form or a more comprehensive chart. It can be a chart divided by the day, by the week, or by the month. Whichever mechanism the patient and the family, in collaboration with the provider, decides is the easiest format to use should be the one implemented into the treatment plan.

Establish a Set Time and a Set Place to Take the Pills Routines that are consistent (set times) are helpful in remembering to "take your pills." Many of the ARV agents are taken twice a day (bid). That usually is interpreted as meaning morning and evening. The specific times need to be established based upon the patient's needs and ADL. The emphasis is to take the pills at the same time each day. Establishing a set place to take the pills also enhances adherence especially if the pills can be stored at the designated place.

Plan for Changes in the Activities of Daily Living Routine Changing the daily routine increases the risk for "forgetting" to take the pills. Plan ahead if the changes are known, such as planned travel. Discussion during the planning phase about the potential for changes in the patient's routine would be helpful and exploring options for dealing with the changes would also decrease anxiety about the "pill taking" requirements.

Follow-up and Monitoring It is critical that follow-up and ongoing monitoring be an integrated component of the treatment adherence plan. New behaviors need to be supported and reinforced. Routine ongoing monitoring for factors that may interfere with the patient's ability to manage the treatment is essential. Even if the patient has established an appropriate plan for maintaining adherence and appears to be following the plan, assessment of current status may reveal some treatment fatigue impacting on the patient's ability to follow the regimen. Ongoing monitoring for side effects should also be part of the routine monitoring activities.

Other Strategies to Enhance Adherence Pill boxes can be useful in remembering to take medication. Some weekly pill boxes are divided into daily compartments and others are actually two (2) compartments per day weekly boxes. In limited resource settings, the availability of pill boxes may be inconsistent. Using other containers, including recycled jars, etc. could be helpful. Providers filling containers that have been labeled appropriately for the daily doses and/or weekly doses is a strategy that may ease the burden for the patient. "Pill trials" using candies (jelly beans), nuts, or seeds have been utilized to initiate trial runs of ARV therapy

regimens. This strategy allows the patient to try out a drug regimen before initiating ARV therapy. The trial may identify issues previously unrecognized by either the patient or the provider. Jellybean trials have been used in various settings, including teaching situations. No research data on the strategy has been reported in the literature.

Use of peer counselors/volunteers in the community clinic can also be a strategy to enhance and support adherence to the treatment regimens. Peer counselors/volunteers can be trained by providers to assist patients and their families to meet their treatment goals. Support groups can also be established. If the issues of stigma and fear have been addressed in the community and support for people with HIV disease has been demonstrated, support groups could provide the incentives for patients to continue treatment and adhere to their drug regimens. Support groups can also provide education and assistance to families engaged in caring for patients.

Adherence Case Management

For some time**,** nursing case management has been accepted in the United States as an effective method of providing quality nursing care that includes the overall responsibility of managing the therapeutic plan of care. In some other countries, care coordination may be the model that is used to provide a continuum of care. Culturally appropriate models of coordinating care should be used to provide support and guidance in integrating medication regimen adherence strategies into the patient's treatment plan.

The nursing process of assessment, planning, implementation, and evaluation fits well within the framework of case management (care coordination). Utilizing case management to assist patients and their caregivers in managing their ARV treatment programs can make a significant difference in patients' lives and in their ability to manage their treatment and their responses to treatment. The strategies discussed previously fall within the domains of the nursing process. The teaching, monitoring, planning, ongoing follow-up, evaluating, and supporting strategies are essential activities of the adherence process. Developing a nurse case management (care coordination) system within the community and/or care facilities has the potential for improving the overall quality of treatment and care through more effective implementation of the above strategies.

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Key Concepts

* Adherence is a critical component of ARV treatment.
* The term adherence indicates a shared decision-making collaboration between the patient and the provider.
* Adherence involves more then just pill taking behavior.
* Adherence includes all aspects of the care and treatment plan.
* Non-adherence has been a problem before the advent of ARV and before the identification of HIV.
* There are numerous reasons for non-adherence.
* Studies found significant percentages of patients are missing doses of ARV agents.
* Simply forgetting to take their meds was one of the major reasons for missing doses of ARV agents.
* Non-adherence allows for the development of resistant strains of HIV.
* Studies show that 90-95% of doses must be taken to achieve optimal suppression of the virus.
* Age, socioeconomic status, and race/ethnicity are not predictors of adherence.
* Active drug/alcohol use/abuse, active mental illness, depression, lack of education, lack of access to primary care and treatment, and poor patient-provider relationships are predictors of non-adherence.
* support from family/friends and providers facilitate adherence.
* Assessing for readiness to initiate an ARV treatment program is essential to have successful adherence.
* Being able to control side effects of the ARV agents enhances adherence behaviors.
* Patient education about the care and treatment is vital to maintaining adherence.
* The patient's health beliefs and cultural perspectives impacts adherence behaviors.
* Side effects and pill burden negatively influences adherence behaviors.
* Patients take self-determined "drug holidays."
* ARV regimens should fit into the patient's life.
* Clinic environments can have a positive or negative impact upon the patient's adherence dependent upon the characteristics of the setting.
* All the measurements of adherence have limitations.
* Adherence is a process not an advent.
* Adherence expertise and skills are learned behaviors.
* Clarifying the regimen, tailoring the regimen to fit into patient's ADL, diaries, set time and place for taking

medications, follow-up/monitoring are all strategies aimed at enhancing adherence.

* Treatment fatigue is possible even after maintaining appropriate adherence.
* Peers counselors and support groups are positive strategies.
* Engage the family in the treatment plan.
* Nursing case management improves overall care, patient outcomes, and enhances adherence.
* Simplify the ARV regimen, if possible, but the treatment goal of maximum viral suppression must be considered.

Nursing Implications

* Implement a case management system utilizing the nursing process as a framework within which patient-provider relationships can be developed so that critical issues are not missed, adherence behaviors are improved, and overall patient outcomes are improved. Develop skills in effective communication, using active listening techniques reflecting back to the patient what was heard.

* Expect some missed doses, especially during the early phases of the treatment program. Keep in mind that adherence is a process not an event. Explore, in collaboration with the patient, the circumstances of the missed dose (s), and initiate strategies to address the situation. Focus on creating a supportive environment, so that patients are encouraged to reveal missed doses an/or any difficulties they are encountering with the treatment plan.

* It is essential that the assessment phase of the adherence process be ongoing and occur with each interface of the nurse provider and the patient. Asking specific questions not just general broad questions, provides needed information about ADL, side effects, patient's behaviors to deal with the side effects, the effectiveness of the interventions for side effects, various aspects of the therapy agents, and the mental health of the patient. It would be helpful to review the treatment plan during each session to ensure that the correct medications at the correct dosages at the correct frequency and time are being taken. Review of the patient's diary or chart should be done during each session also. Be aware of the potential for treatment fatigue. Teaching and re-enforcing new knowledge and new behaviors during each session is helpful in improving

adherence behaviors. Do not rush the process of initiating ARV therapy. Take the time to do the initial assessments to determine the patient's readiness for starting drug therapy. Taking the time to carry out these activities each time also allows the provider to assess the mental and/or emotional status of the patient

* Follow-up with patients during the first couple weeks after initiating drug therapy in order to assess level of success with the regimen, to re-enforce new behaviors, and provide support. Use family members, peer counselors, or volunteers where available.

* Do not make assumptions about individual's abilities in managing their regimens. Continue to provide ongoing support and encouragement routinely. Continue monitoring and evaluation adherence activities and in collaboration with the patient, modifying the treatment plan as needed.

Review Questions

1) Define the terms adherence and compliance. Discuss the differences between the two (2) terms.
2) What are the findings in studies about adherence?
3) What is the clinical significance of adherence?
4) What factors/characteristics are predictive of adherence?
5) What factors are not predictive of adherence?
6) What are some of the reasons given for missing doses?
7) What are some of the issues from the patient's perspective that could impede adherence?
8) What are some of the provider factors that could impede adherence?
9) What are some of the regimen factors that impact adherence?
10) What are some of the environmental factors that impact adherence?
11) Discuss various measurements of adherence and the limitations.
12) List and discuss strategies to facilitate and/or improve adherence.
13) Discuss the advantages of utilizing a nurse case management system.
14) Discuss methods for teaching adherence.
15) Explain, "adherence is a process not an event."

Case Study

Natalie is a 25 year old woman living in a slum area just outside an urban center. She has three (3) children living, ages 8, 6, 4. Natalie was diagnosed with AIDS when her youngest child was diagnosed with AIDS at 6 months. This infant has recently died and Natalie is very depressed about the baby's death. The other children appear to be healthy. Natalie's husband died the previous year. She thinks it was AIDS, but he was never diagnosed. Natalie's family lives in a rural area. They do not know about Natalie's diagnosis or that her baby has died. Natalie makes baskets to sell at the roadside. Her house has no inside toilet or running water. Natalie's CD4 T cell count is 205 and her viral load is over 80,000 copies. Natalie receives health care at the local clinic. Recently ARV medications have become available. Her provider wants to start her on a multiple ARV drug regimen, but Natalie is feeling overwhelmed and doesn't know what to do.

Questions to Consider

1) What are the issues that must be identified by the patient and the provider to determine the appropriate treatment plan, including whether or not to start ARV therapy?

2)What are the assumptions that providers could and do make about the patient's ability to manage her care and treatment?

3) What are the potential and real barriers for this patient to manage a multiple ARV regimen?

4) As the Nurse Case Manager (NCM) develop a care and treatment plan, including the possibility of initiating an ARV drug regimen.

5) If an ARV treatment plan is a started, what are some of the strategies that could be initiated to support Natalie and increase the possibilities of her being able to manage her care and adhere to the regimen?

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Cultural Issues that Influence HIV/AIDS Care and Treatment

Overview

In the United States, our society has long believed in the "melting pot" paradigm that values immigrants who assimilate into this society and adapt to and adopt the values of the majority, Euro-centric, white culture. Our institutions and public systems usually reflect this dominant paradigm. The majority perspective is pervasive, persistent, and profound, frequently to the detriment of immigrants and people of color. Because of the majority cultural overlay created by the "melting pot" phenomenon, non-dominant differences and issues become lost or invisible. Attitudes and beliefs change slowly over time, but emerging trends emphasize viewing ourselves as part of the global village, encouraging us to view ourselves as interdependent rather than ethnocentric and independent from other cultures and societies. It has been advocated that we see the world

> ……*as a tapestry woven of many, different strands. Those strands differ in size, color, intensity, age, and place of origin. All strands are integral to the whole; yet each retains an individuality that enriches the beauty of the cloth. The tapestry symbolizes the cultural diversity among people…….*
> (Lipson, Dibble, & Minarik, 1996, p.iv)

One of the most complex challenges of the HIV/AIDS pandemic is the cultural diversity of health and illness beliefs and practices that impact prevention, care and treatment. To ignore the influence of culture on how an individual responds to the interventions of health care providers functioning within a delivery system that may be alien to the individual is to jeopardize the successful development of an effective patient care and treatment plan. Ignoring cultural influences that could impact upon adherence to drug therapy facilitates treatment failure and poor patient outcomes.

Many cultures and countries reflect the dominant/non-dominant paradigm to the detriment of its non-dominant people. Most of a society's health care providers have been educated in institutions and work in settings that reflect the mainstream patterns. Stereotypic and prejudicial images are reinforced in this paradigm and frequently contribute to the poor and/or negligent care received by many people from the non-dominant group. These experiences contribute to the lack of trust demonstrated by individuals from the non-dominant group. As responsible,

competent health care providers, we must break these patterns and create new paradigms that integrate the diversities of culture and people reflected in our societies in order to provide the best health care possible.

Objectives

Upon completion of the training on this module, the learner will demonstrate increased knowledge of:

- definitions of culture
- the culturally competent provider
- the cultural issues of HIV/AIDS care
- the impact of culture on treatment adherence
- approaches to reduce/eliminate cultural barriers to adherence

Definition of Culture

Culture is defined as much more than race or ethnicity. Culture, as the sum way of living, embraces not only language, dress, customs, rituals, food, religion, and music; but also includes health beliefs and practices, death and birth rituals, sexuality and gender issues, issues of family structure, relationships, and dynamics, social practices, values, and beliefs that define personal space, eye contact, time orientation, nonverbal communication behaviors, patterns of thinking, and much more. Individuals are socialized into the society by being taught and learning the cultural patterns.

Experience of Difference

Milton J. Bennett (1986) designed a continuum to demonstrate a developmental approach to training for intercultural sensitivity. It promotes a process rather than an event of becoming culturally sensitive, and, hopefully, culturally competent.

Denial, the beginning phase occurs when people deny that there is a difference and may be seen when individuals have lived in physical or social isolation or minimal exposure to cultural diversity.

Defense "involves attempts to counter perceived threat to the centrality of one's world view" (p.183).

Minimization occurs when cultural differences are acknowledged but the differences are trivialized.

Acceptance when cultural differences are acknowledged and respected. Differences are fundamental.

Adaptation occurs as behavior and thinking changes are demonstrated by empathy. Cultural pluralism is a form of adaptation. Behavior is more appropriate to the other culture and is perceived by the other culture as appropriate.

Integration considered to occur when an individual is not only multicultural, but able to integrate differences and perceived these differences as processes and adapt to these processes.

One can be at different places on this continuum based upon how differences are aligned with our values.

Definition of Cultural Competency

Culture competency is more than cultural awareness or cultural sensitivity. Competency implies skills and expertise to work with and within diverse cultural groups with sensitivity and effectiveness. Cultural competency includes appropriate attitudes, beliefs, behaviors, interventions, policies, and advocacy. In other words, cultural competency implies not only ways of thinking and believing, but ways of acting as well.

Characteristics Of a Culturally Competent Provider

In all domains of practice the provider demonstrates skills and expertise not only in appropriate interventions, but also in his/her attitudes and beliefs about the value of the cultural context of the patient's life. The provider strives to understand the meaning of the patient's perspective and advocates for policies and protocols that "fit" the context of the patient's culture.

In order to fully relate to another culture and to be sensitive to the nuances in the other culture, a provider must be aware and sensitive to his/her own culture and how his/her biases and values impact upon others. The competent provider is comfortable with the differences in culture, and understands that there are greater differences **within** a culture than **between** cultures (that is, the domains across cultures are similar).

A culturally competent provider is knowledgeable about the impact of oppression, racism, discrimination, and stereotyping upon both the patient and upon the provider.

A Provider Recognizes that Differences May Exist in:

* Racial & Ethnic History
* Verbal & Nonverbal Communication
* Eye Contact
* Time Orientation
* Sexual Orientation
* Family Structure & Dynamics
* Clothing & Ornaments
* Use of Chemical Substances
* Economics & Work
* Religion/Spiritual Beliefs & Practices
* Illness Beliefs
* Privacy & Confidentiality
* Symptom Management
* Language
* Reading Ability
* Personal Space
* Touch
* Beliefs about Sexuality & Gender
* ADL & Self Care
* Food Preferences/ Prohibitions
* Social Values, Rituals, & Customs
* Birth & Death Rituals
* Health Beliefs & Practices
* Care Seeking

The culturally competent provider accepts these differences and works with these differences to structure a culturally appropriate care and treatment plan. It is essential that during the initial assessment phase of developing the treatment plan, the provider spend some time exploring, with the patient, some of the above areas of potential differences, specifically those areas regarding care, treatment, health and illness beliefs and practices, symptom management, and others that might impact upon how the patient responds to care and treatment.

Cultural Issues of HIV/AIDS

Some of the numerous cultural issues of HIV/AIDS include the following, but are not limited to the following: 1) health and illness beliefs; 2) symptom management; 3) sexuality and gender; 4) self care and care seeking; 5) religion and spiritual beliefs and practices. If a patient believes that illness and health is an act of God, then he/she may be hesitant and/or skeptical about instituting ARV therapy and other interventions. A patient may use herbal remedies to treat (cure) illness or symptoms rejecting the more traditional Western medical intervention. Decisions about a patient's care and treatment may be made by an older male family rather then the patient. A sexually transmitted disease, such as HIV, may offend/violate cultural values and beliefs. Infection as a result of injecting drugs may also offend cultural values. In some cultures because of the significant imbalances in power between men and women, women have a higher risk of becoming HIV infected. Using condoms to prevent transmission violates certain religious beliefs. These are only a few of the many cultural values/beliefs that have emerged in the HIV/AIDS pandemic.

Impact of Culture Upon Treatment Adherence

The impact of cultural beliefs and practices on HIV care and treatment have been numerous and significant and will continue to be so. Adherence behaviors are obviously impacted by cultural patterns and beliefs. As an example, if a patient is skeptical about Western medicine will he/she be able to follow a drug regimen, especially if the patient is suffering from side effects of the medications. The issue for providers is to attempt to meet the treatment goals within the patient's cultural framework.

Approaches to Reduce/Eliminate Cultural Barriers To Adherence

We can not disregard patients cultural systems in order to provide quality HIV/AIDS care and treatment. We must modify the care and treatment plan to "fit" within the patient's cultural framework even if we have to institute treatment that we believe is less then optimal. As responsible providers, we may not want to accept this concept, but we must ask ourselves, "If I don't accept the patient's beliefs about his treatment and insist on implementing what I think

is the correct treatment will the patient adhere to the treatment?" We need to remember that adherence is a process, and patients will make decisions about their care and treatment whether we are aware of their decisions or not. We need to continue to provide care, support, and encouragment, continue to monitor the patient's process and progress, continue to collaborate with the patient on treatment modifications, and continue to evaluate patient responses and clinical outcomes. Consider the concepts expressed in the following model:

The LEARN Model for Cultural Competency

L *Listen* with empathy and understanding to the person's perception of the situation (issue)

E *Elicit* culturally relevant information and *Explain* your perception of the situation (issue)

A *Acknowledge* the similarities and the differences between your perceptions and his/hers

R *Recommend* options/alternatives and *Respect* the person and his/her choices

N *Negotiate* agreement

(Berlin & Fowkes, 1983. Adapted from materials developed by the AIDS Education Project, Hawaii AIDS Education & Training Center).

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Key Concepts

* "melting pot" phenomenon refers to the assimilation of immigrant populations into the majority-overlay culture.
* a different symbolic model for diversity in cultures would be a tapestry woven of many different strands.
* Culture can be defined as the sum total of living embracing many domains.
* Individuals are socialized into a culture.
* Acquirement of cultural competency is a developmental process.
* Cultural competency implies skills and expertise with and within diverse cultural groups and includes attitudes, beliefs, behaviors, interventions, policies, and advocacy.
* A culturally competent provider is aware of his/her own culture, biases, and values and how they impact on others.
* A culturally competent provider values the cultural context of the patient's life.
* Cultural competency is much more then cultural awareness or cultural sensitivity.
* The culturally competent provider accepts differences and works within the patient's cultural values and patterns to develop culturally appropriate care and treatment plans.
* Many cultural issues have emerged in the HIV/AIDS pandemic.
* Cultural beliefs have had a significant impact upon adherence behaviors.
* Continued acceptance, support, and encouragement is necessary even when patients make choices that are different then the recommendations as to care and treatment regimens.

Nursing Implications

* Interviewing the patient in order to identify cultural norms, values, and beliefs should be integrated into the initial assessment phase of the development of the care and treatment plan. Collaborate with the patient and the patient's family to address the specific cultural issues that potentially could impede the initiation of the treatment regimen. Build the treatment plan on the issues not in conflict. Negotiate the differences where possible. Be aware that the plan may need to be implemented in incremental steps. Continue to clarify and review the plan with the patient during routine visits. Continue to monitor and evaluate the patient's progress and clinical outcomes. Adapt the treatment plan as needed to meet the patient's treatment goals. In collaboration with the patient, periodically review the treatment goals and explore the potential treatment options.

* Experiment with some of the adherence strategies discussed in the previous module. Utilize the patient's knowledge and interest to individualize the strategies to support the patient's efforts in managing his/her self-care and care and treatment regimens within a culturally appropriate framework.

Review Questions

1) Define culture.
2) Define "melting pot" paradigm.
3) Describe the continuum of cultural competency.
4) What is cultural competency?
5) What are characteristics of a culturally competent provider.
6) Discuss some of the cultural issues of HIV/AIDS.
7) What is the impact of culture on treatment adherence?
8) What are some approaches to reduce the cultural barriers?
9) What is the LEARN model for cultural competency.
10) Explain the differences between cultural awareness, cultural sensitivity, and cultural competency.

Case Study

Samuel is a 39 year old male who has recently returned to his home village from the region's largest gold mine where he worked in the tunnels digging ore. Samuel was usually away from his home for months at a time. He is married and his wife and their 4 children, ages 14, 12, 10, and 7 live in the village with his parents. During the time he is away from working in the mines, he visits the prostitutes that live in shacks just outside of the mining company's gates. He never uses condoms. When Samuel or anyone in his family is ill, they visit the village healer, an old woman, who provides the only care in the village. The village healer makes her own remedies from herbs and roots. She also performs all the other activities associated with health and illness and serves as the village midwife. The village community is very traditional in their beliefs and practices. There is a larger village located about 12 kilometers away. The larger village has a medical clinic that nurses from the university staff three (3) afternoons a week providing primary care, as well testing and counseling for HIV.

Samuel was fired from his job at the mine because he was "getting sick." He has lost weight, has night sweats, a chronic cough, pain and swelling in his armpits and in his groin area. The medical officer at the mining company clinic had treated him for STIs several times during the past 3 years. When Samuel returned to his home village, his family urged him to see the village healer, which he did, and she gave him a potion to build his strength back up. After 3 weeks of taking the potion and not feeling better, Samuel went to the clinic in the neighboring village without telling his family.

After interviewing Samuel and doing a brief physical exam, the nurse case manager counseled him about HIV testing. Samuel was scared, but agreed to be tested. He returned 2 weeks later for the results. His HIV test was positive, his CD4 T cell count was 188 and his viral load test was 75,000 copies of HIV RNA. He was counseled about potential options for treatment, including ARV medications that recently had become available in his country and could be prescribed through the clinic. Samuel didn't know what to do or who to talk to. He had not told his family about being tested or even attending the clinic.

<u>Questions to Consider</u>

1) What are the numerous cultural issues in this case study?
2) Which issues would need to addressed before initiating any therapy?
3) What would be the first steps in this situation?

4) What are Samuel's treatment options?
5) You are the nurse case manager and primary care provider, develop an initial care and treatment plan addressing the cultural issues, the care issues, and the treatment issues. How would you address the family situation? What resources would you seek to aid you in your interventions for Samuel?

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Nursing Care Issues in HIV/AIDS

Overview

Since the beginning of the HIV/AIDS pandemic nurses have been actively engaged in providing care and support for persons with HIV/AIDS and their families. In fact, early in the epidemic, before the development of antiretroviral medications, nursing care interventions were the primary treatment therapies for HIV disease. Enhancing continuity of care through a case management multi-disciplinary team approach, providing psychosocial support for patients and families, assisting patients to deal with symptoms of OIs, providing nursing care in the home, and ensuring relief of suffering by providing palliative care during the terminal stages of illness are core functions of nursing. With the advent of medical treatment for OIs and ARV therapy regimens, the role of nursing in HIV/AIDS care has become more complex, but still within the core domains of nursing. Adherence to multi-drug regimens requires ongoing monitoring and support. Nurses are uniquely prepared to provide this care.

This module will briefly discuss some of the nursing issues of case management, symptom management, home care, and palliative care. Some of the psychosocial issues are also briefly discussed. Basic principles of infection control will also be included. Much of the material for this module is based upon the **ICN/WHO/UNAIDS Fact Sheets on HIV/AIDS for Nurses and Midwives**. **Copies of these Fact Sheets can be located in Appendix E.** In addition, instead of case studies at the end of the module, personal communication about some of the issues discussed in this module from providers around the world is included.

Objectives

Upon completion of the training on this module, the learner will demonstrate increased knowledge of:

- the management of the continuum of care
- the impact of psychosocial issues upon patients and families
- the basic principles of Universal Precautions

by increasing scores on posttests, analyzing case studies, and demonstrating increased skills of care management in role plays.

Case Management

The core concepts of case management are not new, but the terminology has changed over the past several decades. In the United States in the early 1900's, public health nursing used the term, community service coordination, to identify the scope of care monitoring and integration. What is explicit in the term is that

there is a continuum of care for the individual patient that is perceived as valuable and by integrating the needed services the patient's responses to health problems improves and his or her quality of life also improves. Over the years as the scope of integrated services expanded, the term, case management, became accepted as defining a well organized and integrated system of identifying needs and implementing a coordinated plan of care along a continuum. Over time, case management evolved into two models, a medical/nursing model and a social service model as providers recognized that frequently patients needed both health care services and social services.

In HIV/AIDS care establishment of case management systems varied from setting to setting dependent upon the skill mix of personnel and the agency's designated services responsibilities. As a result, care was inconsistent and, significant gaps in services were observed. Integrated, comprehensive care is patient-centered and is determined by the individual patient's needs and resources. In order to provide care along a continuum, integration is the key and the ideal model of delivery is a multi-disciplinary team program. HIV disease treatment and care is complex requiring a variety of skills and interventions, using a multi-disciplinary team approach with a nurse case manager as the care coordinator, can ensure that adequate and appropriate comprehensive services are implemented thereby improving patient outcomes. The ideal multi-disciplinary team includes nursing, medicine, social services, mental health services and other health care professions to meet the specific needs identified by the patient, the patient's family, and the team.

The above discussion of case management and a continuum of care is referring primarily to the current models and practices in the United States. In other countries and regions different models and practices exist. In African countries the focus of care is not the individual patient as it is in the United States, but rather the focus of care is the family, as well as the patient, requiring different terms, models, and practices. Care coordination may be a term that is used, but refers to coordination of the care of the family and patient usually within a community care model. The desire is to integrate HIV/AIDS care within the existing primary care structure. Care coordination may require relationship building and/or resource management in the community. The role of the nurse is not as a case manager, but more as a team leader, mentoring and teaching. The nurse often trains volunteer community health workers (CHWs) who, in turn, provide much of the family/patient care. As an example, in Zambia, the model is

called community health program and the volunteer CHWs are called community support groups. In Botswana, home based care is called community home based care and involves family members, skilled health care workers, and other members of the community.

Another difference between United States models and African models is the role of traditional healers in the provision of care. Many African societies/communities have great trust in traditional healers and highly value their role in providing care. As an example, in Botswana, there are six (6) associations of traditional healers that have significant influence in the provision of health care within that country.

It is important that nurses understand the cultural basis of the different models of care coordination and models/practices of care provision, in order to meet the health care and social service needs of patients and families within a culturally appropriate framework. To facilitate that understanding the following information utilizes the ICN/WHO/UNAIDS Fact Sheet 3 on Continuum of Care from the **Fact Sheets on HIV/AIDS for Nurses and Midwives** that defines comprehensive care across a continuum

> *"involves a network of resources and services which provide holistic, comprehensive, wide ranging support for people living with HIV/AIDS (PLHA) and their families. A continuum of care includes care between hospital and home over the course of the illness. There must be adequate resources (financial, supplies, services, staff, volunteers, government and community support), and connections between them. Care must incorporate clinical management, direct patient care, education, prevention, counseling, palliative care and social support." (p.1).*

Components Related to Comprehensive Care The ICN/WHO/UNAIDS Fact Sheet 3 lists the following components necessary for a system of comprehensive care:

- Clinical management and direct care for the patient and his/her family
- Education for providers, family, volunteers, community
- Involvement of the patient
- Counseling (social, spiritual and emotional support)
- Voluntary testing and follow-up
- Adequate resources (medicines, medical supplies, linen, food, clothing, shelter, funds)

- Advocacy and legal aid
- Prevention strategies
- Care for the caregivers
- Protection and infection control
- Strategies to promote the acceptance of the PLHA, and reduce stigma and isolation in institutions and communities

Basic Principles in a Continuum of Care include the following:

- Respect for the patient and family, listening to their issues and concerns in order to plan care appropriately.
- Integration of the care and treatment in order to provide a comprehensive, holistic system of care.
- Non-discrimination and non-judgmental care environments are critical to quality care and programs that are based upon respect for human dignity.
- Confidentiality of patient and family information and issues are core values in a system of comprehensive, quality care.
- Provision of appropriate referral service to meet the patient's needs, including counseling and support networks.
- Prevention of HIV-related infections (OIs) which decreases morbidity and mortality, as well as cost of care.
- Involvement of community resources and local people when appropriate to enhance patient care.
- Continuum of care includes quality terminal care at home as an option. Adequate support for caregivers is critical in providing quality terminal care.
- Provision of education, appropriate supervision and support for staff and other care givers is necessary for a comprehensive, holistic care program.
- Including families and patients in advocacy and planning for resources and implementing comprehensive, holistic care.

(Adapted from ICN/WHO/UNAIDS Fact Sheet 3 Continuum of Care). Additional information on Continuum of Care can be found in the above document located in appendix E.

Home Care

In the United States, home care for individual patients is provided by professional caregivers. Care is also provided

by family members and/or friends. The focus is the patient, and the plan of care is developed by the care team in collaboration with the patient. In Africa, the model most frequently implemented is the community home-based care (CHBC). In Botswana, the Ministry of Health (MOH) has implemented a CHBC program with care being provided by family members, skilled health care workers, and members of the community. Caregivers (family members and volunteers) are trained by the health care workers. Many religious organizations have also implemented caring projects. The MOH evaluated the program and found:

- Patients go home without support
- Poverty is a major problem – lack simple basics, such as food
- Many families may live in one house
- Volunteers may be as poor as the families receiving care
- Training should begin in the hospital before patient and family are at home
- Volunteers may need more intensive training and skill development
- Include community based organizations (CBOs) in care provision (a new area for CBOs)

The World Health Collaborating Center (WHOCC) at the School of Nursing (SON), University of Botswana in Gaborone developed and implemented a CHBC model in a small community outside of the city. The nursing faculty and students developed guidelines, set up mechanisms for training, conduct research in CHBC, assist in expansion of CHBC to other countries, and serve as resource persons. WHOCC activities included development of several CBO groups (the only CBO group in the community was the development council). The CBOs developed were: AIDS Council, peer approach to counseling teens (PACT), and a CHBC group. Cultural sensitivity emerged as an important concept. Community ownership was emphasized and supported.

An abstract presented during the XIII International AIDS Conference in Durban, validated the success of an integrated community-based home care (ICHC) project in rural KwaZulu-Natal, South Africa (SA). This region is reported to have the highest HIV infection rate in SA and formal health care services are being overwhelmed. Collaboration between the hospital, hospice, and clinic implemented the ICHC model. Community caregivers are jointly selected, trained and supervised by all three agencies to provide hands on care and support to HIV+

patients and their families at home. A continuum of care is provided with a focus on palliative care.
Other countries, such as Zimbabwe and Zambia have also implemented CHBC programs using family members and community volunteers to provide the care for patients and their families. Some of the common needs that have emerged are:

- Family members and community volunteers need to have appropriate and adequate training and skill development. Training should be ongoing.
- Caregivers need ongoing support.
- Many volunteers are poor and may need some assistance, such as food baskets similar to what is provided for patients and their families.
- Bereavement counseling needs to be available and accessible.
- Adequate supplies to provide the care should be available to the caregivers.
- Community involvement in the selection and training of community volunteers.
- Preparation and involvement of the community, including the leadership, before the implementation of CHBC programs.
- Stable staff (caregivers) providing the care.

There is a saying in the United States, "necessity is the mother of invention." In countries severely impacted by HIV/AIDS and with values that reflect a focus on family and community, the CHBC model of home care for patients and their families is culturally appropriate, economically feasible, and capable of being realistically implemented.

Symptom Management

One of the major challenges for people living with HIV/AIDS and their care providers is managing symptoms associated with the disease and its treatments. All of the ARV medications have side effects, some more severe than others, causing a variety of symptoms that effect patients ability to adhere to treatment and negatively impacts the quality of their lives. Symptom management is a core domain of nursing requiring the utilization of the nursing functions of assessment, planning, implementation of treatment, and evaluation.

* Assessment – to identify symptoms, the patient must be the primary source of information about the symptoms. What is the patient's symptom experience? Caregivers and health care providers can not correctly identify the symptoms that are impacting the patient's life. Nursing

research has found that the provider often misdiagnoses symptoms that are distressful for the patient when input from the patient about his/her symptoms is missing. Information such as, the frequency and intensity of the symptom.

* Planning – should be done in collaboration with the patient, the family, the caregivers, and the health care providers. Knowledge of potential practices is essential and knowing what's available and accessible locally can aid in managing the symptoms and preventing exacerbation of the condition.. If possible, knowing the potential interactions of the products, if products are used, could prevent significant problems.

* After the planning process is completed, which includes an evaluation component, the plan is implemented and the evaluation component is initiated. More then one intervention option may be chosen. The second option to be implemented after a short evaluation of the first option, particularly if the first option is less then satisfactory.

* Evaluation – an ongoing assessment should be done to determine if the intervention alleviates the symptom and if so, to what degree. It may be necessary to change the intervention based upon the outcomes of the management strategy. Has the functional status of the patient improved? Has his/her quality of life improved?

Symptom management interventions can be initiated by the patient, the caregiver, and/or the health care provider, and are an important component of the continuum of care occurring in all settings.

Opportunistic infections (OIs) also cause symptoms that need to be managed. Patients and family caregivers frequently use "home remedies" (alternate treatments for managing the symptoms). Even in the United States many people living with HIV/AIDS disease use non-prescription medications, such as vitamins and herbs. In Africa, traditional healers are frequently asked to treat symptoms of disease, including HIV/AIDS disease. Research demonstrated that there appears to be less stigma associated with use of traditional medicine and traditional healers. Currently, studies are being conducted by nurse researchers in several southern African countries in collaboration with nurse researchers

from the United States to identify non-western medical practices used by people with HIV/AIDS disease to manage their symptoms.

The ICN/WHO/UNAIDS Fact 4 Nursing care of adults with HIV-Related illness , located in Appendix E, contains a brief list of interventions to manage some of the more common symptoms associated with HIV disease, such as skin problems; sore mouth and throat; fevers and pain; coughs; diarrhea; weight loss and nutrition. **(See Appendix E for specific interventions).**

In the United States and other countries with greater resources, symptoms are treated with similar practices as above. In addition, numerous prescribed and over the counter medications to treat and manage the symptoms associated with HIV disease and also those symptoms, such as neuropathy of the feet, that are directly related to taking antiretroviral (ARV) medications. Gastrointestinal discomfort and diarrhea are very common among patients on ARV drug regimens.

The importance of using available resources to manage symptoms can not be over emphasized. Knowing if the patient is receiving treatment from the community's traditional healer is also critical to providing the best care possible. Extensive research is lacking in the potential interactions of herbal remedies and most of the prescribed medications used to treat HIV disease. In order to protect patient from harm, the first step is to know what the patient is taking and to be aware and on the alert for drug interactions.

Palliative Care

The ICN/WHO/UNAIDS Fact Sheet 8 HIV palliative and terminal care, defines palliative care as "the combination of active and compassionate therapies to comfort and support individuals and families living with a life-threatening illness." (p.1). The primary theme of palliative care is the relief of suffering and the enhancement of the quality of life.

Palliative care is provided in patients' homes and also in institutions, such as hospices. A team approach reflecting the physical, emotional and spiritual needs of the patient and his/her family and operationalized within an appropriate and sensitive cultural framework, can provide the most holistic and comprehensive care.

The role of the nurse in the palliative care setting is critical to the successful provision of care. One of the editors in a foremost text on palliative nursing, Textbook of Palliative Nursing, compares the

role of the nurse in palliative care nursing to the role of the nurse in acute care nursing as follows:

> *In the acute care or disease-focused model of nursing care, there is much less emphasis on the individuality of the patient and the relationship between the patient and the nurse. The individual care provider is considered of limited importance within the system. In palliative care nursing, however, the active total care of patients whose disease is not responsive to curative treatment…where control of pain, of other symptoms and of psychological distress and spiritual distress is paramount, the individual counts in the healing process. The nurse counts and the nurse's individual relationship with the patient and family counts. The relationship, together with knowledge and skills, is the essence of palliative care nursing (p.3)*

Palliative Care Philosophy - According to the Fact Sheet 8 for Nurses, palliative care philosophy (p.2) includes the following statements:

- affirms the right of the individual and the family to participate in informed discussions and make treatment choices
- affirms life and regards dying as a normal process
- neither hastens nor postpones death
- provides relief from pain and other distressing symptoms
- integrates psychological and spiritual aspects of care
- provides a support system to help person living with AIDS live as actively as possible until death
- provides a support system to help the family and loved ones cope during the person's illness and/or death

Principles of palliative and terminal care – The ICN/WHO/ UNAIDS Fact Sheet 8 (p.3) also lists the following principles of palliative care:

- enhance the patient/family control and the quality of life
- provide practical support/advice for the person living with AIDS and their loved ones

- provide adequate pain relief and symptom control
- maintain the comfort and dignity of the individual
- provide spiritual and emotional/grieving support for the person living with AIDS and their loved ones
- prepare the person living with AIDS, their families and caregivers for death. This includes advice concerning avoiding any traditional death rites which could spread infection.
- ensuring that appropriate provision is made for the children involved and that their rights are respected
- provide bereavement support to the family and loved ones following death.

There are many, and sometimes unique, challenges in HIV/AIDS palliative care nursing. Frequently, the person dying is young and the fear of death, as well as the stigma and isolation associated with HIVAIDS is devastating. It is not unusual for the person with AIDS to be alienated from their family and friends, and community resources and support may also be lacking due to the stigma and alienation. Caregivers, both family members and friends as well as providers, may be overwhelmed with the dying process and the anticipatory grieving. In African countries, many families have lost numerous loved ones to the disease which impacts the number of people available to care for the terminally ill, and can trigger feelings of depression, guilt, and hopelessness. Also the poverty of many people in Africa prevents families from providing essential supplies/medications for the patient. Sometimes there is not sufficient food to provide adequate nutritional meals. HIV/AIDS has become one more problem for so many families and communities, and because resources are scare and stigma and denial is so prevalent, many caregivers develop feelings of helplessness and have extreme difficulty coping. It is vital that those societies with the most resources assist those societies with less resources.

Infection Control

Exposure to and transmission of HIV, as well as other bloodborne pathogens, such as Hepatitis B (HBV) and Hepatitis C (HCV), is a significant risk for health care providers and caregivers unless adequate and appropriate infection control procedures are instituted and continuously practiced. HIV has been identified in blood, semen, vaginal and cervical secretions, breast milk, urine, feces, saliva, tears, and wound, pericardial, synovial, cerebrospinal, and amniotic fluids. Some of these contain a higher concentration of the virus then others. The primary methods of transmissions of

HIV have been through contact with blood, semen, vaginal, and breast milk fluids. Occupational transmissions of HIV, HBV and HCV among health care providers have occurred only through blood exposures. The risk of transmission of HIV is less than one percent (<1%), and is dependent upon the severity of the exposure, the prevalence of HIV infection, and the compliance of personnel to established infection procedures. In the early 1980's in the United States (US), the Centers for Disease Control, US Department of Health and Human Services, developed infection control procedures to prevent transmission of bloodborne pathogens titled, Universal Precautions (UPs). UPs addresses the handling of sharp instruments and needles, the appropriate protective gear and when to use the gear, the disposal of biohazard wastes (wastes containing potentially contaminated fluids), and appropriate handling of soiled linens, dressings, gowns, and other potentially infected materials.
(The comprehensive guidelines, Updated U.S. Public Health Service Guidelines for the Management of Occupational Exposures to HBV, HCV, and HIV and Recommendations For Postexposure Prophylaxis, can be found online, http://www.cdc.gov/hiv/dhap.htm).

The following information on infection control and Universal Precautions is taken from ICN/WHO/UNAIDS Fact Sheet 11 HIV and the workplace and Universal Precautions (Fact Sheet 11 Can be located in Appendix E.)

Creating a safe work environment is essential to the prevention of transmission of bloodborne pathogens. Fact Sheet 11 (p.3) outlines the necessary conditions in establishing and maintaining a safe work setting. In resource poor countries it may be difficult to implement all the conditions required for safety, but it is the responsibility of all care providers to work towards the appropriate and adequate establishment of safe work environments, including settings in the community and patient homes.

Universal Precautions – Universal Precautions (UPs) are standards of infection control developed to prevent exposure and transmission of bloodborne pathogens (HIV, HBV, HCV). UPs should be implemented and practiced at all times by all health care providers and caregivers in all settings (hospital, clinic, community settings, and patient homes). UPs include the following:

- careful handling and disposal of all sharps
- hand washing with soap and water before and after all procedures
- use of protective barriers, such as gloves, gowns,

masks, goggles when in direct contact with potentially infected body fluids
- proper disinfection of instruments and other contaminated equipment
- proper handling of soiled linen

Sharps and Needle Sticks The greatest risk of HIV transmission is through mishandling of or accidents with contaminated sharp instruments or used needle stick injuries. Most of these injuries are with hollow-bore needles, and happen when needles are recapped, cleaned or improperly disposed. Containers for used needles should be located close to where they are being used, and containers should be punch resistant. When containers are full, they should be disposed of as biohazard waste in a location that is safe and not accessible to children or injection drug users. Containers can be incinerated or buried in a deep pit if an incinerator is not available. Generally, used needles should not be recapped, but sometimes recapping may be necessary (if need to transport used needles and container for used needles is not available). If recapping is necessary, one-handed scoop capping is the recommended method.

Every health care setting should develop procedures for infection control using UPs. Additionally, protocols for treating needle stick injuries and splash exposures should be established. As an example, needle stick injuries need to be flushed with running water and washed with soap; if stick site is bleeding, allow to bleed. If water is not available, antiseptic solutions may be used. All injuries and/or splashes should be evaluated for level of risk and reported to the appropriate personnel. If testing is available, base line testing should be done and voluntary confidential counseling should be offered. If antiretroviral (ARV) medications are available and are warranted based upon level of risk, they should be offered within 24 hours of the injury (appropriate treatment information is provided in the CDC Guidelines found online). A safe and supportive environment needs to be created so that any personnel who sustains an injury, feels sufficiently secure in reporting the injury.

Safe Cleaning of Equipment Appropriate scrubbing of equipment with soap and water removes most organisms if equipment has only been in contact with intact skin. Gloves should be worn and all equipment should be dismantled before scrubbing. Gowns or aprons and goggles should be worn if splashing is possible. If equipment has been in contact with non-intact skin and/or mucus membranes, then equipment should be sterilized by boiling or with

chemicals. If equipment or instruments have penetrated the body, then sterilization should be done or one-time use disposable equipment should be used. Autoclaving or dry heat (oven) or boiling in water for at least 20 minutes is recommended. If equipment is heat sensitive, chemical disinfection agents can be used. Chemicals that disinfect (inactivate HIV) are chlorine-based (bleach) agents, 2% glutaraldehyde, and 70% ethyl or isopropyl alcohol.

Cleaning of Floors, Walls, and Furniture Routine cleaning of the environment, such as floors, walls, beds, toilets, and rubber draw sheets can be done with detergents and hot water. Gloves should be worn if cleaning up spills of body fluids. Absorbent materials, such as cloths/dressings, should be used to mop up the spilled body fluids before scrubbing. The area can then be scrubbed with a chlorine-based solution (bleach) and wash with detergent and hot water. The contaminated absorbent materials should be placed in a leak proof container and incinerated or buried in a deep (at least 7 feet) pit.

Soiled linens should be handled as little as possible. Linens should be bagged at collection site in leak proof bags and transported to laundry area. If leak proof bags are not available, soiled linens should be folded with soiled areas inside and handled carefully.

Waste Disposal Solid waste that is contaminated with body fluids should be placed in leak proof containers and incinerated. If incineration is not possible, the leak proof containers should be buried in a deep pit (at least 7 feet) and 30 feet from a water source. Liquid wastes containing body fluids should be poured down a drain (if connected to an adequately treated sewer system) or poured into a pit latrine.

For additional information on creating a safe work environment and planning and management of equipment and adequate supplies, see ICN/WHO/UNAIDS Fact Sheet 11 HIV and the Workplace and Universal Precautions located in Appendix E.

Psychosocial Issues

A comprehensive discussion of the psychosocial issues associated with HIV/AIDS is beyond the scope of this module, but a brief discussion of some of the more critical issues facing patients, health care providers, and caregivers will be reviewed. These topics include fear, stigma, isolation, gender issues, and grief/bereavement.

Fear, Stigma, and Isolation Since the beginning of the pandemic fear, stigma, and isolation have been, and continue to be, monumental issues that negatively impact the quality of care and the infected person's quality of life. Frequently the stigma of HIV/AIDS triggers discrimination against the person who is infected. Discrimination against the person living with HIV/AIDS (PLWHA) is manifested in his/her personal and professional worlds, in his/her healthcare settings, in his/her living situation, and, unfortunately, in his/her familial and friendship relationships. It has not been unusual for a PLWHA to be evicted from his/her home, fired from his/her job, denied appropriate care, rejected by partners/spouses, parents, children, and friends, and, far to often, at significant risk for becoming victims of violence. No other disease, currently effecting human societies, is burdened with the degree and intensity of the stigma associated with HIV/AIDS. One of the primary causal factors of this HIVAIDS associated stigma is the route of transmission of the virus. HIV is classified a sexually transmitted infection (STI), transmitted through sexual behaviors, some of which are judged to be deviant behaviors in many of the world's societies. HIV is also transmitted through injection drug use, again, behaviors that carry a negative moral interpretation in most societies. HIV is also perceived as a preventable disease, in that individuals make choices about their behavior that may have negative outcomes and are considered undesirable by the larger society. Another factor contributing to the stigma associated with HIV/AIDS is that infection is often manifested in populations already stigmatized and marginalized by the community and/or society.

The impact of stigma upon the PLWHA and their family is emotionally, physically, socially, and spiritually devastating. Stigma exacerbates an already fear-laden situation and frequently leads to secrecy about his/her HIV infection and self imposed isolation. Infected individuals may not seek health care because of fear of rejection and discrimination. In African countries, many HIV infected women nurse their infants and risk transmitting the virus to them rather than bottle feeding them due to fear of being identified as having AIDS and thereby risking rejection and eviction from the family and the community.

Many fears about HIV and its transmission are based upon misinformation, even among health care providers. We still see and hear the myths about HIV and the false information that is still being propagated in every society. Currently, HIV/AIDS is a terminal disease, particularly without the intervention of ARV medication regimens, and even in countries with massive

resources, including medications, such as the US, we continue to have people dying of HIV disease. Fear of dying continues to impact those that are infected and their families. Grief and bereavement become significant issues in the HIV- impacted family.

Grief and Bereavement In countries with large numbers of people infected with HIV, such as in Africa, many people are becoming ill and dying. In some of the African societies, such as in sub-Saharan Africa, HIV infection has been a significant problem for several decades. The disease has severely destroyed many families killing multiple members within a family and effecting multiple generations of families. Children are caring for parents with the disease and grandparents are raising grandchildren because the parents have died from AIDS. In Uganda, a 70 year old woman is caring for 35 grandchildren with the assistance of her last remaining daughter. Ten (10) of her eleven (11) adult children have died from AIDS.

Grief is overwhelming in these families with multiple deaths. Additionally these families are being overwhelmed with the burden of care, both for infected family members and the dependent children of those family members that have died or are dying. Studies demonstrate that families with members that have died or are dying from AIDS are also severely impacted by the decreasing resources, loss of income, and worsening economic situation. Food productivity is severely compromised in many villages and communities due to the loss of members in the prime of life. Remaining family members have difficulty providing education for the children of dead or dying parents (education in Africa is not free). Significant levels of depression are manifested in many people due to some of these multifactorial causes.

Gender Issues In many African societies there are significant gender differences in issues of control and power. Cultural, social, economic, political, and sometimes religious, factors influence and support these power imbalances between men and women. Women have little control over their bodies and sexual behaviors, and they are dependent upon their husbands for economic support for themselves and their children Women's societal roles and inequitable conditions in African societies does not allow them to say no to unwanted, unprotected, sexual activities even if they know their husbands are HIV infected.

If a woman's husband dies, any property/wealth may revert back to the husband's family. Cultural traditions require that the family

care for the wife and the children, but that does not always occur, particularly if the woman and/or any of her children are HIV infected; and the assumption is that the woman (wife) infected the husband and not that the husband infected his wife. In some societies, polygamy is practiced and men sometimes also have girl friends, particularly if the men are forced to travel great distances from their homes/communities to find work. In some countries, men from rural communities may travel to cities to work and only go back to their villages at planting/harvesting time. Living for long periods of time away from their wife/wives, these men may have girl friends or purchase sex from prostitutes.

Traditional practices of requiring men to accumulate a dowry or bride price before marrying also impacts male sexual activities. The standard bride price for a wife is 10-11 head of cattle paid to the family of the young woman, so that men are often single for a long time, and when they chose a prospective bride, she is frequently much younger then the man and a virgin. Many HIV infected women have only had sex with their husbands, yet it is not unusual for these men to deny that they are infected and to reject testing (if available). The wife is blamed for the infection and transmitting the virus to her husband and her children. In Africa, over ninety percent (90%) of HIV is heterosexually transmitted. Young women have a slightly higher infection rate then young men in the same age category, and the greatest risk factor for African young women is being married.

Potential Intervention Strategies First, it is essential that we understand that the HIV/AIDS pandemic is more then a health problem that focuses on the behaviors of individuals. Jonathan Mann, the first Director of the Global AIDS Program at WHO and an outspoken speaker on the many issues impacting HIV transmission, has advocated for framing the pandemic within the context of human rights and social justice rather then a pandemic of an infectious virus that is transmitted only by individual risk behaviors. Discrimination, marginalization, stigmatization, racism, sexism and power imbalances, homophobia, poverty, political persecution, civil conflict and genocide create conditions for increased risk of HIV infection. More and more we are seeing that the people most at risk for HIV/AIDS are those individuals without rights who have little control and/or few options to direct their lives and/or the lives of their families. By viewing the pandemic in this framework, we can direct our energies and our interventions to address the factors and conditions responsible for facilitating the pandemic. In June of last year (2001), the United Nations had a special session on the worldwide impact of HIV/AIDS. Out of that

special session came a document, Declaration of Commitment on HIV/AIDS: "Global Crisis – Global Action". It can be viewed at: (http://www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html)

The distribution of ARV medications alone will not stop the pandemic. Discrimination, stigma, racism, sexism, and poverty must also be addressed. Adequate health care including appropriate social services and mental health services, education, and economic progress must also be implemented and supported. Addressing the social inequities, empowering women and children, stabilizing governments, and preventing the negative aspects of globalization can improve the living conditions of many people and must be part of any comprehensive program to stop the pandemic and prevent transmission of HIV. This struggle must be undertaken by all societies, all governments, and by all peoples.

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Subj:	**[procaare] HCC: Care, treatment and support - 1**
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HCC: Care, treatment and support - 1
Dr Gert Marincowitz, South Africa
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Basic Home Care: Care Treatment and Support.

When I first became aware of the need for Home Care, I saw people who needed compassion and care, more than overfull wards. I feel that home care has more to do with the need of people for compassion care and dignity than the fact that hospital care is very expensive. The truth is that in an environment where the system is geared to cure people, patients with incurable and/or terminal diseases are seen as icons of failure. Not many of us have the ability to give the best to our failures. What I would like to argue is that home care is not only about sound economics, but it is about quality of care in resource poor environments. Due to this inability to care with compassion of cure-focused institutions, the hospice movement took off. In resource poor areas (I admit economics does come in now!) a hospice could not be the first choice (but may have some role to play in the system).

The second motivation for home care is the value of a familiar environment. If it is then so, that Medical Care cannot cure a patient, the environment in which he/she has to spend during his/her illness should at least be familiar. For many of our rural patients the advanced technology and the fast pace of a modern hospital environment leave them feeling very uncomfortable, even with the best of care. The presence of loved ones in a familiar, friendly environment could make a big difference.

Most of the time only very basic care is needed to comfort a person with a terminal or incurable illness. This would include commodities that would be taken for granted in a resource rich environment i.e. relevant information, the presence of an understanding listener, a friendly word and a compassionate caretaker who can help with very simple basic chores in and around the home. All these things make a world of difference in people's lives. Many would consider a clean bed, clean clothes and food as a basic assumption. Many of us from privileged circumstances could not imagine that these basics could make a difference.

In societies that are based on meaningful relationships, the presence of loved ones makes a huge difference. Many times conflict and misunderstandings have had an impact on their lives. Addressing these issues will have a positive influence and have an impact on the care of a suffering individual.

I feel basic home care does not require much more treatment than what is available from clinics on an outpatient basis. The most difficult aspect for patients to deal with is the logistics of accessing it. In a well-organized home care system, where there is close contact between the patient, the family, the home based care worker and the local clinic; much can be achieved to make life bearable for those who suffer. It is often difficult to convince others that addressing these basic difficulties in resource poor areas can make a difference in these people's lives.

The impact of these basic care strategies I mentioned above has been well documented in the past. The positive effect of support in the lives of terminally ill patients has been

researched and proven by Siegel et al (1989) and Fawzy et al (1993). Moira Stewart summarized the most important aspects of caring: She felt the two broad distinctions for a health worker are a partnership-relationship and the understanding of medicine which is ideally based on a holistic and integrated approach. The first step to such a healing partnership is through LISTENING. People who felt heard become better sooner. The second aspect of the relationship is caring, empathy, support and compassion. The third is trust and control. She quoted Seifert who described the process as having the following sequence: Listening, Trust, Willingness to change, Skills, that finally leads to the power to take Control over their own lives. Sharing power and control is associated with positive outcomes. The last step she added is the finding of Common Ground. She felt mutual goal setting is essential in the empowerment process. She quoted William et al's study that describes the empowering process with the following steps: Trust, Connecting, Caring, Mutual Knowing and Mutual Caring. (Stewart, 1998).

Basic home care can be summarized as the availability of someone who will listen, care and support with empathy and compassion, facilitate trust and healing in relationships and to allow patients to gain some control of their own lives.

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Subj:	**[procaare] HCC:Care, treatment and support - 14**
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HCC:Care, treatment and support - 14 * A country perspective *
Felicity Hatendi, Zimbabwe
****

In Zimbabwe, the concept of Home and Community Care, was introduced in the late 1990s. This was in response to the increasing numbers of sick and terminally ill patients overloading an already overburdened, costly and ailing hospital or clinic service. The health services were unable to cope due to poor quality and quantities of services afforded in the public sector and also in an attempt to continue the continuum of care from the health service to the community and family - HCC was seen as a possible solution.

Unfortunately this new and noble initiative in my opinion as a State Registered Nurse and former Community based Health Visitor and Educator was not well thought through- by the health planners/administrators, policy makers and influential others. The community was not party to this decision. At the very onset it was necessary to have conducted a stakeholders meeting and series of consultative meetings - at all levels of society and ensure that the ²carers" who were mostly women's' voices, were heard and listened to.

Cognizance was not taken or considered of "who" was to continue the "care" in the community, "where" was the care to be conducted, "what" type of back up services or support was available in the community (referral facilities and services- private or public), particularly in a generally poor and improvised communities and households. " How" was the care to be conducted? Under whose supervision, "who" would monitor that the patient or client was getting optimum care?

Holistic "care" is necessary for both the caregivers and the cared for. The question should have been: could this be provided on a case-by-case basis, in varied and uneven circumstances and contexts. Emphasis here would have been the need for a comprehensive situational analysis on the, society, communities and typical families expected to provide care and support to caregivers and the sick. I still personally believe as health workers that we abdicated our professional and moral responsibilities in forcing the introduction of this concept to an ill prepared, poorly equipped in everyway community. We can rightly be accused of "dumping" the sick in most cases.

Unfortunately care-giving has always been the domain of the African women. In light of HIV and AIDS, she now has additional roles to perform, with little or no support from her nuclear family or extended family or community. It is no wonder that caregivers are overwhelmed. We should not underscore the fact that "nursing" or "tending to the sick" and particularly the terminally ill is not everybody " strong point", "calling" or appointment in life. What kind of support are we affording these women? There are very few back up services. Caregivers support groups are non-existent. These are necessary to deal with the stress and burnout commonly and frequently experienced by caregivers – but largely unnoticed by the majority.

Yes - in some parts of the country we do have private sector or civil society assistance in the form of Home and Community Care Teams. The teams are also largely composed of volunteers (women) with other chores to perform. They are frequently poorly trained and inadequately equipped with basic " nursing" skills and caring kits or packages etc. There

is a need for a enabling environment that can provide emotional, mental, social and spiritual support to the sick, their families and importantly Caregivers.

Lastly there is need to strengthen the linkages with the health services - whether these are at the local clinic or hospital levels. Care givers should be able to feel that they can link up, have their questions answered and importantly be supported by those "who know better' and are professionally trained to provide care and support.

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Subj.	**[procaare] Gaborone CHBC 2001 - Gender, Culture and Stigma (1)**
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1st SADC Conference on Community Home Based Care
5th - 8th March 2001
Gaborone, Botswana
- HDN KC Team
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Gender, Culture, Stigma and CHBC (Part 1)
Gender and Home Based Care

The crowded conference breakout session on gender, culture and stigma and CHBC examined the dynamics of gender, culture and stigma in relation to community and home based care. This followed from an interesting morning plenary presentations on gender and on stigma. All but one of the seven presentations was based on the experience of Botswana. As so many important issues were raised there are two separate postings on this session:

Part One will discuss issues relating to gender and home-based care
Part Two will focus on the stigma of HIV and its implications for Home Based Care. Audience reactions are included in part two.

Part One - Gender and Home Based Care

'Who needs home based care?'
Increasing numbers of people are falling ill as a result of HIV infection. The situation is particularly acute amongst young women as women are infected at a younger age than men and consequently fall ill at a younger age. Home Based Care was introduced in Botswana in 1992, as hospitals were not coping with increased numbers of patients and the increased burden on the health care budget. Home Based Care effectively transfers the burden of care onto the community, the presenters in this session argued that the burden of caring falls disproportionately on women as a result of gender and cultural norms.

Who cares for HIV positive women?
It was evident from all the presentations that men and women receive very different standards of care. Married men are usually cared for by their wives and daughters, and in fact very few male patients were reported in their programmes. It was speculated that this was because many local men had wives to care for them or that were migrant labourers who returned home to their wives when they fell ill. In contrast to this, women are often blamed for their husbands' illness and several speakers described the situation where in-laws chase women out their house on their husband's death. This leaves many women destitute, with no possibility of receiving care should they fall ill.

In all home-care programmes presented, the vast majority of patients were single women - unmarried or widowed. Olivia Moemele's experience from Boteti District, Botswana, has led her to conclude that often if a woman becomes ill, even if she has a husband, he will not care for her and he will ask her family to come take her away, so that the responsibility of care falls on her mother, sisters and other female relatives. Many women are dependent on hospital care as they have no one to care for them.

In addition, Florence Mhonie argued forcefully that women need hospital care in order to

get the rest they need and to be able to eat regular meals. Ms Mhonie carried out focus group discussions with over 700 participants in Northern Botswana, asking them to chart what they had eaten over the last 24 hours. The study found that many women regularly missed meals, typically getting the leftovers after the men and children have eaten: "women scrape the bottom of the pot." As a result women get much less protein and other vital nutrients than other family members. Despite having clear needs for hospital care, women also have the least access to health services as they are seldom employed and have no money to pay for transport, prescriptions and other costs.

Although the burden of care on women's physical and emotional health was discussed, however the additional burden of care on already weakened HIV-positive women was missing in the discussion. Positive women jeopardise their own health through the constant struggle to care and provide for their families.

'Gender norms complicate home care provision'
Caring for sick relatives at home is stressful and difficult, and made much worse by the severe lack of resources within the households. A 1996 baseline study, reported by Banyana Monyena-Parsons, found that only 12% of caregivers received material support from the government and 8% from churches. Of the 80% who received no material care it was suggested that HIV-related stigma and shame prevented caregivers or their patients from requesting help.

Women under intense psychological and physical stress need help but often families refuse to care for them because of the stigma attached to caring for someone with HIV infection. So who looks after sick women? Their parents will often only get involved at the very last stage when the patient is dying or even just for the funeral. In Botswana and elsewhere there is a deeply embedded view that "women should suffer in silence" .It is difficult for women to express that they are tired, hungry, unwell. A good woman is expected to care for her family without complaint. As a woman's domestic role is culturally entrenched, contesting it may leave her isolated, vulnerable and even subject to violence. Medical professionals have not supported women through these experiences and Ms Parsons described a medical view that women's resistance to domestic subordination is dismissed as 'housewife neurosis'.

Young girls suffer an immense burden of providing care particularly for their sick mothers or for their father and siblings, if the mother is too ill or has already passed away.
Even girls who are in school are withdrawn to care for sick family members. Olive Moemele described a common situation that the men increasingly disappear and spend longer in bars rather than being at home caring for a sick wife or child. Men will often keep themselves busy at work or out drinking with friends rather than helping out at home. Olive disagreed with the presenters who said that men often help with transport. In her experience men won't even call for an ambulance.

Involving men in home based care
All the presenters agreed that recruiting men and boys into home based care has been extremely difficult and to date, unsuccessful. However it was stressed that as men prefer to receive and discuss prevention messages from men not women, there is an important role for men to play in providing care. Substantial barriers inhibit men's involvement in home-based care, however. Men do not want to be seen doing menial roles such as cooking and cleaning. Men are regarded as breadwinners, they need paid work and do not accept the concept of volunteerism.

Men need more training than women because they are less informed about care issues in general and are unused to domestic tasks. When women volunteers in Zimbabwe were asked whether they thought that men could provide home based care, they responded that men should not do chores but rather attend to male patients - helping them to bathe and

transporting them to the clinic. They could also be involved in giving advice and teaching.

Priscilla Mataure from SAFAIDS in Zimbabwe explored the possible role home-based care in HIV prevention. Working directly with affected families, she stressed, created many opportunities for family members to assess their own risk of infection, which could promote behaviour change. The home also provides a safer space to discuss sensitive issues such as gender roles and violence. Counseling becomes more focused and practical and ensures cultural relevance. By targeting the family directly, she felt that it was easier to then encourage men to take up their responsibilities for care.

Health risks associated with home based care
Families in Botswana are given information about universal precautions but they often still do not understand why it is important. Even when they are given gloves and disposable nappies, they are not advised how and where should they dispose of them. These issues are often not thought through and again as women are the primary caregivers, are more vulnerable to any of the possible risks.

Monyena-Parsons described a typical home based care programme in a Botswana village - it currently has 116 patients, 3 nurses of whom only one is full-time, and 18 active volunteers, 17 of who are women. One social worker and one vehicle is shared between 4 villages. They can use the vehicle once a week, but apart from that day there is no transport to take people to hospital if they need to be admitted. The presenter emphasized a clear need to develop strong links between home-based care programmes and the hospital. She also expressed urgent need for the development of respite care, to provide good medical and psychological care for patients and also give caregivers a short break from their responsibilities so they don't get burnt out.

There is also a need to recognize that home based care can be very physically demanding particularly for women and children who feel weak and malnourished themselves.

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Subj.	**[procaare] Gaborone CHBC 2001 – Gender, Culture and Stigma (1)**
Date:	6/18/01 11:47:56 PM Pacific Daylight Time

From: correspondents@hdnet.org (HDN KC Team)
Sender: owner-procaare@usa.healthnet.org
Reply-to: procaare@usa.healthnet.org
To: procaare@usa.healthnet.org

1st SADC Conference on Community Home Based Care
5th - 8th March 2001
Gaborone, Botswana
- HDN KC Team
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Gender, Culture, Stigma and CHBC (Part 2)
Stigma and Home Based Care

Part Two - Stigma and home based care

The crowded conference breakout session on gender, culture and stigma and CHBC examined the dynamics of gender, culture and stigma in relation to community and home based care. This followed from an interesting morning plenary presentations on gender and on stigma. All but one of the seven presentations was based on the experience of Botswana. This is the second of two reports on the session, with the focus of this report on stigma in community home base care.

One of the presenters, Florence Mhonie, presented findings from over 70 focus group discussions involving 731 participants in Chobe District in 1999. Chobe is a region of northern Botswana that borders of Zimbabwe, Namibia and Zambia. The area has been severely affected by HIV. In 1999 antenatal HIV tests revealed that 50.8% of pregnant women tested positive for HIV infection, out of these, more than 70% were single mothers. The main objective of the study was to gather baseline data to assist the District Multi-sectoral AIDS Committee to plan and implement a comprehensive HIV/AIDS prevention and care programme. Focus group discussions revealed that knowledge about HIV was very low except amongst teachers and young people in school.

Myths abound about how and why a person is infected with HIV was prevalent. One of the most common was that a man would be infected if he had sex with a woman who had just had an abortion, or who was in mourning. There was a strong belief that AIDS is a punishment from God and many people, men in particular, expressed the belief that one can rid oneself of HIV by sleeping with as many people as possible - that this would dilute the amount of HIV in the body. Other myths concerning the dangers of abstention were widespread particularly among young people. Condoms were universally unpopular with men who felt that condoms go against their culture by preventing procreation.

Even more startling was the reported attitudes that focus group members expressed towards HIV-positive people. Many stated that they felt that HIV-positive people should be killed in order to stop the spread of HIV. When asked how, or who by, it was suggested that people with HIV should be burnt or that nurses could kill them. It was also suggested and supported by many people, that HIV-positive people should be marked on the body, such as a tattoo under the armpit so that sexual partners could recognize then they take off their clothes.

Some participants felt that people with HIV should be cared for, but in hospital isolation wards. This raised many issues: some thought hospitals were too congested and could not accommodate people with HIV. Others felt people with HIV were not treated well in hospital and had heard that nurses kill patients when their condition becomes hopeless. Nurses were

criticized for being rude and uncaring. An old man, tired of the whole discussion, said "the hospitals discovered this thing so let them deal with it."

These findings were presented to the local chiefs, councilors, teachers and other community leaders. As a result of the study, there is now local support for a counseling centre and entertainment programmes have been developed for young people that incorporate educational elements and provide a distraction from drinking in bars.

Mr. T Mogotlhwane took a broader view of home-based care by questioning the status of the home. He felt that the fabric of society, where people cared for one another is disintegrating and felt that this was substantiated by the steep rise in violent crimes such as rape and sexual abuse. He called on parents to take responsibility for their children's well being and moral education. He called on neighbours to show interest and begin to care for one another as in times past. In order to reduce the stigma of HIV, home-based care should be based on a social response rather than placing the burden entirely on individuals and their families.

Much of the lively but short discussion that followed focused on the involvement of men in home-based care: One man suggested that men had been alienated over the years by approaches that focused on women and development, maternal health, and prevention of mother to child transmission of HIV. "They leave us out and then they say we are not participating" this received a huge round of applause.

A development worker from Botswana noted that every presenter had used a different definition of the term gender and that all too often gender is synonymous with women. She argued that we should be precise about the terms we use, particularly if we wish men to become more involved.

A delegate from Botswana felt that women and men are made differently and that women are indeed more compassionate by nature. She suggested that if we want men to be involved in home based care that we must think of roles that they can perform without compromising themselves as men. She accepted that men would not bathe patients but felt that there must be something else they could do.

Another delegate from Botswana expressed a common criticism of home-based care in that it often starts too late once the patients are very sick. A Ugandan delegate felt that there is a need to address the issue early through counseling so that people with HIV feel as if they have a say in how they will be cared for, where and by whom.

Another observation was that while women's role to produce children had been discussed, the dilemmas facing HIV positive women was not acknowledged. Women's relatives expect women to have children yet HIV counselors advise women not to get pregnant. How can the stigma felt by HIV positive pregnant women and mothers be reduced? The Ugandan delegate explained how stigmatizing it is for mothers to bottle-feed their babies instead of breast-feeding. They are publicly criticized and castigated by family members such as their mothers in law.

Recommendations:
- Need to tackle entrenched traditional gender barriers and stereotypes (the how was unfortunately not proposed or discussed).
- Need a concerted effort to get men involved (again lacking how this should be done)
- Every family member must be involved in caring for the sick and that socialization of men must begin at an early age.
- As both women and men contribute to the problem of HIV, both must be part of the solution.
- Poverty reducing strategies as even families considered middle class are becoming

impoverished as the breadwinner stops work due to illness.

Presenters:
1. Priscilla Mataure - Integrating HIV prevention into Home Based Care Programmes. Priscilla@safaids.org.zw
2. Dr Phaladze, University of Botswana - Gender and CHBC in Botswana. phaladze@mopipi.ub.bw
3. Josephine Kgolagano CHBC - a woman's burden - Boteti experience
4. T Mogotlhwane - Home based care but are there homes? mogotlw@mopipi.ub.bw
5. Olivia Moemele Gender issues in CHBC - burden of care on women and girl child, the role of men in home based care
6. Banyana Monyena-Parsons - Women as caregivers in the HIV/AIDS era. uisys@it.bw
7. Florence Mhonie - Impact of culture and stigma on community and home based care. mhonie@botsnet.bw

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The Insight Initiative Project is managed by Health & Development Networks (HDN) in collaboration with the Thailand Red Cross Society, the World Health Organization and the Royal Thailand Government, with financial support from AusAid and UNAIDS.

For more information about this project (the 'Insight Initiative'), visit the HDN website at: http://www.hdnet.org

Fifth International Conference on Home and Community Care for Persons Living with HIV/AIDS
Chiang Mai, Thailand - 17-20 December 2001
Website: http://www.hiv2001.com

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APPENDIX A. CASE STUDIES

CASE STUDIES

Introduction

Case studies are used to examine diverse situations impacting persons with HIV/AIDS or at risk for HIV infection. Not only physical conditions can be identified and potential intervention options addressed; a client's mental health and psychological issues can also be discussed. Trainers are urged to create actual case studies from their own clinical experiences to fit their specific training needs. The more specific and relevant the case study discussions can be to the learners' real life experiences, the more valuable the learning experience will be. The use of case studies is an excellent strategy to introduce practitioners to the multiple and complex issues impacting HIV infected people who may be preparing to start ARV therapies.

When training nurses from other countries and of different cultures, it is essential that collaboration with nurses from the specific country/culture be the foundation for the development of case studies. Case studies should reflect the cultural values, norms, and practices of the partnering country in order to ensure appropriate determination of ARV therapies for and nursing care of clients/patients from the specific culture.

Large Group
[10 minutes]

The facilitator will divide the large group into smaller groups and assign each small group a case study.

Small Group
[20 minutes]

Each small group will develop a comprehensive, multidisciplinary plan for care coordination based upon the history and assessment provided. The plan should include results of the problem list as developed by the nurse in collaboration with the patient and the patient's family. The plan should also include the identified patient and family needs, the potential barriers to ARV therapies, the intervention options to overcome the barriers, and recommendations for additional resources and/or referrals. Each small group should be given a flip chart paper sheet to record the plan. (Refer to the study questions listed below).

Large Group
[45 minutes]

Each small group with report back to the large group on the proposed plan for care coordination. Each group will have 5-8 minutes for this activity.

Study Questions for Small Group Discussion

In the designated small groups answer the following questions for your assigned case study. Explore in depth as much as possible the potential assumptions, barriers, options, and strategies for each case study.

1. What are some assumptions that providers could and do make about patients and their families ability to manage the care and ARV therapy?

2. What are the issues that must be identified by the provider and patients and their families to identify the appropriate ARV therapy?

3. What are the potential barriers to each patient's ability to Manage the therapy?

4. What are some strategies that could facilitate each patient and patient family to manage ARV therapies?

(Materials in this appendix were adapted from Frank & Miramontes, Health Care Providers Adherence Training Curriculum HAB, HRSA: Washington, DC., 1997.).

APPENDIX B – ROLE PLAYS

ROLE PLAYS

Introduction

Role plays are practice sessions to try out strategies and approaches to challenging issues. Role plays draw on your past experiences and introduce a variety of view points within a short time frame. Practicing role plays can lead to actual changes in attitudes and behaviors by increasing skill, comfort, and problem solving ability, and provides practice opportunities to rehearse new and/or difficult responses.

Role plays can be structured in a variety of ways to provide optimal learning involvement. Participants are reminded to practice a simulation, comparing the practice to a fire drill. Role plays may be set up as:

* Dyads – Debrief by asking each pair to describe the interaction, focusing on how the learners felt, what was successful, and what was not successful.

* Triads – While two of the group members role play, the third person acts as an observer who assists with debriefing after the interaction. Be sure that the observer is rotated through the triad so that each learner has a chance to role play the different roles.

* Quads – Similar to the triad, but the fourth person act as a "coach" to provide back up upon request, and take the pressure off of players who may feel self-conscious.

* Spontaneous Role Plays – If an issue arises that seems difficult to do, immediately set up a role play that would address the specific issue.

Feedback

<u>Guidelines for Giving and Receiving Feedback</u>

<u>General Principles</u>:

- Start with something the practitioner did well during the role play,
- Discuss an aspect that could be improved,
- Provide an example,
- Select one or two areas of focus.

Specific Guidelines

- Give feedback that is specific and concise,
- Link feedback to techniques presented during the training, rather than personal experience,
- Describe the behavior, rather than evaluating it,
- Offer concrete examples of how to improve the behavior. Reinforce positive aspects of efforts.

Receiving Feedback

- Seek clarification if the feedback is not clear,
- Avoid defensiveness,
- Ask for specific examples from the observer if these are not given.

Large Group [10 minutes]

Divide into triads. The roles will be patient, provider, and observer. Each triad will have three role plays. Each participant will rotate through each of the roles. The focus of each role play will be to use the communication techniques of barrier assessment and intervention strategies to provide appropriate guidance about ARV therapies.

Triads [50 minutes]

Each role play will last for 15 minutes. The patient and the provider should interact for approximately 8-10 minutes and the observer will provide feedback for about 5 minutes using the techniques described above. The facilitator will announce when it's time to change roles.

Large Group [30 minutes]

Debriefing about the role plays will occur in the large group. This debriefing session can be an important learning experience for all participants.

Questions to Consider

1. What practitioner activities/questions were most helpful during the role plays interaction?

2. What activities/questions didn't occur that could have enhanced the interaction?

3. What activities could have been included if there more time?

(Adapted from Frank & Miramontes, Health Care Providers Adherence Training Curriculum. HAB, HRSA: Washington, DC, 1997.).

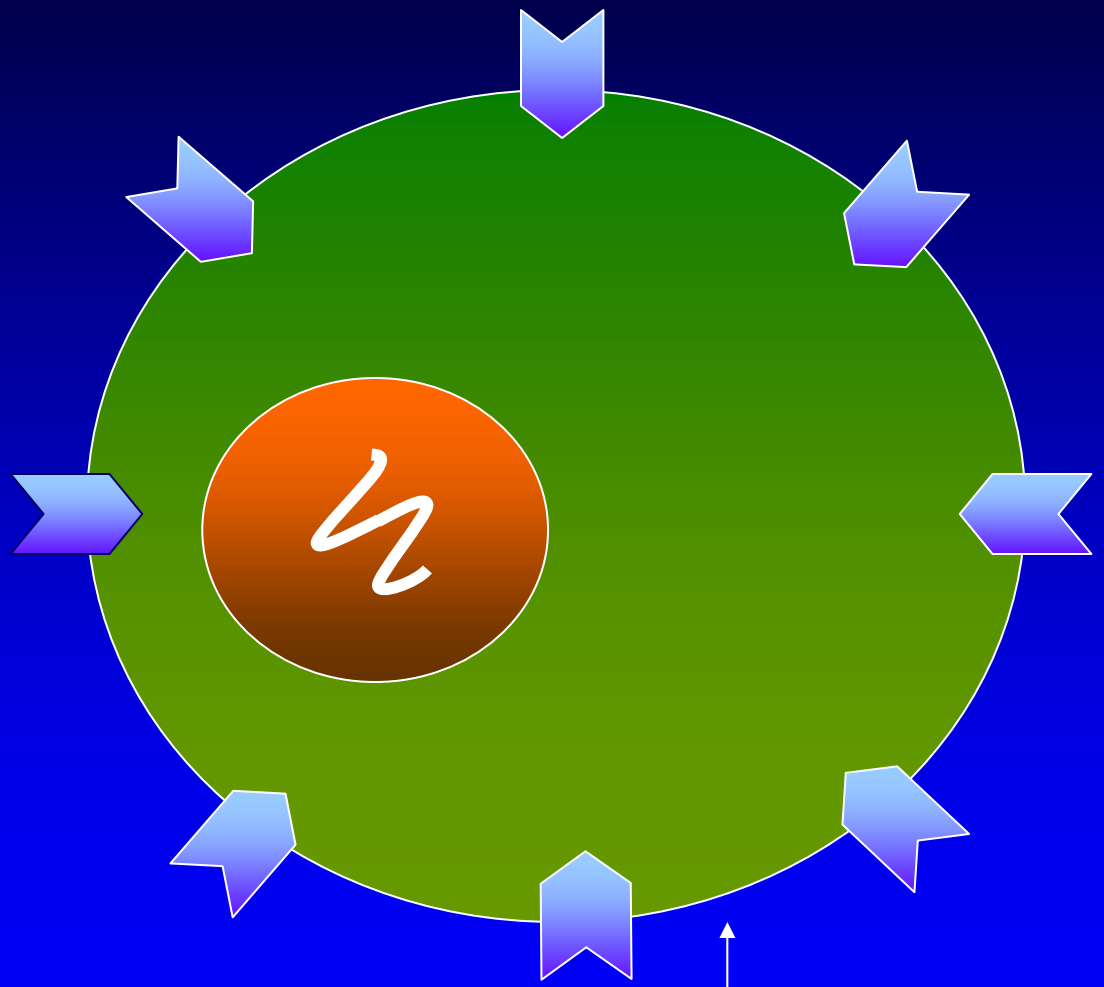
APPENDIX C – ARV THERAPIES & ADHERENCE EXERCISES

APPENDIX D – CULTURAL EXERCISES

APPENDICES E – ICN/WHO/UNAIDS FACT SHEETS FOR NURSES & MIDWIVES

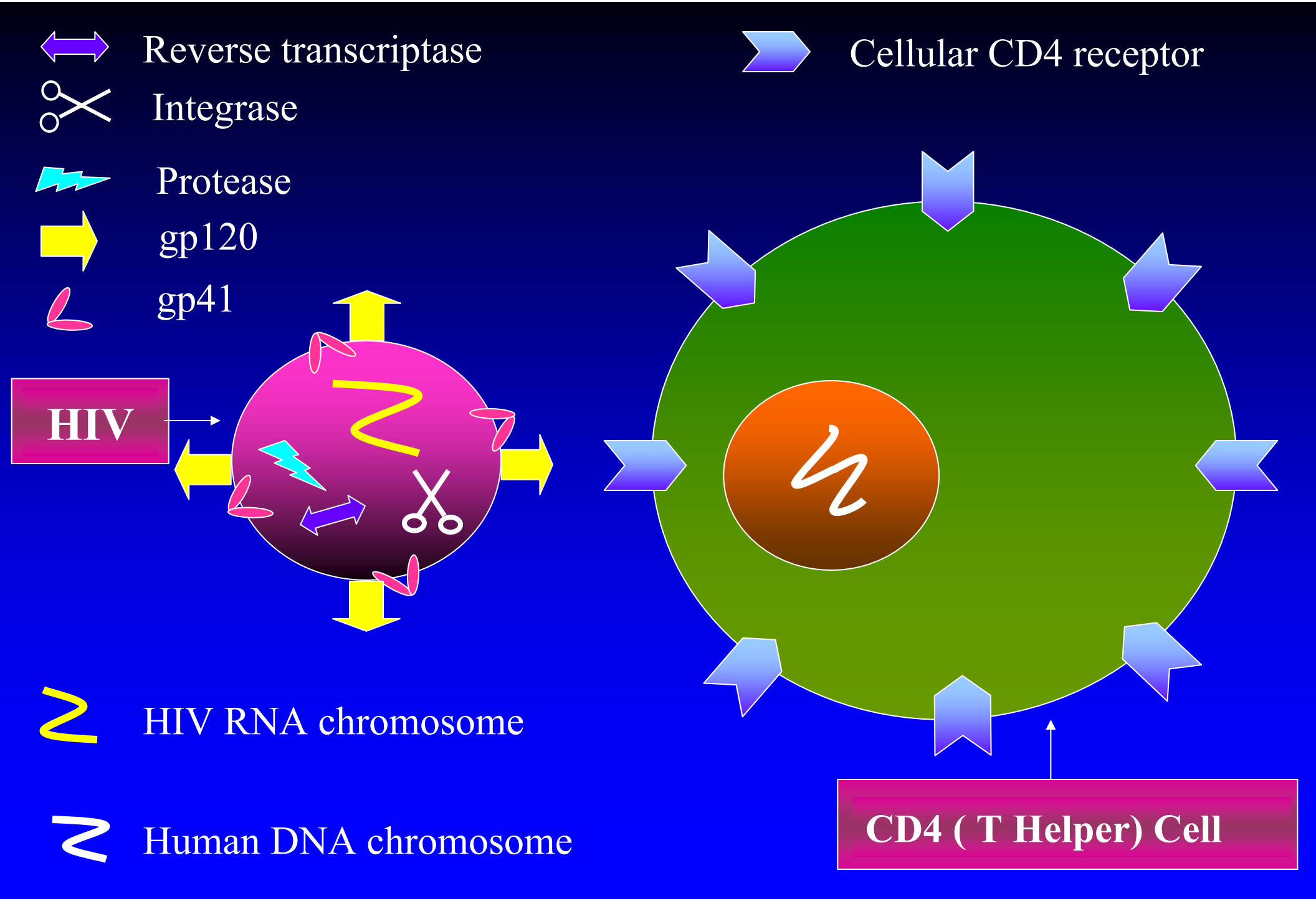
APPENDICES F – WHO USE OF ART IN LIMITED RESOURCE SETTINGS

Cellular CD4 receptor

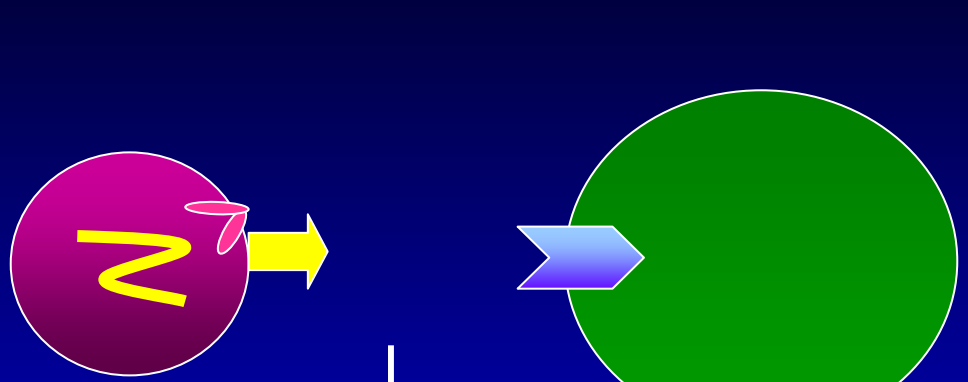


Human DNA chromosome

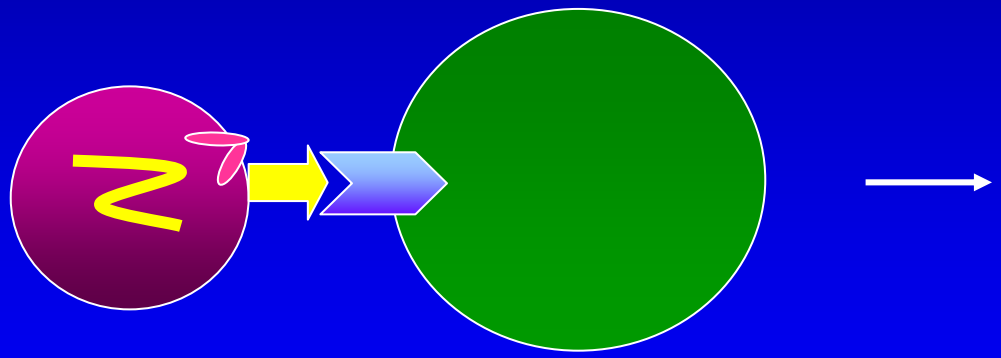
CD4 (T Helper) Cell


Reverse transcriptase
Integrase
Protease
gp120
gp41
HIV
Cellular CD4 receptor
HIV RNA chromosome
Human DNA chromosome
CD4 (T Helper) Cell

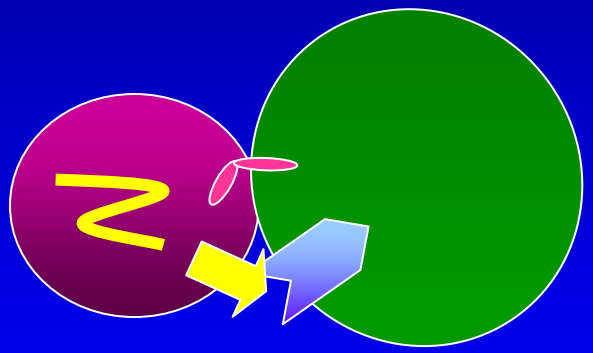
1. HIV approaches CD4 cell



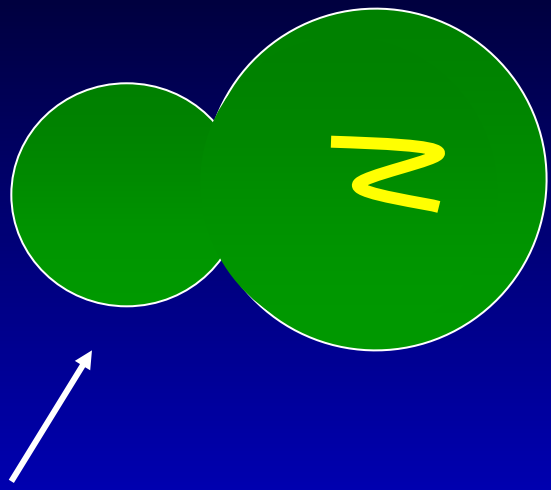
2. Gp120-CD4 interaction

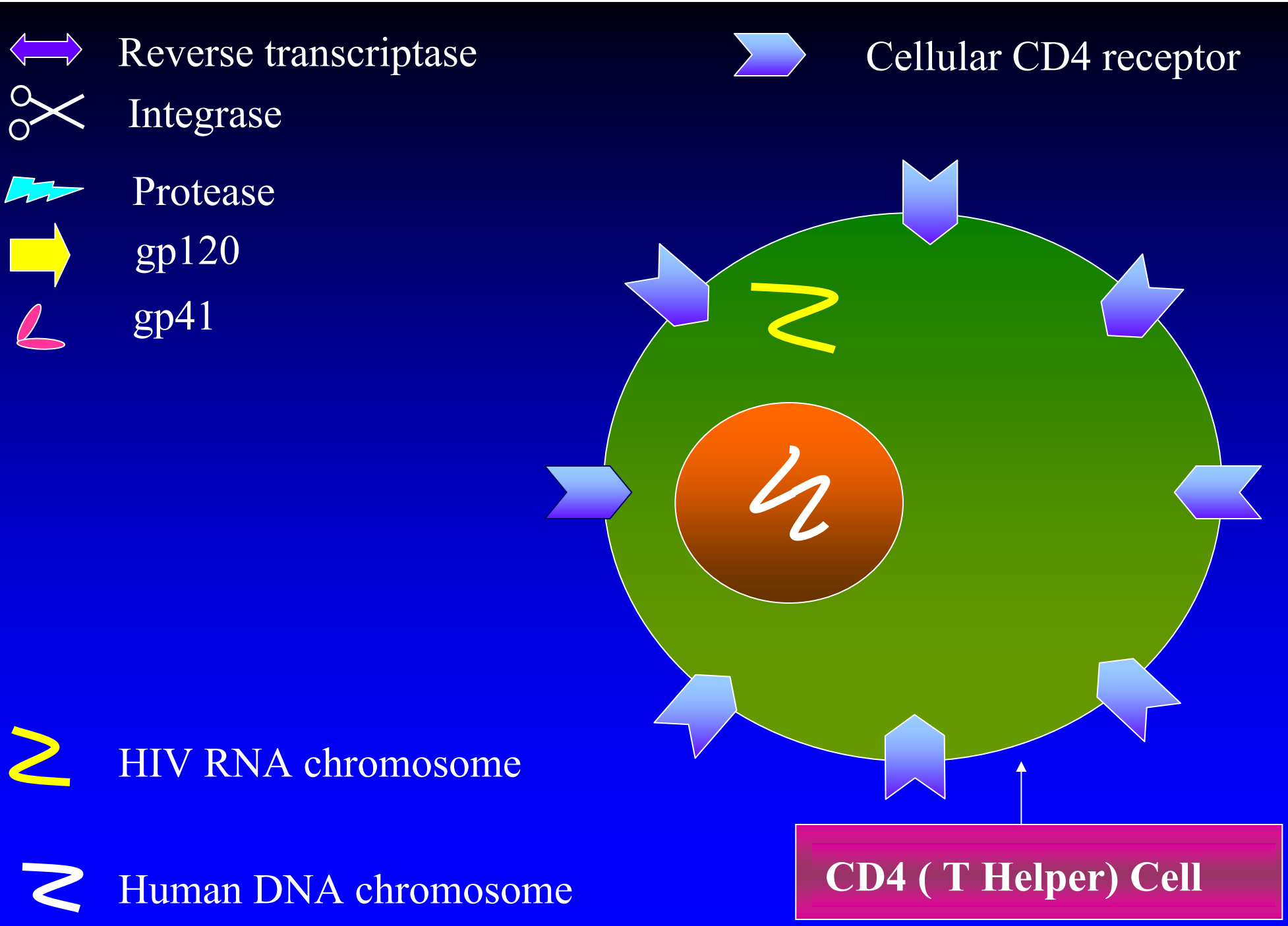


3. Conformational change in gp120, exposing hydrophobic fusion protein (harpoon) of gp41



4. Fusion of cell and virus




Reverse transcriptase
Integrase
Protease
gp120
gp41
Cellular CD4 receptor
HIV RNA chromosome
Human DNA chromosome
CD4 (T Helper) Cell

Reverse transcriptase

Integrase

Protease

gp120

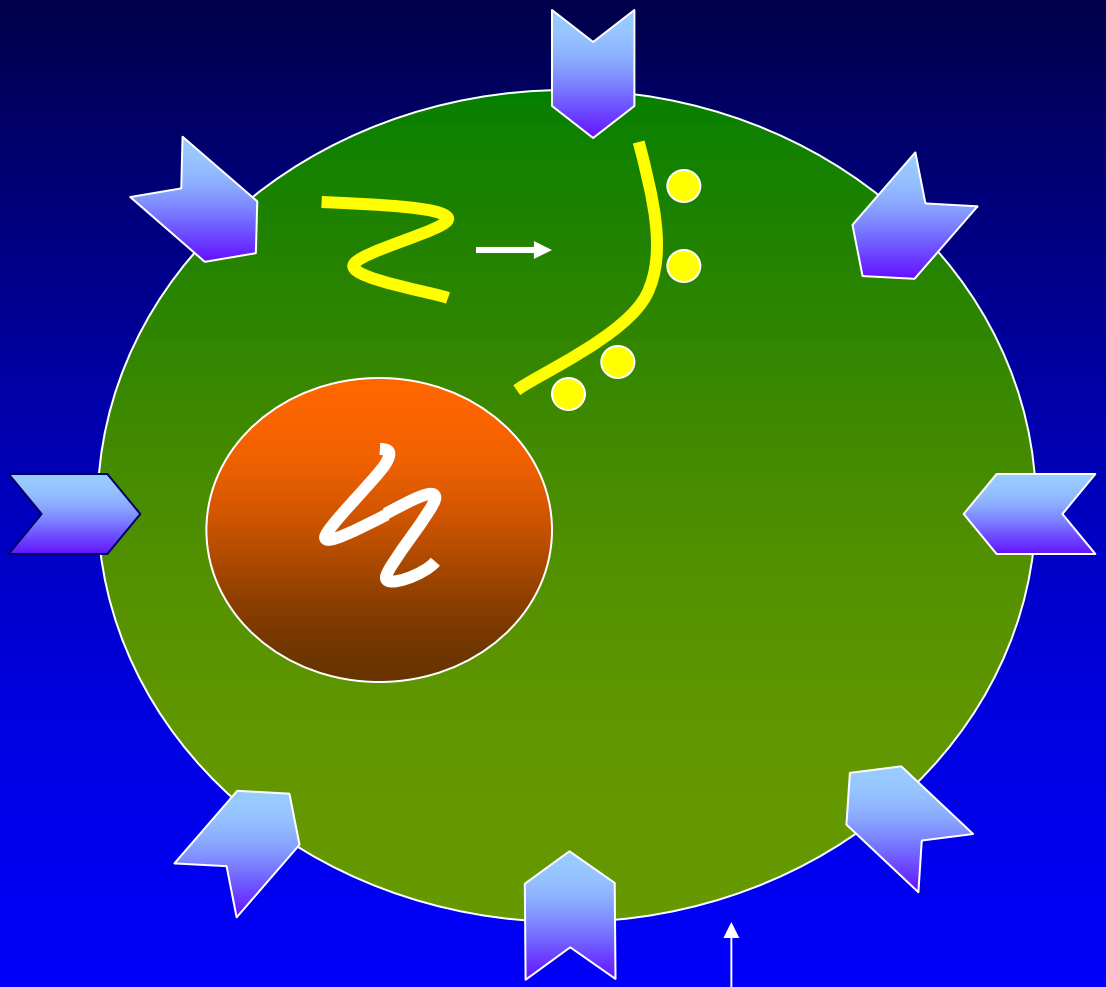
gp41

RNA nucleotides

HIV RNA chromosome

Human DNA chromosome

Cellular CD4 receptor



CD4 (T Helper) Cell

Reverse transcriptase

Integrase

Protease

gp120

gp41

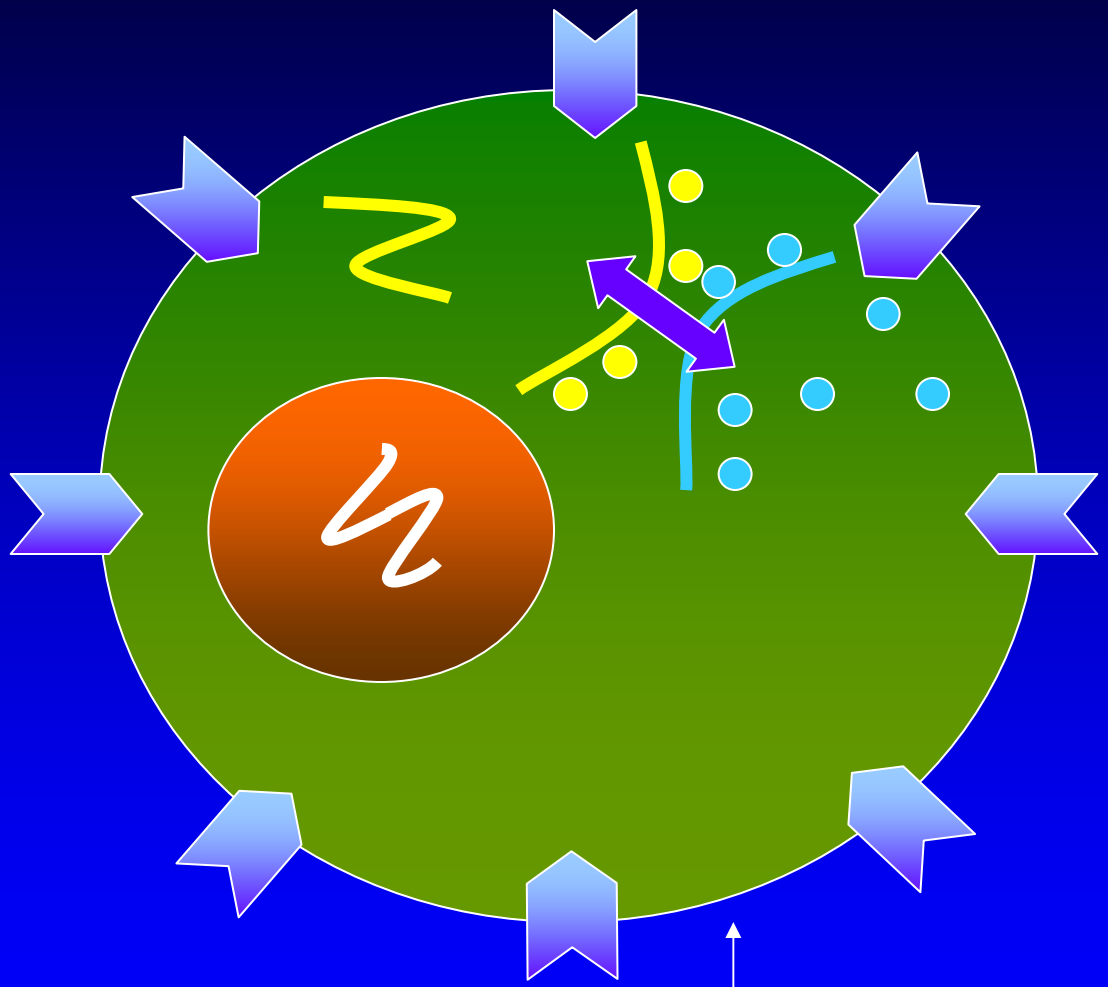
RNA nucleotides

DNA nucleotides

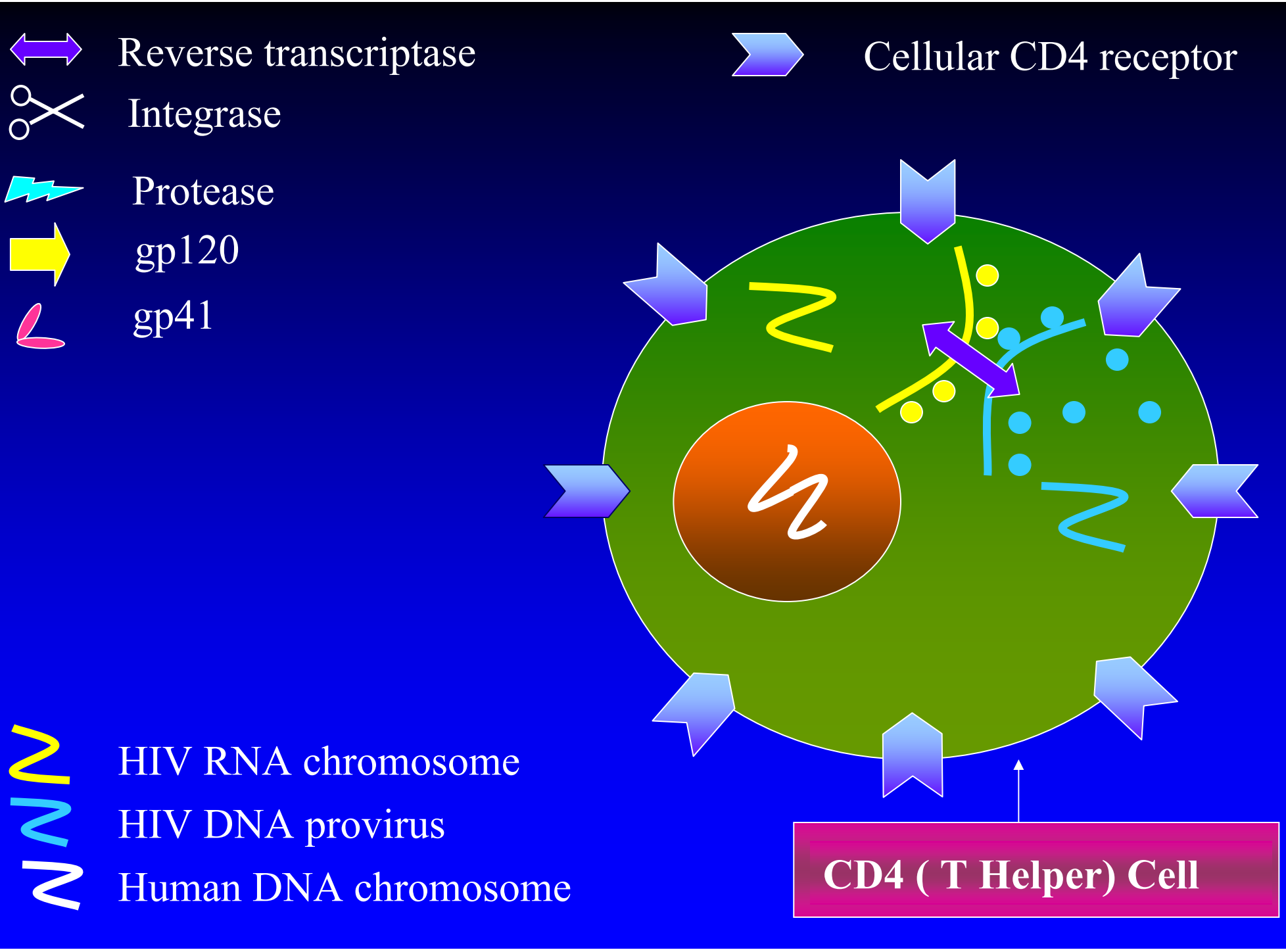
HIV RNA chromosome

Human DNA chromosome

Cellular CD4 receptor



CD4 (T Helper) Cell


Reverse transcriptase
Integrase
Protease
gp120
gp41
Cellular CD4 receptor
HIV RNA chromosome
HIV DNA provirus
Human DNA chromosome
CD4 (T Helper) Cell

Reverse transcriptase

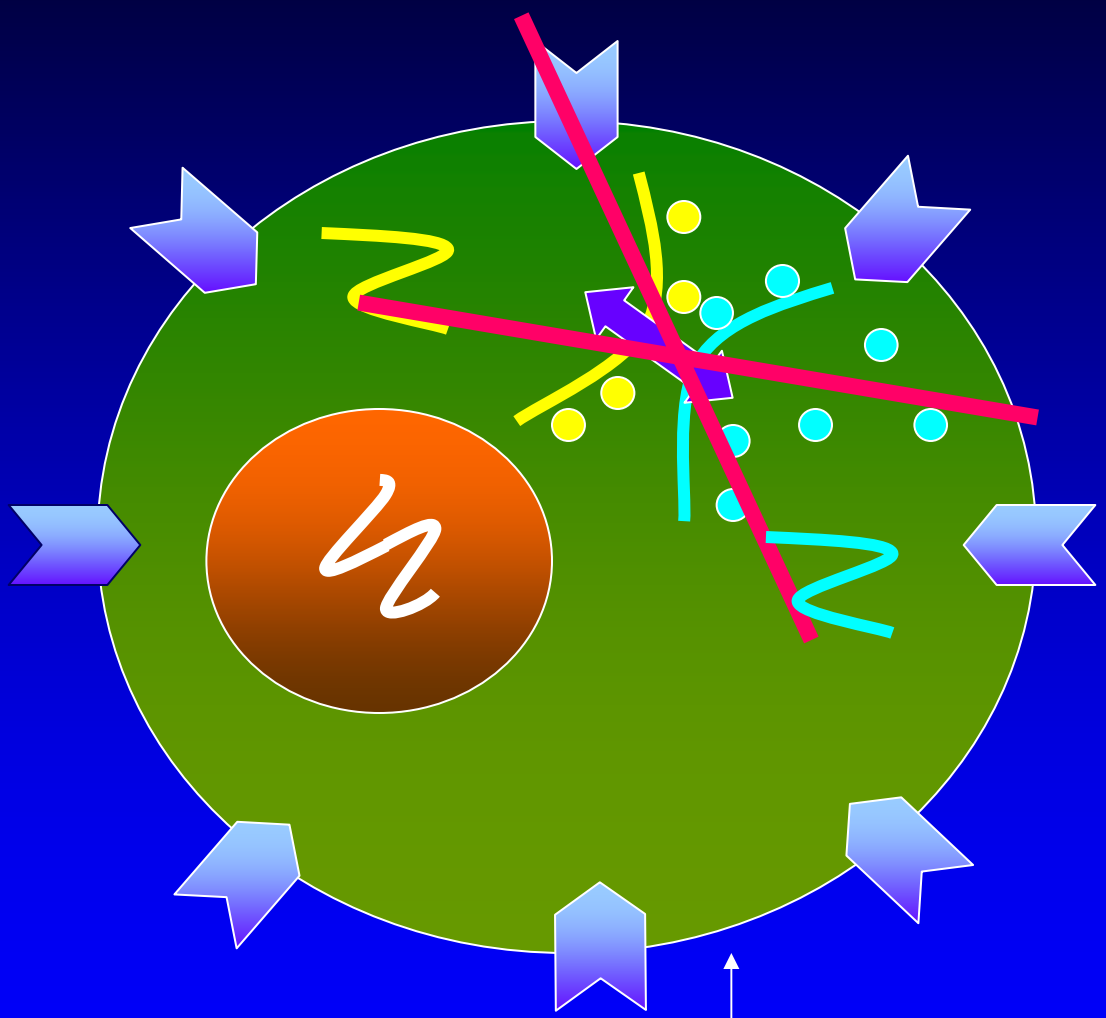
Integrase

Protease

gp120

gp41

Cellular CD4 receptor



Reverse Transcriptase Inhibitors:

Nucleosides and Non-Nucleosides

HIV RNA chromosome

Human DNA chromosome

CD4 (T Helper) Cell

Reverse transcriptase

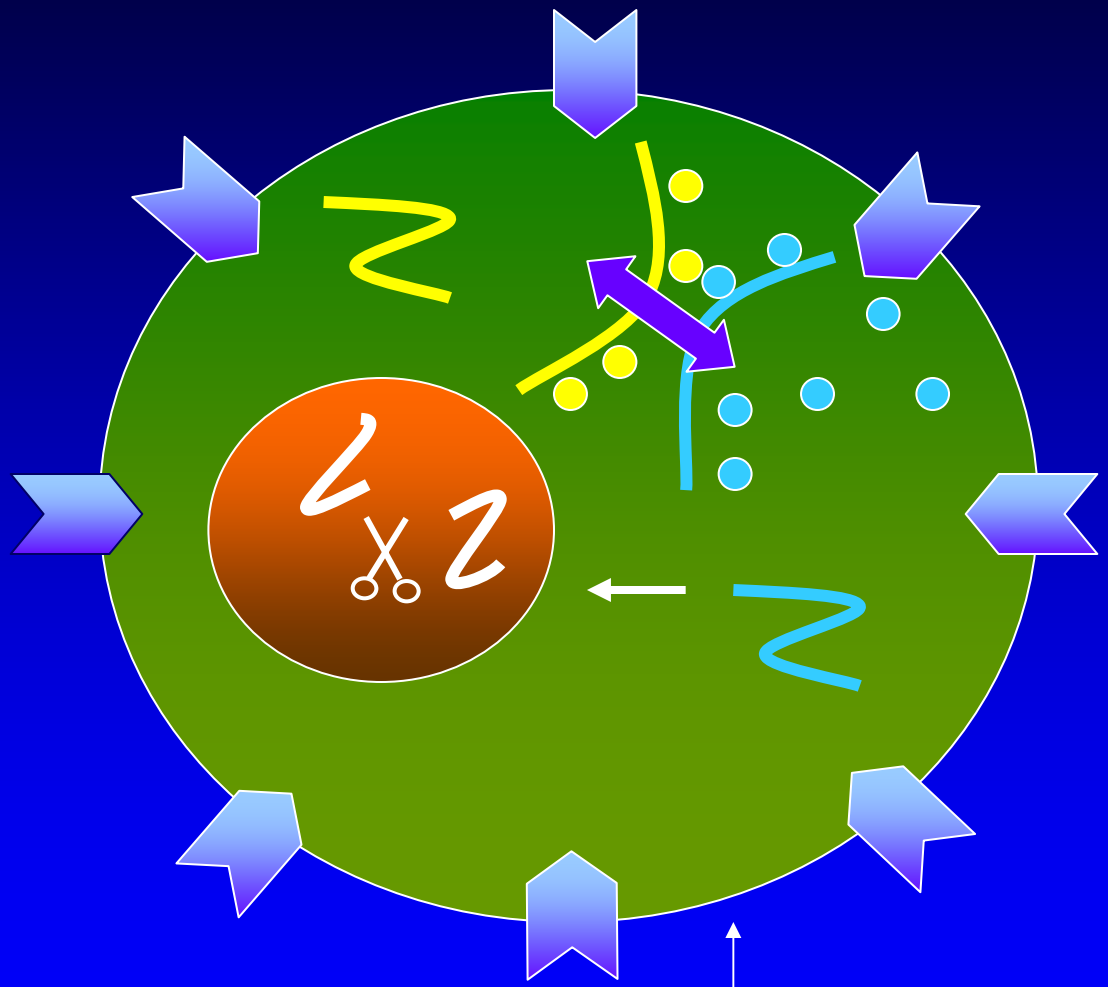
Integrase

Protease

gp120

gp41

Cellular CD4 receptor



HIV RNA chromosome

HIV DNA provirus

Human DNA chromosome

CD4 (T Helper) Cell

Reverse transcriptase

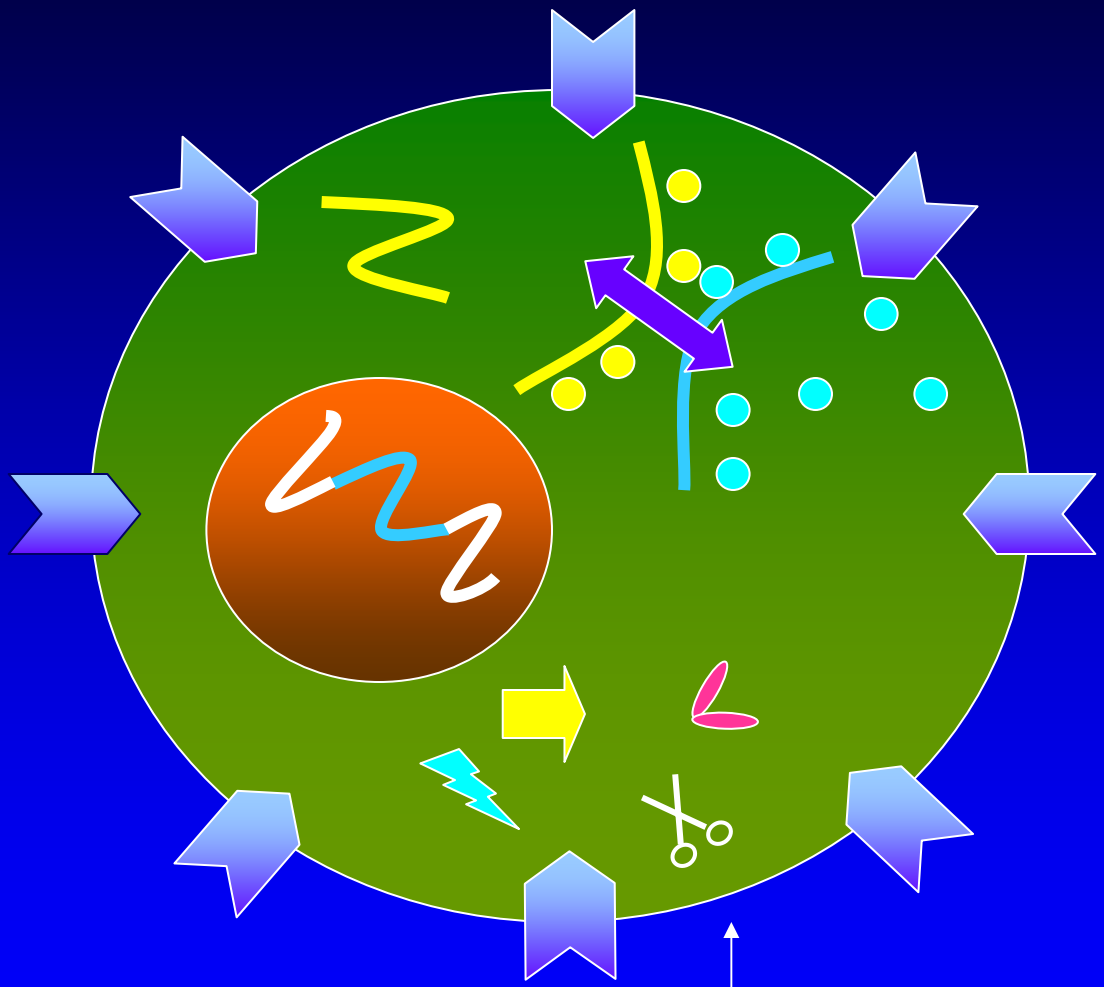
Integrase

Protease

gp120

gp41

Cellular CD4 receptor



Cellular Activation

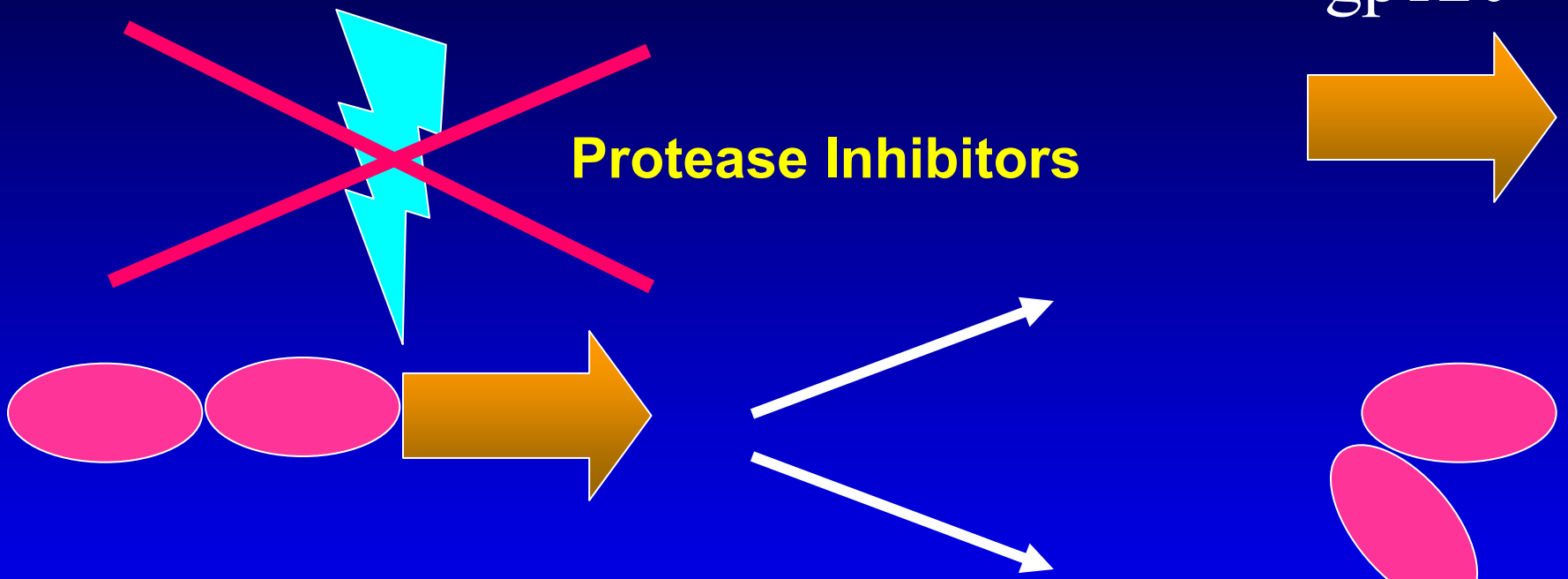
HIV RNA chromosome

HIV DNA provirus

Human DNA chromosome

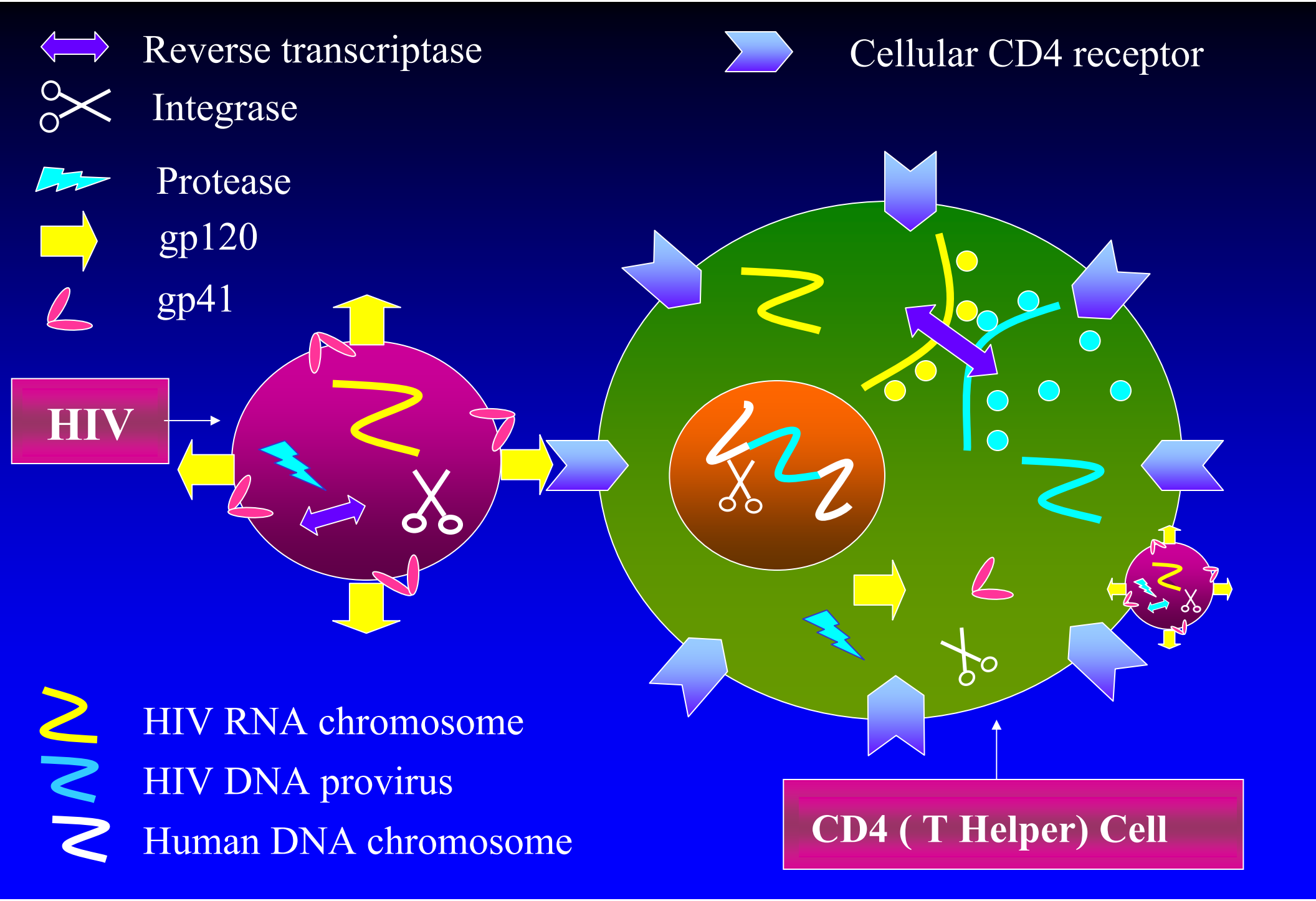
CD4 (T Helper) Cell

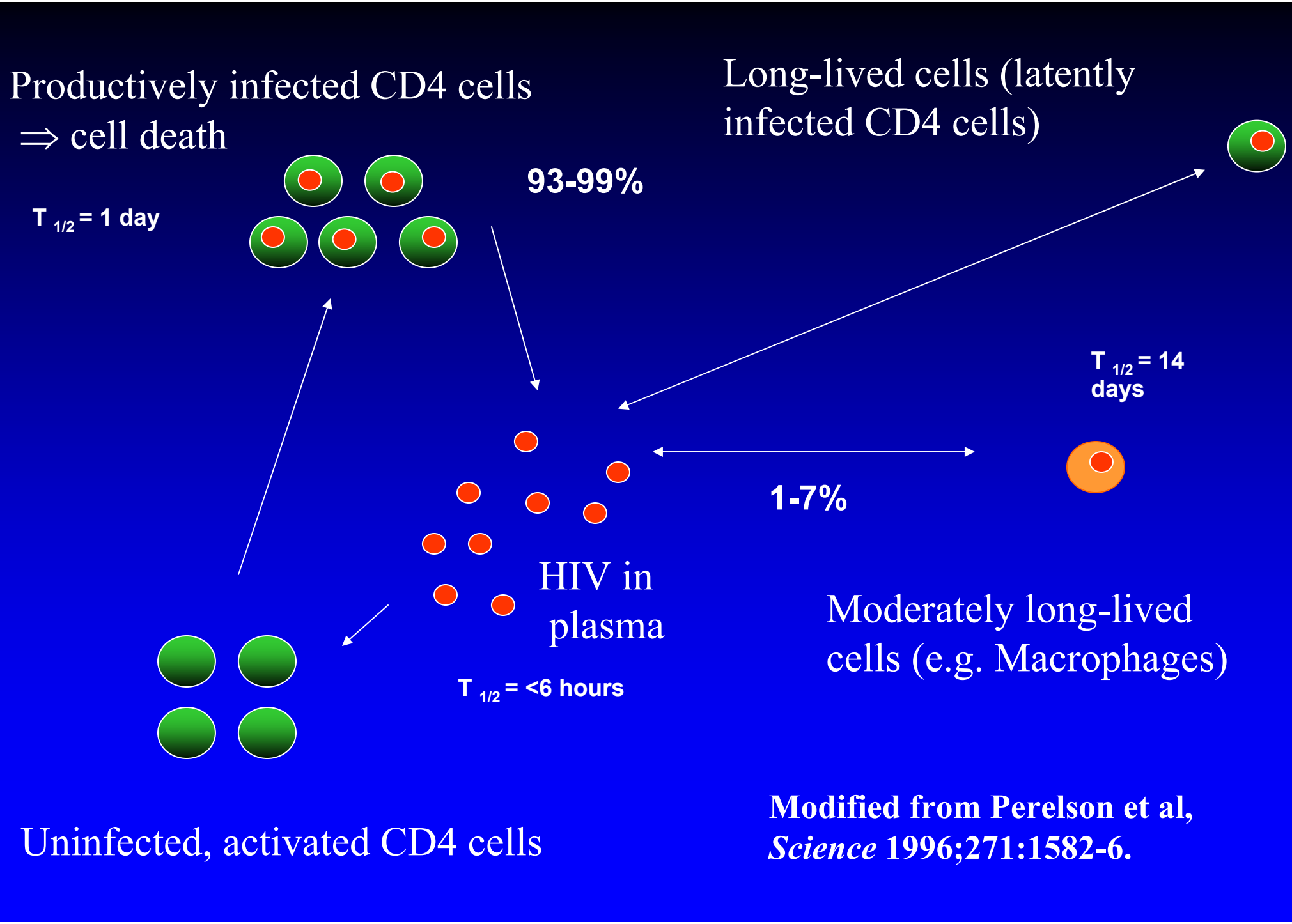
HIV Protease

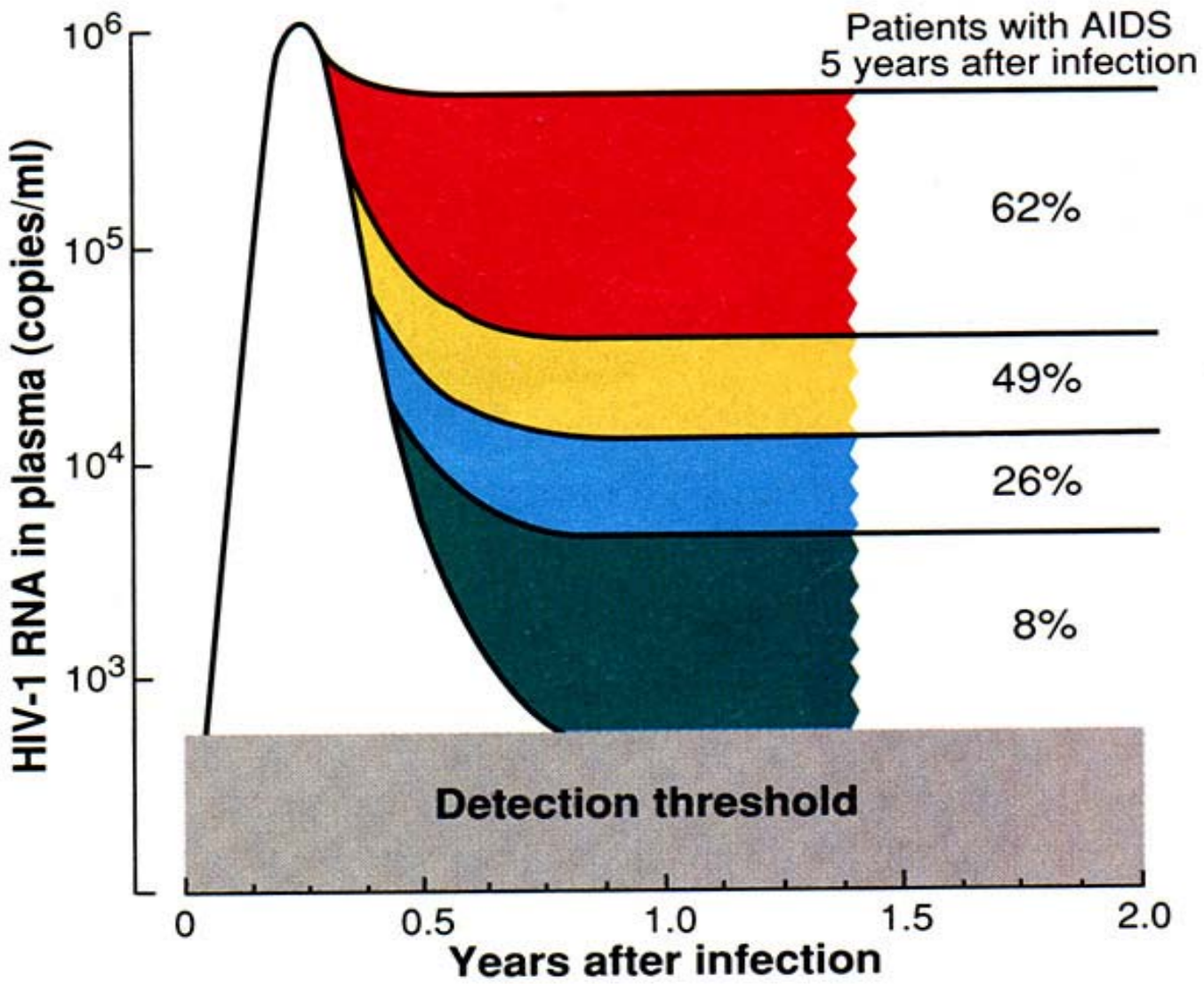


Non-functional
gp160 precursor

Functional proteins


Reverse transcriptase
Integrase
Protease
gp120
gp41
Cellular CD4 receptor
HIV
HIV RNA chromosome
HIV DNA provirus
Human DNA chromosome
CD4 (T Helper) Cell

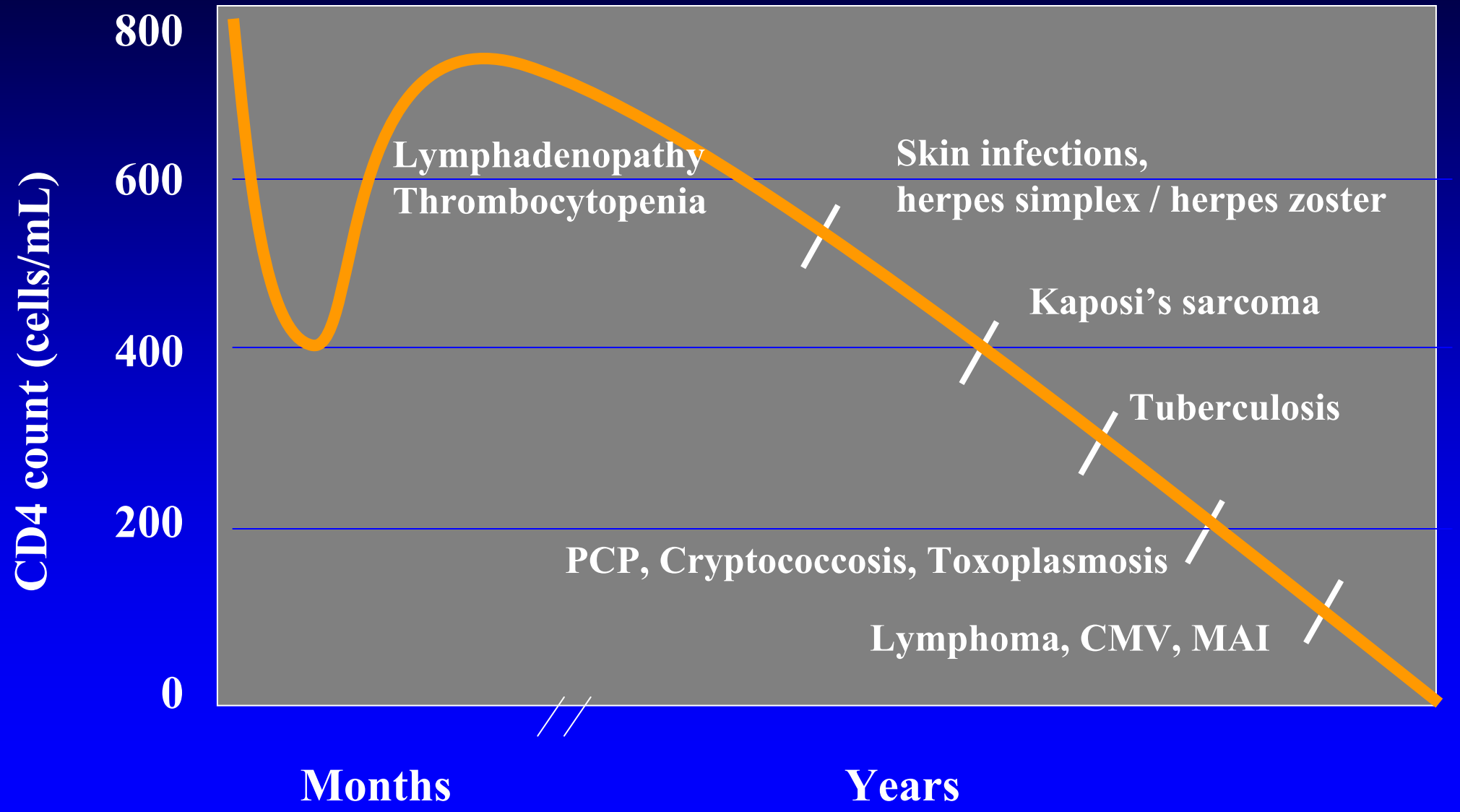

Productively infected CD4 cells
⇒ cell death
T 1/2 = 1 day
93-99%
Long-lived cells (latently infected CD4 cells)
T 1/2 = 14 days
1-7%
HIV in plasma
T 1/2 = <6 hours
Moderately long-lived cells (e.g. Macrophages)
Uninfected, activated CD4 cells
Modified from Perelson et al, Science 1996;271:1582-6.

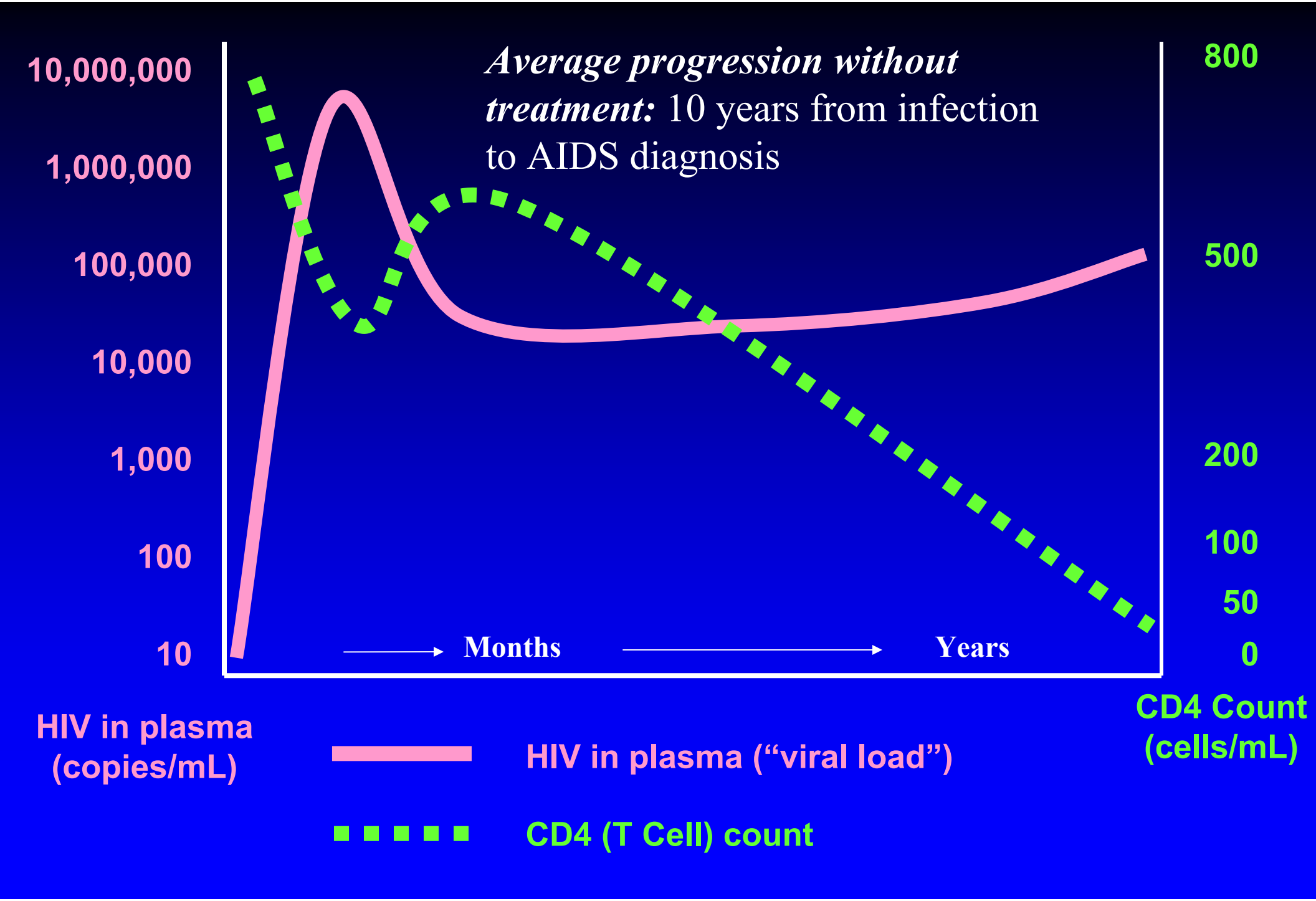


Viral 'Set Point' and risk of progression to AIDS

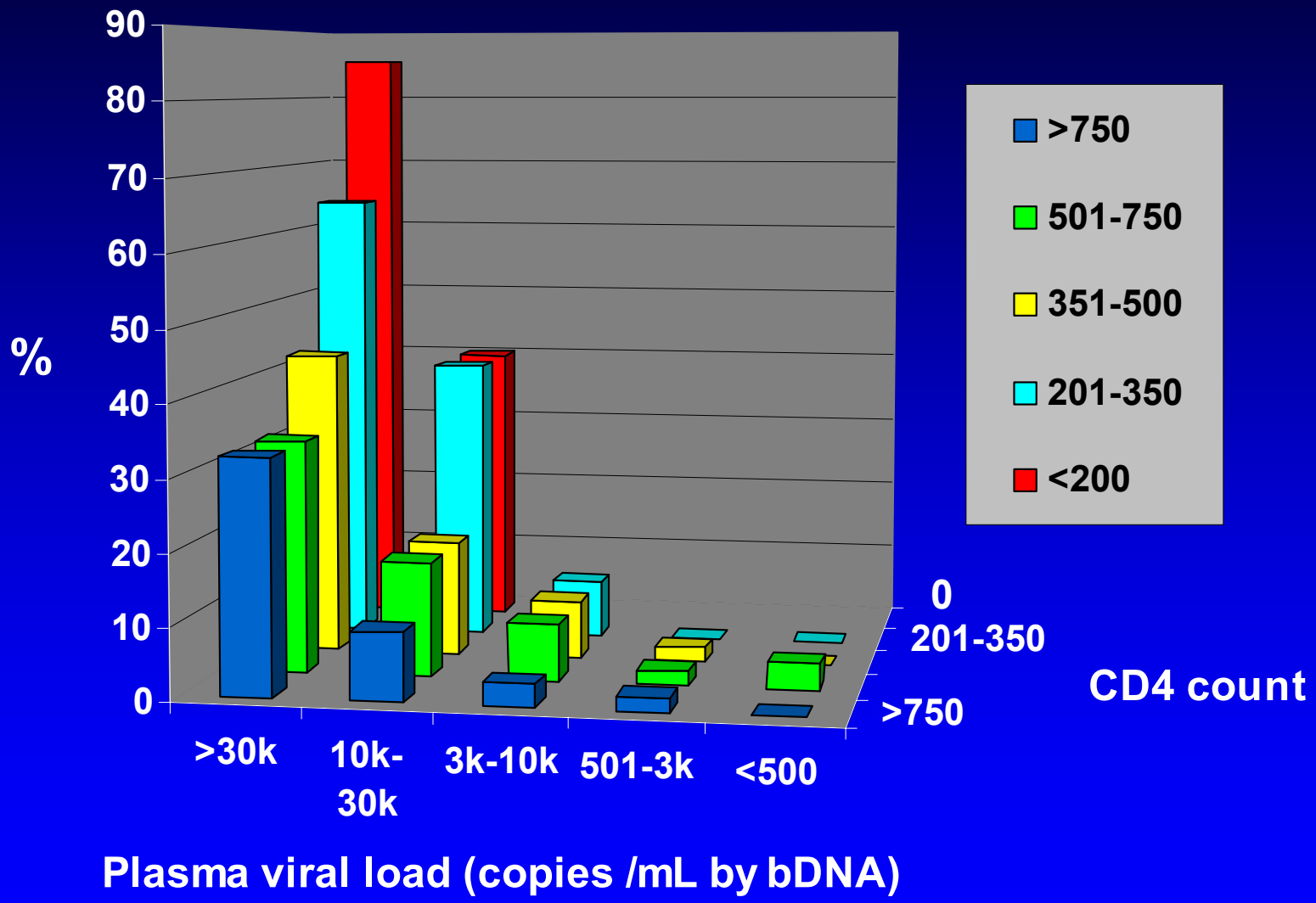
Ho DD, *Science* 1996;272:1124-5

Opportunistic Disease Thresholds with Declining CD4 Counts




10,000,000
1,000,000
100,000
10,000
1,000
100
10
HIV in plasma (copies/mL)
800
500
200
100
50
0
CD4 Count (cells/mL)
Average progression without treatment: 10 years from infection to AIDS diagnosis
Months
Years
HIV in plasma ("viral load")
CD4 (T Cell) count

Likelihood of Developing AIDS within 3 Years



MMWR 1998;47(RR-5)

Licensed Antiretroviral Agents

Reverse Transcriptase Inhibitors (RTI's)		Protease Inhibitors (PI's)
Nucleoside Analogs (NRTI's, "nukes")	**Non-Nucleoside Analogs (NNRTI's, "non-nukes")**	
(AZT) zidovudineto (Retrovir®)	delavirdine (Rescriptor®)	saquinavir (Fortavase®)
(ddI) didanosine (Videx®)	nevirapine (Viramune®)	indinavir (Crixivan®)
(ddC) zalcitabine (Hivid®)	efavirenz (Sustiva®)	ritonavir (Norvir®)
(3TC) lamivudine (Epivir®)		nelfinavir (Viracept®)
(d4T) stavudine (Zerit®)		amprenavir (Agenerase®)
abacavir (Ziagen®)		lopinavir (Kaletra®)

Previous Recommendations on Starting Antiretroviral Therapy

International AIDS Society[1]	DHHS, Kaiser Foundation[2]
• Acute HIV infection • Symptomatic HIV infection • Asymptomatic infection and CD4 350-500 cells/mL or viral load > 5,000-10,000 copies/mL	• Acute HIV infection • Symptomatic HIV infection • Asymptomatic infection and CD4 <500 cells/mL (possibly < 300 cells) or viral load > 10,000 copies/mL by bDNA or >20,000 copies/mL by PCR

[1]Carpenter CC et al, *JAMA* 1998;280:78-86; [2]*MMWR* 1998;47(RR-5):43-82

New Guidelines for Starting Antiretroviral Therapy

- All patients with the acute HIV syndrome
- Patients within six months of HIV seroconversion
- All patients with symptoms ascribed to HIV infection
- In general, treatment should be offered to asymptomatic patients with fewer than 350 CD4 cells or plasma HIV RNA levels exceeding 30,000 copies/ml (bDNA) or 55,000 copies/ml (RT-PCR assay)

Guidelines for the use of antiretroviral agents in HIV-infected adults and adolescents, DHHS and Henry J. Kaiser Foundation. February 5, 2001 (Available at HIVATIS.org)

Why Choose the New Starting Criteria?

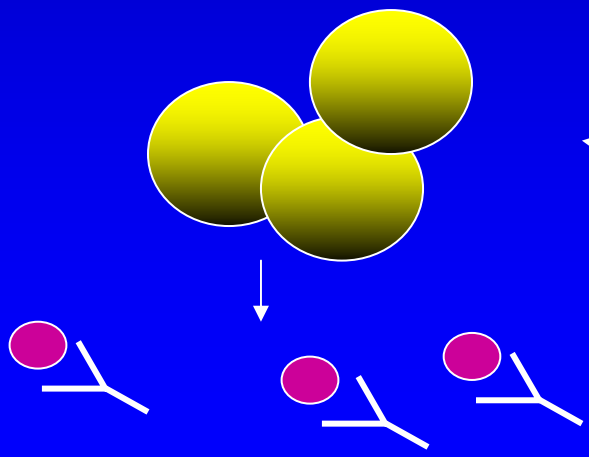
- To avoid drug toxicity, issues of adherence, cost, and decreased quality of life as long as possible
- Delaying initiation of therapy is based on relatively recent proof that increases in CD4 counts after therapy is started signify true reconstitution of the immune system
- A CD4 count of 350 has been chosen because the risk of progression above this level is relatively small, but increases significantly below 350 (and especially below 200)

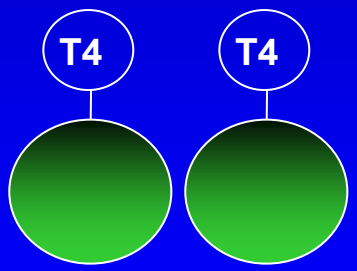
The Human Immune Response to HIV

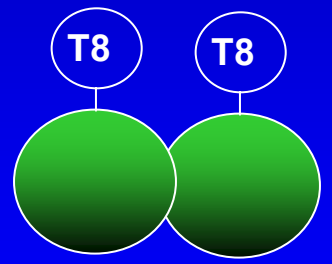
Humoral arm:
Anti-HIV
Antibodies
(made by B cells)

Cellular Arm:
Anti-HIV CD4 Cells
(Orchestrators)

Cellular arm:
Anti-HIV
Killer cells
(CD8 cells)





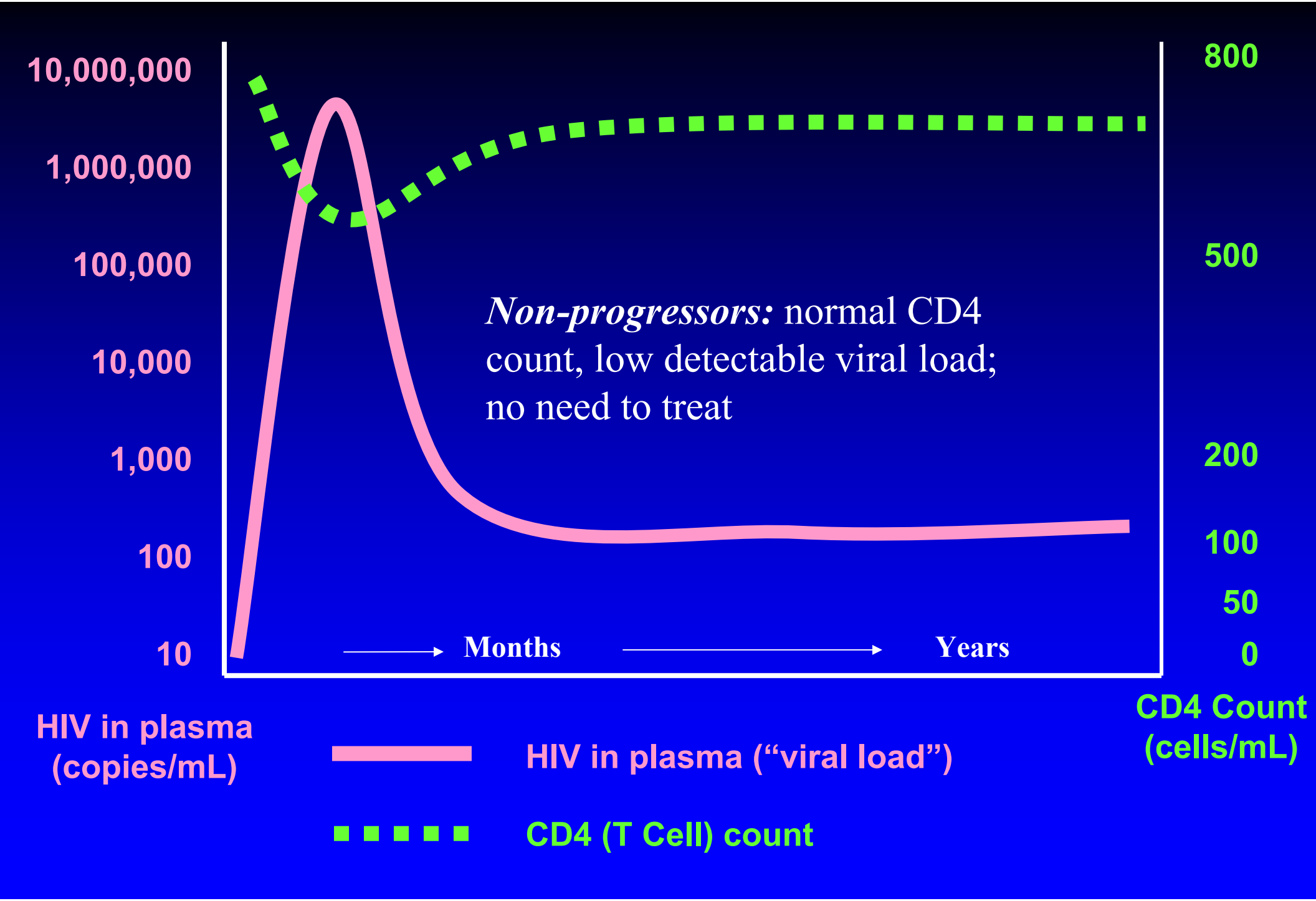


"Cytotoxic T lymphocytes" (CTL)

= HIV

Untreated HIV Infection

- Anti-HIV B cells, CD4 cells and CD8 cells are generated during acute infection, accounting for the decrease in viral load from an initially high level during acute infection to some lower "set point"
- However, because HIV-specific CD4 and CD8 cells are activated in the presence of HIV, they are preferential targets for infection and destruction by HIV
- Thus, HIV infection in the untreated state destroys the immune system response designed to control it

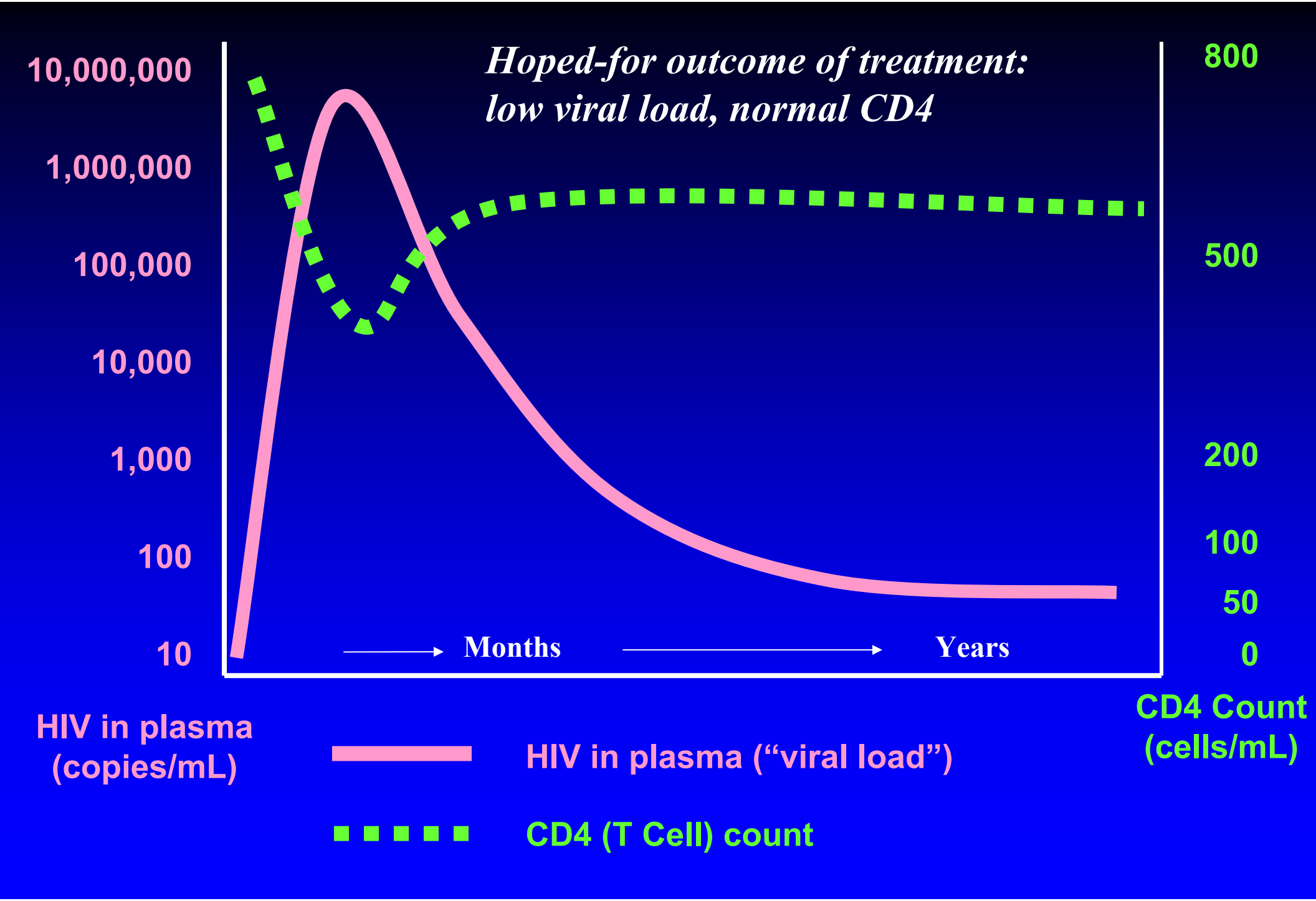

10,000,000
1,000,000
100,000
10,000
1,000
100
10
HIV in plasma (copies/mL)
800
500
200
100
50
0
CD4 Count (cells/mL)
Non-progressors: normal CD4 count, low detectable viral load; no need to treat
Months
Years
HIV in plasma ("viral load")
CD4 (T Cell) count

Long-Term Non-Progressors

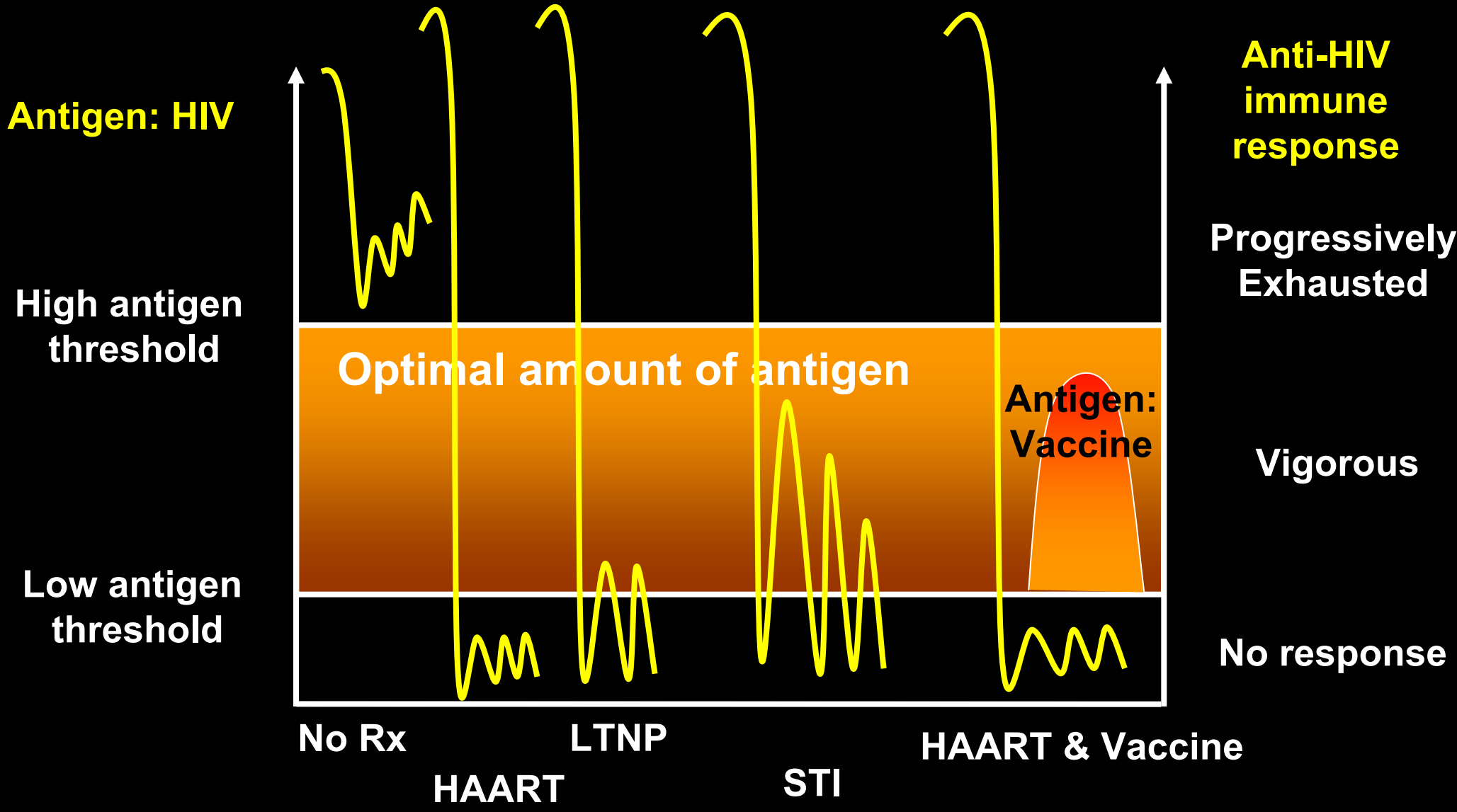
- These individuals appear to have sustained their HIV-specific CD4 and CD8 cells, maintaining the capacity to continuously suppress HIV and even to adapt to new mutations in HIV
- The continued presence of HIV-specific CD4 cells also maintains the production of anti-HIV antibodies from B cells
- Viral levels are low but not undetectable, providing the continuous stimulation by HIV needed to maintain an immune response against HIV

Treated Patients

- Successful treatment suppresses HIV to very low levels (e.g., < 50 copies/mL), preventing destruction of CD4 cells by HIV
- However, if treatment is withdrawn, viral rebound occurs quickly (because of latently-infected CD4 reservoirs)
- Minimal (or no) HIV-specific immune response is maintained during treatment, since such low virus levels do not provide the ongoing stimulus needed to maintain it


Hoped-for outcome of treatment:
low viral load, normal CD4
10,000,000
1,000,000
100,000
10,000
1,000
100
10
800
500
200
100
50
0
Months
Years
HIV in plasma
(copies/mL)
CD4 Count
(cells/mL)
HIV in plasma ("viral load")
CD4 (T Cell) count

Immune Control of HIV: The Threshold Hypothesis



Adapted from J. Lisziewicz, XIIIth AIDS Conf WeOrA480

HIV Drug Resistance

- During every cycle of viral replication, errors in reverse transcription lead to changes in the gene structure of HIV
- Many of these errors are “fatal” (leading to non-viable viruses), but some (by chance) will provide a selective advantage over “wild-type” viruses in the context of anti-HIV drugs
- Given 1 billion viral replications/day in the absence of viral suppression, this can lead to the development of multiple genetic mutations that lead to resistance

Increasing Transmission of Resistant Viruses in North America

- Resistance to HIV drugs in 408 patients newly infected with HIV has been tracked in 8 North American cities for the past 5 years (Birmingham, Dallas, Denver, L.A., San Diego, Seattle, Montreal, Vancouver)
- Comparing 1996-98 and 1999-2000, high-level resistance to NNRTI's increased from 1% to 7%, and to PI's from 2% to 6%
- 4% had resistance to 2 or more drugs
- Time to viral suppression was longer for patients with greater than 10-fold resistance

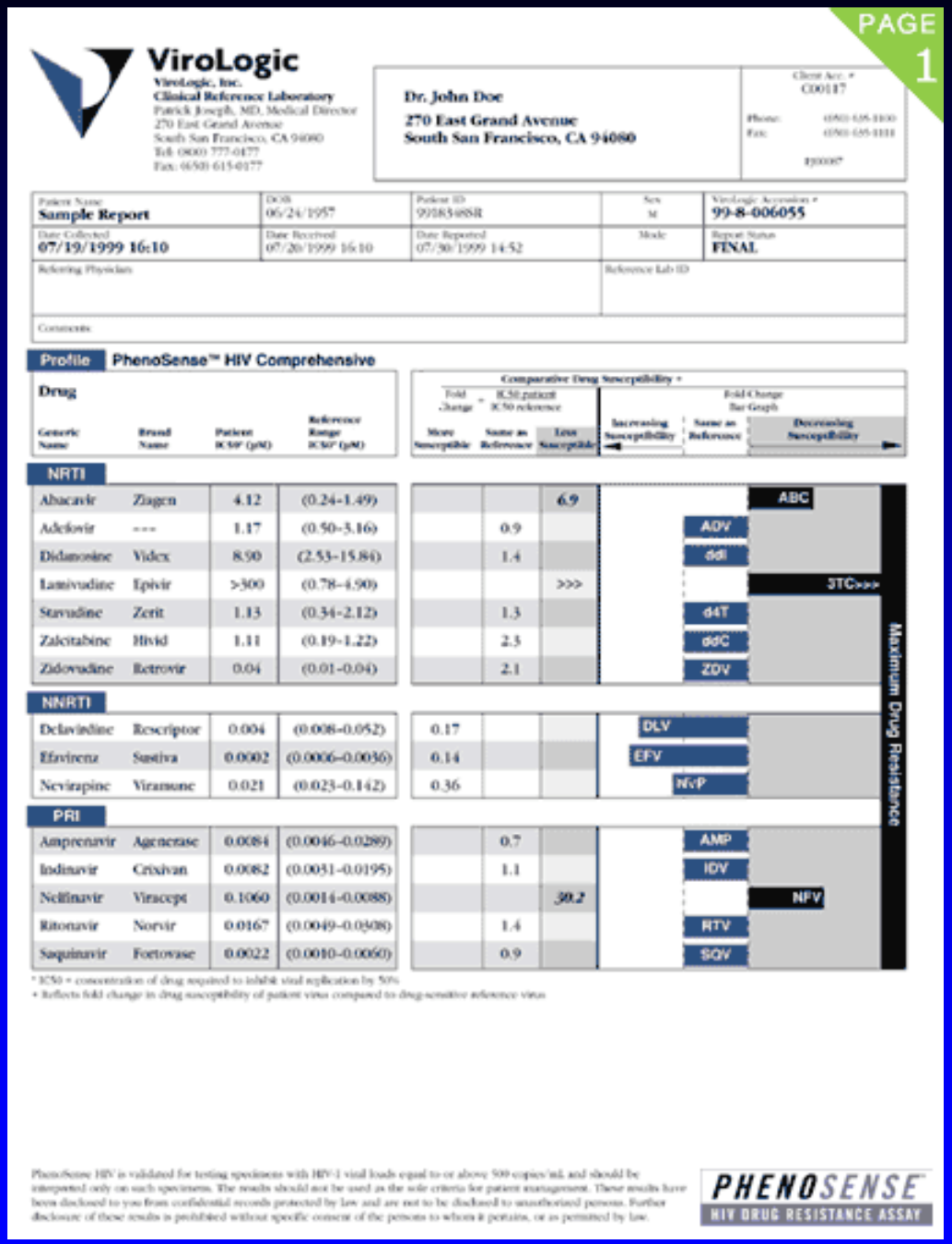
SJ Little et al, 8th CROI 2001, Abstract 7576

Types of Resistance Tests

- Genotypic
  - Analyze the genetic sequence of a patient's dominant strain, looking for the presence of mutations believed to confer resistance (e.g. M184V: a substitution of valine for methionine at amino acid position #184)

Types of Resistance Tests

- Phenotypic (phenotype = “behavior” or “appearance”)
  - Measures the capacity of a patient’s virus to grow in various drug concentrations, as compared with wild-type viruses
  - EG: a patient’s virus may require 10-fold higher drug concentration to suppress it than is required for wild-type



PAGE 1

ViroLogic
ViroLogic, Inc.
Clinical Reference Laboratory
Patrick Joseph, MD, Medical Director
270 East Grand Avenue
South San Francisco, CA 94080
Tel: (800) 777-0477
Fax: (650) 615-0177

Dr. John Doe
270 East Grand Avenue
South San Francisco, CA 94080

Client Acc. # C00117
Phone: (555) 555-1000
Fax: (555) 555-1111
ID0007

Patient Name	DOB	Patient ID	Sex	ViroLogic Accession #
Sample Report	06/24/1957	9918498R	M	99-8-006055
Date Collected	Date Received	Date Reported	Mode	Report Status
07/19/1999 16:10	07/20/1999 16:10	07/30/1999 14:52		FINAL
Referring Physician			Reference Lab ID	
Comments				

Profile PhenoSense™ HIV Comprehensive

Drug				Comparative Drug Susceptibility *			
Generic Name	Brand Name	Patient IC50* (μM)	Reference Range IC50* (μM)	Fold Change = Patient IC50 / Reference IC50			Fold Change Bar Graph
				More Susceptible	Same as Reference	Less Susceptible	Increasing Susceptibility ← Same as Reference → Decreasing Susceptibility
NRTI							
Abacavir	Ziagen	4.12	(0.24-1.49)			6.9	ABC
Adefovir	---	1.17	(0.50-3.16)		0.9		ADV
Didanosine	Videx	8.50	(2.53-15.84)		1.4		ddI
Lamivudine	Epivir	>300	(0.78-4.90)			>>>	3TC>>>
Stavudine	Zerit	1.13	(0.34-2.12)		1.3		d4T
Zalcitabine	Hivid	1.11	(0.19-1.22)		2.3		ddC
Zidovudine	Retrovir	0.04	(0.01-0.04)		2.1		ZDV
NNRTI							
Delavirdine	Rescriptor	0.004	(0.008-0.052)	0.17			DLV
Efavirenz	Sustiva	0.0002	(0.0006-0.0036)	0.14			EFV
Nevirapine	Viramune	0.021	(0.023-0.142)	0.36			NVP
PRI							
Amprenavir	Agenerase	0.0084	(0.0046-0.0289)		0.7		AMP
Indinavir	Crixivan	0.0082	(0.0031-0.0195)		1.1		IDV
Nelfinavir	Viracept	0.1060	(0.0014-0.0088)			30.2	NFV
Ritonavir	Norvir	0.0167	(0.0049-0.0308)		1.4		RTV
Saquinavir	Fortovase	0.0022	(0.0010-0.0060)		0.9		SQV

Maximum Drug Resistance

* IC50 = concentration of drug required to inhibit viral replication by 50%
+ Reflects fold change in drug susceptibility of patient virus compared to drug-sensitive reference virus

PhenoSense HIV is validated for testing specimens with HIV-1 viral loads equal to or above 500 copies/mL and should be interpreted only on such specimens. The results should not be used as the sole criteria for patient management. These results have been disclosed to you from confidential records protected by law and are not to be disclosed to unauthorized persons. Further disclosure of these results is prohibited without specific consent of the persons to whom it pertains, or as permitted by law.

PHENOSENSE HIV DRUG RESISTANCE ASSAY

Virologic phenotypic resistance assay

Virologic.com

Clinical Use of Resistance Testing

- Should be used
  - In treating acute HIV infection (resistant strains may have been transmitted)
  - When HAART has failed (should be tested on drugs)
  - When HAART has led to suboptimal viral suppression
- Should not be used
  - In untreated, chronically infected patients (even if resistant strains were initially transmitted, these have no selection advantage off therapy and will likely be minor species that will not be detected)
  - With plasma viral load less than 1000 copies/mL

P-Glycoprotein

- P-glycoprotein is a pump in some cell membranes which is able to transport certain drugs, such as protease inhibitors, into or out of cells
- P-gp may be responsible for pumping PI's back into gut (decreasing absorption), into bile (increasing clearance), or out of central nervous system (accounting for "sanctuary sites"?)
- P-gp can be inhibited by certain drugs (including some PI's), potentially increasing the effect and distribution of other PI's, and also induced by others (St. John's wort, rifampin)

P-Glycoprotein

- The degree of P-gp expression may be influenced by genetics and race
- P-gp can also inhibit HIV replication, and in some laboratory experiments can suppress HIV replication by 40-0 fold

C Flexner and R Speck, 8th CROI, 2001, S4

Hepatitis C

- Recognized for > 13 years – previously "Non-A, Non-B Hepatitis"
- Chronic infection can lead to liver failure, cirrhosis and liver cancer
- HCV is now the leading reason for liver transplantation in the U.S.

Hepatitis C Transmission

- Blood contact (needle sharing)
  - 10 times more than with HIV (3% vs 0.3%)
- Sexual contact
  - 10 times less than with HIV

HCV Co-Infection Rates Among HIV-Positive Persons (= 400,000 in U.S.)

- Hemophiliacs: 60-90%
- Inner-city injection drug users: 50-90%
  - (>80% of HCV infections occur during lst year of drug use)
- Men who have sex with men: 4-8%
- Heterosexual men and women: 0-2%

Craven D and Nunes D, *AIDS Clinical Care* 2000;12:71-75

Hepatitis C Natural History

- Less than 1/3 with acute HCV infection will have symptoms (nausea, vomiting, jaundice)
- 20-30% are able to clear the virus in months; the rest are chronically infected
  - Higher rates of clearance if symptoms are present during acute infection
  - 1/3 of chronically infected will have normal liver function tests

Craven D and Nunes D, *AIDS Clinical Care* 2000;12:71-75

Chronic HCV Infection

- Risk of developing cirrhosis increased if
  - Male
  - Older age
  - Alcohol use
  - HIV Co-infection
  - ? Variations in the host immune response
- Rate of liver disease progression (and treatment failure) increases if CD4 count <200

Craven D and Nunes D, *AIDS Clinical Care* 2000;12:71-75

Interaction of HCV with HIV infection

- HCV now appears to decrease response rates to HAART
- HCV can predispose to liver toxicity of HIV drugs
- Reconstitution of the immune system with HIV drugs may lead to flares of HCV-related hepatitis

Treatment of HCV

- Standard of care: alpha interferon and ribavirin
  - Subcutaneous injections (interferon) 3x weekly for 6-12 months
  - Side effects
    - Flu-like syndrome
    - Local pain, inflammation
    - Anemia
    - Depression and suicidality
  - $18,000 per year

Craven D and Nunes D, *AIDS Clinical Care* 2000;12:71-75

Treatment of HCV

- Treatment efficacy (lowered HCV viral load) varies
- 75% of U.S. infections are type 1, the remainder types 2 or 3
    - 30-40% response in types 2 or 3 (twice type 1 response)
    - Lower response rates among minorities, IDU's
- Even if no decrease in HCV viral load is seen, treatment *can* delay progression to cirrhosis & cancer
- In more than 75% of HCV/HIV patients, initiation or completion of therapy may be precluded by substance abuse, depression, or psychosocial problems

Craven D and Nunes D, *AIDS Clinical Care* 2000;12:71-75

PEGylated Alpha Interferon

- One problem with standard alpha interferon is that the molecule is cleared within days, requiring 3x weekly Rx
- One way to make the molecule larger, and therefore cleared more slowly, is to add a molecule of PolyEthylene Glycol (PEG): PEGylated alpha interferon (PEG-INTRON)

Bringing HIV Treatment to Developing Countries

- Since the 7/2000 Durban AIDS Conference, persistent attention has been given to bringing antiretrovirals to the South
  - The U.S. withdrew its lawsuits against foreign manufacturers alleged to be violated patent rights
  - Drug manufacturers withdrew their lawsuit against South Africa's Medicines Act, opening the way to generic manufacturing and importing (as cheaply as $300/year for HAART)
  - Major drug manufacturers slashed prices of HIV drugs

Even If HIV Drugs Were Available for Free, Significant Problems Remain

- Guaranteeing that providers know how to prescribe, and have the technology (CD4 counts, viral loads) to identify eligible patients and to monitor effectiveness
- Preventing rapid development of resistance, especially when drugs can be purchased by patients over-the-counter
- Building up the health care infrastructure (which is already unable to deal with affordable and curable infections like TB) to make sure that medication supply is reliable and that patients have access to providers and medications

Even If HIV Drugs Were Available for Free, Significant Problems Remain

- Ensuring that HIV prevention programs remain a priority
- Making sure that access to palliative medications (antidiarrheals, pain medications) and treatments for opportunistic infections (herpes, candida, cryptococcus, TB, MAI, etc.) are not compromised for sake of anti-HIV medications

Global summary of the HIV/AIDS epidemic, December 2001

Number of people living with HIV/AIDS	**Total**	**40 million**
	Adults	37.2 million
	Women	*17.6 million*
	Children under 15 years	2.7 million
People newly infected with HIV in 2001	**Total**	**5 million**
	Adults	4.3 million
	Women	*1.8 million*
	Children under 15 years	800 000
AIDS deaths in 2001	**Total**	**3 million**
	Adults	2.4 million
	Women	*1.1 million*
	Children under 15 years	580 000

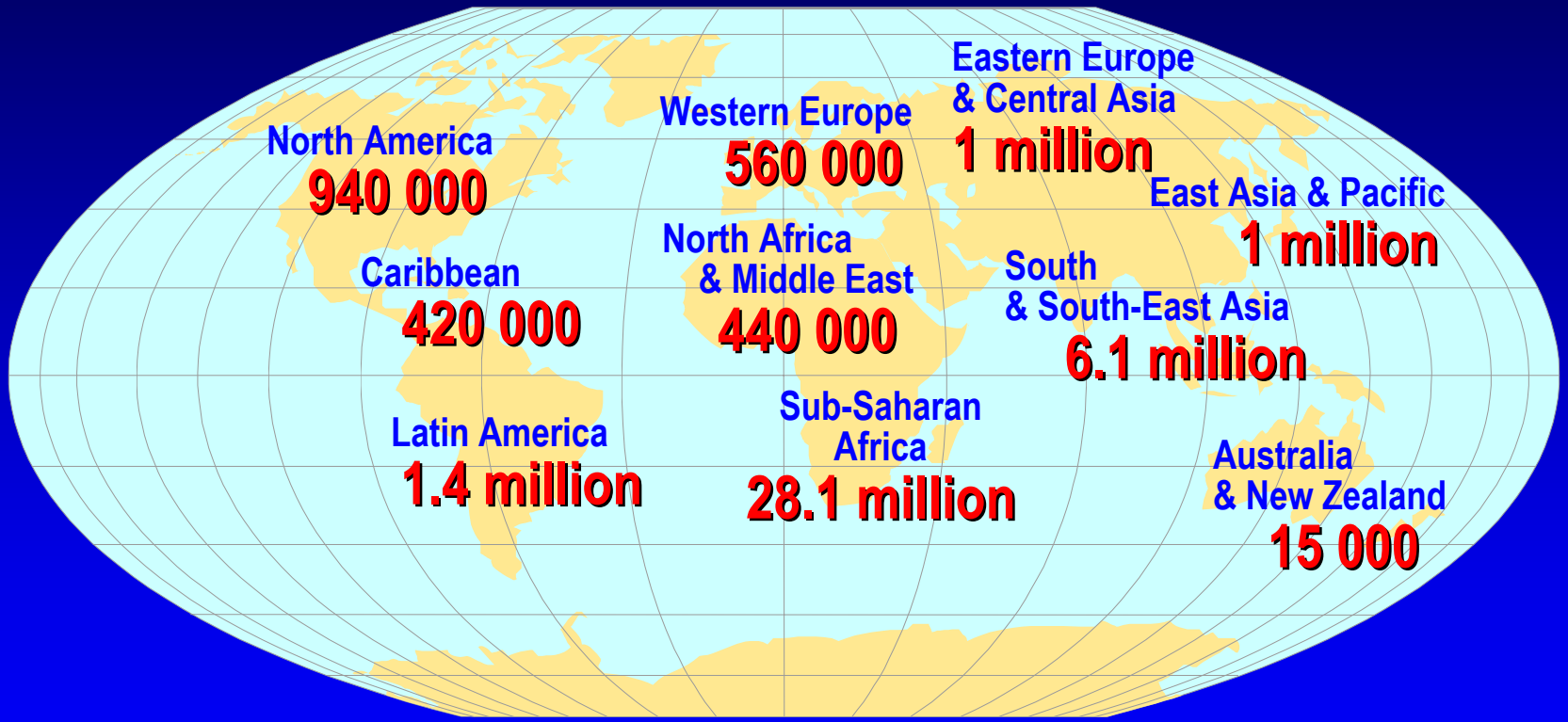
Regional HIV/AIDS statistics and features, end of 2001

	Epidemic started	Adults & children living with HIV/AIDS	Adults & children newly infected with HIV	Adult prevalence rate *	% of HIV-positive adults who are women	Main mode(s) of transmission for those living with HIV/AIDS **
Sub-Saharan Africa	late '70s early '80s	28.1 million	3.4 million	8.4%	55%	Hetero
North Africa & Middle East	late '80s	440 000	80 000	0.2%	40%	Hetero, IDU
South and South-East Asia	late '80s	6.1 million	800 000	0.6%	35%	Hetero, IDU
East Asia & Pacific	late '80s	1 million	270 000	0.1%	20%	IDU, Hetero, MSM
Latin America	late '70s early '80s	1.4 million	130 000	0.5%	30%	MSM, IDU, Hetero
Caribbean	late '70s early '80s	420 000	60 000	2.2%	50%	Hetero, MSM
Eastern Europe & Central Asia	early '90s	1 million	250 000	0.5%	20%	IDU
Western Europe	late '70s early '80s	560 000	30 000	0.3%	25%	MSM, IDU
North America	late '70s early '80s	940 000	45 000	0.6%	20%	MSM, IDU, Hetero
Australia & New Zealand	late '70s early '80s	15 000	500	0.1%	10%	MSM
		40 million	5 million	1.2%	48%	

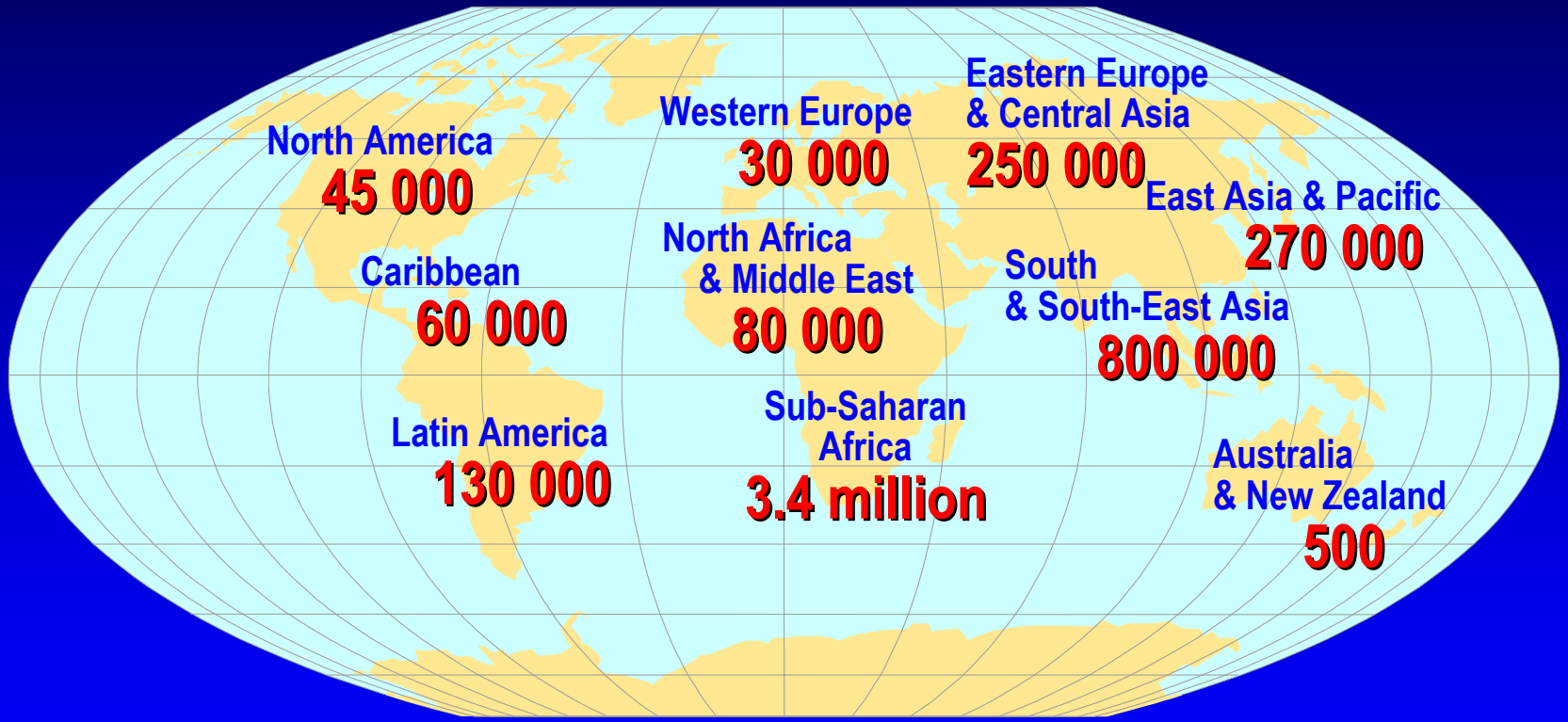
Global estimates for adults and children end 2001

- People living with HIV/AIDS ---------- 40 million
- New HIV infections in 2001 ---------- 5 million
- Deaths due to HIV/AIDS in 2001 ---------- 3 million

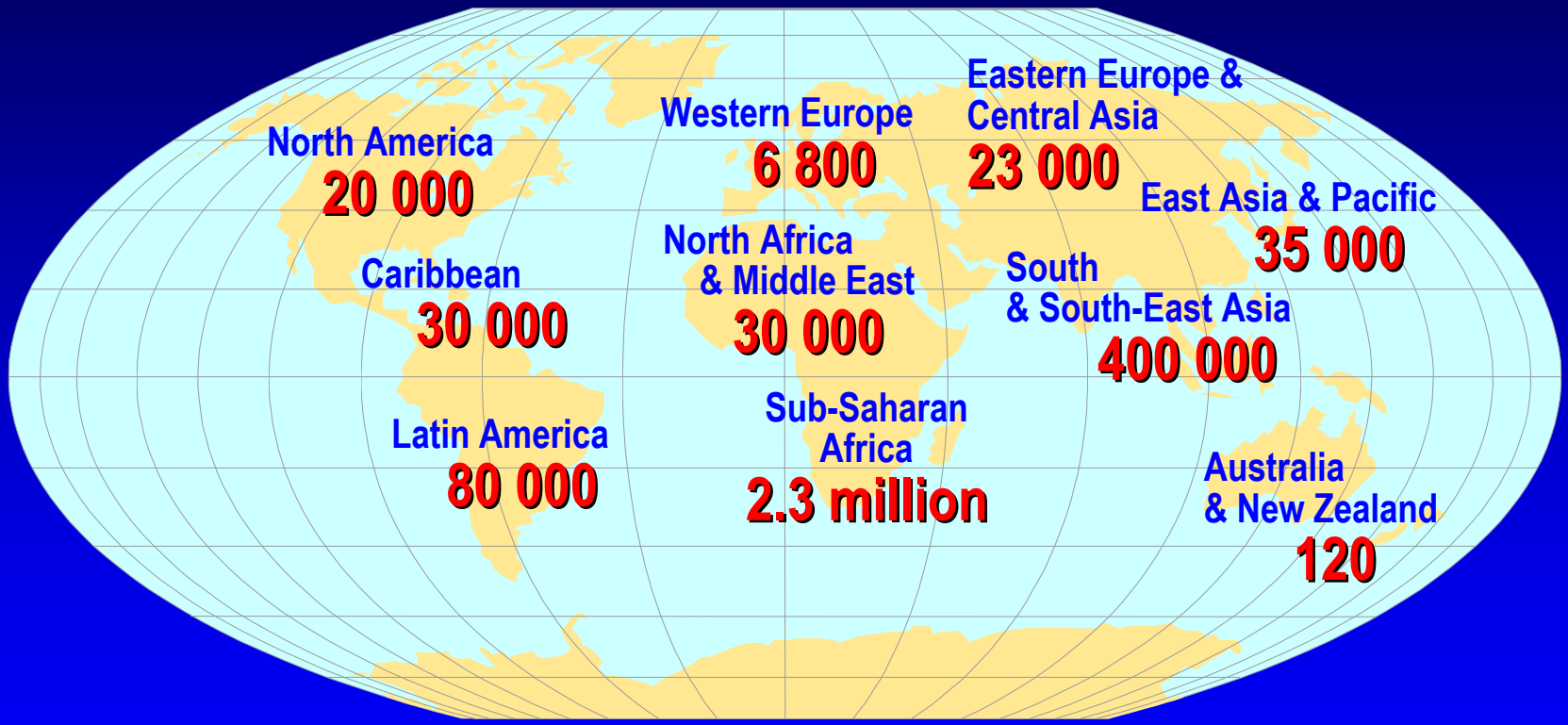
Adults and children estimated to be living with HIV/AIDS as of end 2001



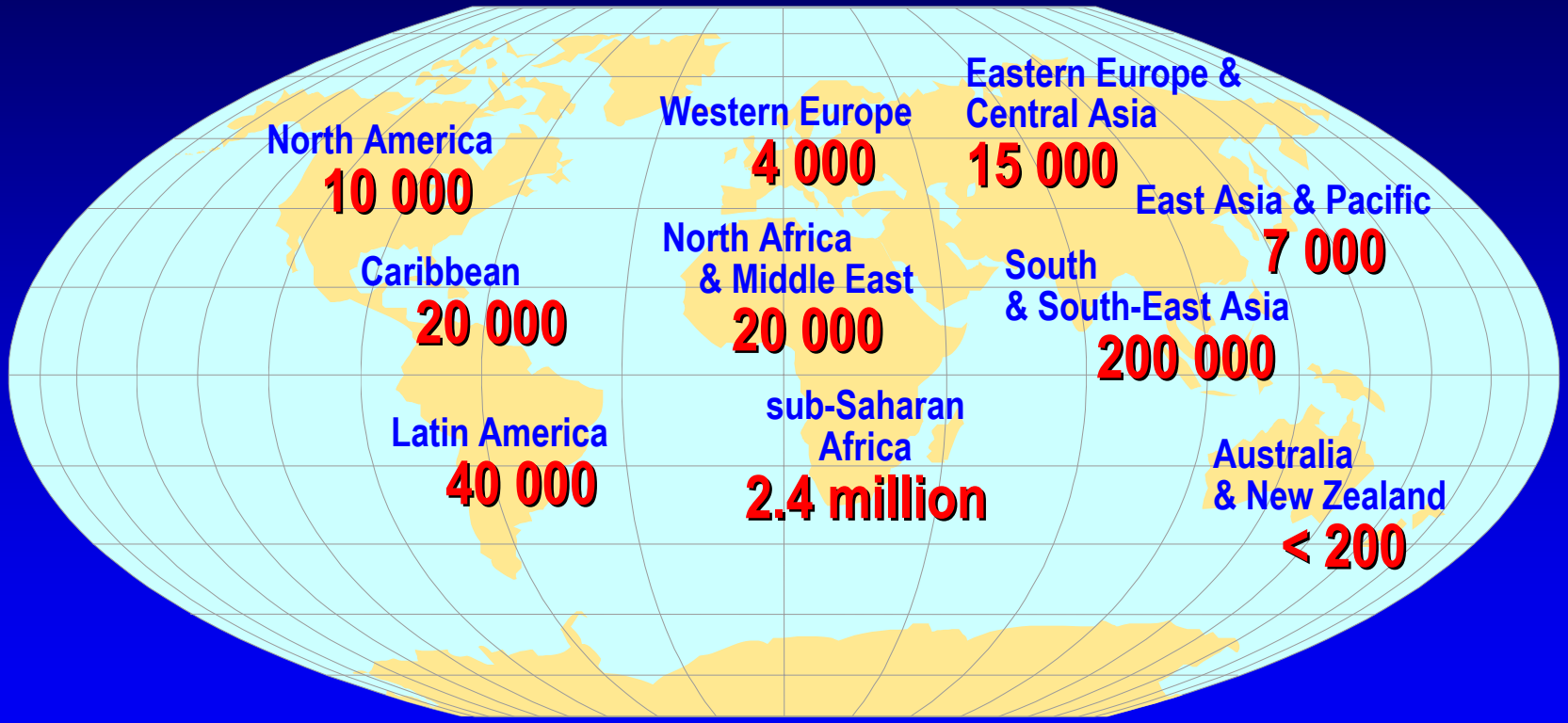
Estimated number of adults and children newly infected with HIV during 2001



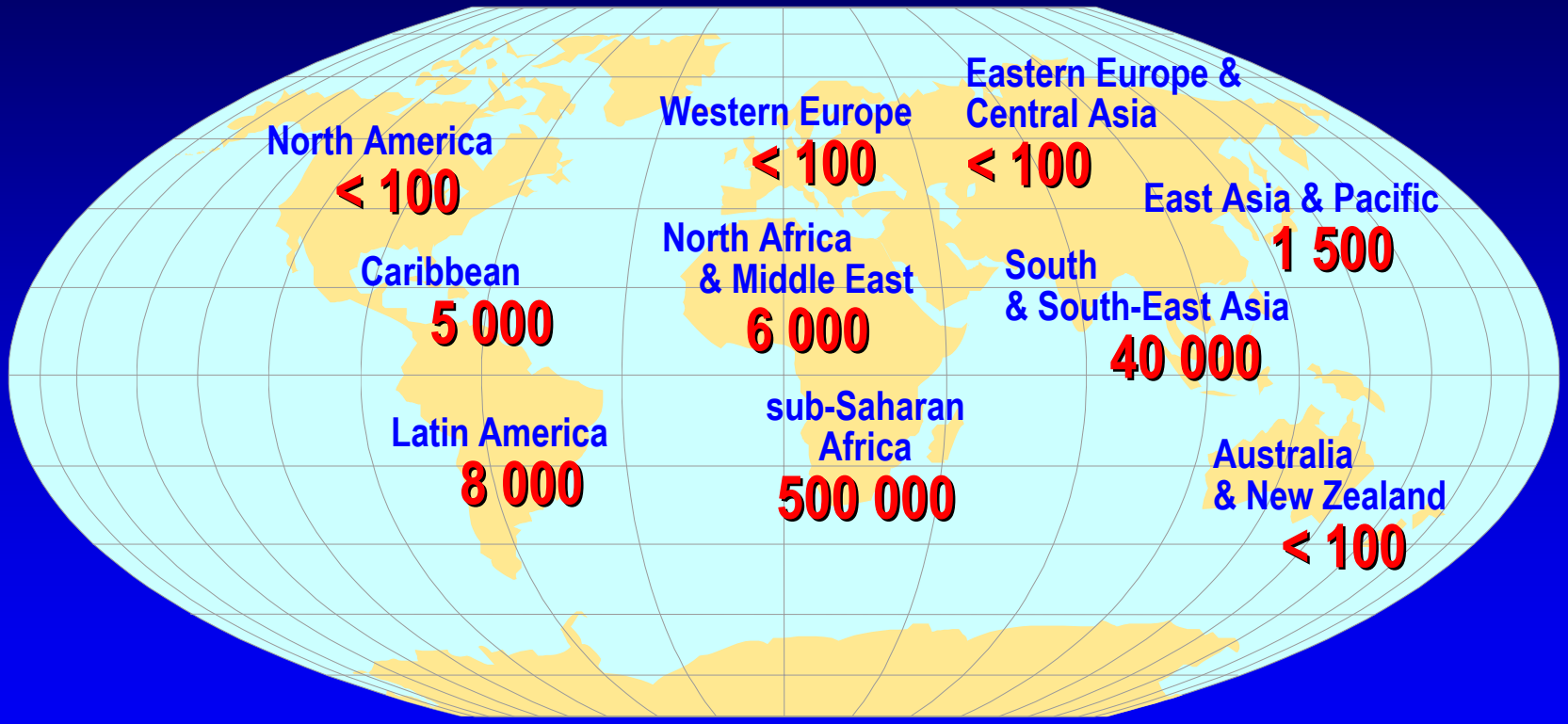
Estimated adult and child deaths from HIV/AIDS during 2001



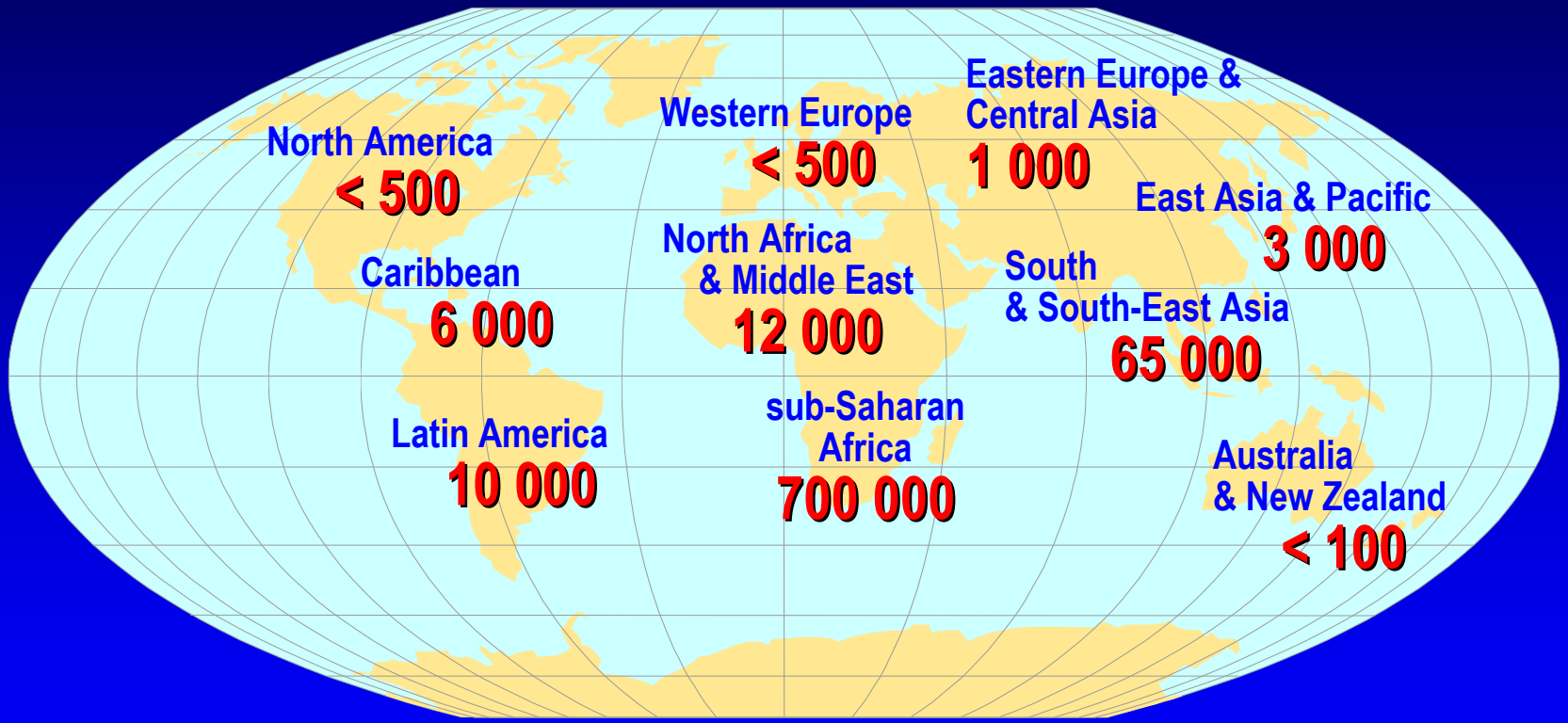
Children (<15 years) estimated to be living with HIV/AIDS as of end 2001



Estimated deaths in children (<15 years) from HIV/AIDS during 2001



Estimated number of children (<15 years) newly infected with HIV during 2001



About 14 000 new HIV infections a day in 2001

- More than 95% are in developing countries
- 2000 are in children under 15 years of age
- About 12 000 are in persons aged 15 to 49 years, of whom:
  - almost 50% are women
  - about 50% are 15–24 year olds

End-2001 global HIV/AIDS estimates
Children (<15 years)

- Children living with HIV/AIDS ..... 2.7 million
- New HIV infections in 2001 ..... 800 000
- Deaths due to HIV/AIDS in 2001 ..... 580 000

HIV Disease Progression

- High risk behavior: transmission
- Primary Infection: 2-4 weeks
  - **>50% experience flu-like symptoms with headaches**
- Seroconversion: 3-12 weeks
  - **HIV antibody positive**
  - **Can take up to 6 months**

(Bartlett, 1998)

Definition of Adherence

(Frank, Miramontes, 1997)

The extent to which a client's behavior coincides with the prescribed health care regimen determined through a shared decision making process between the client and health care provider

Factors Influencing Adherence Regimen (Dunbar-Jacob, 1997)

- Regimen complexity
- Duration of therapy
- Extent of behavior change required
- Amount of resulting life disruption
- Cost of regimen

Factors NOT Predictive of Adherence (Dunbar-Jacob, 1997)

- Age
- Socioeconomic status
- Race/ethnicity

Clinician Contributing Factors in Adherence (Frank, 1997)

- Consistent provider
- Satisfaction with relationship
- Knowledge of clinical regimen
- Treatment experience
- Time for client teaching
- Style matched to client
- Belief in client
- Belief in treatment
- Knowledge of adherence
- Enthusiasm
- Cultural competence

Characteristics of Client-Provider Relationship Within Shared Decision-making Context (Frank, Miramontes, 1997)

- Trust
- Commonalities
- Accessibility
- Continuity of care
- Extent of collaboration
- Communication
- Client satisfaction

Client Contributing Factors in Adherence (Frank, 1997)

- Understand treatment regimen
- Fits with routine
- Skills to carry out regimen
- Stage of disease, level of wellness
- Remembers meds
- Family/caregiver support
- View of health
- Belief in effectiveness
- Cultural relevancy
- Fear of side effects
- Ability to control side effects
- Mental health
- Interaction with street drugs

Client Dynamics Influencing Shared Decision-making (Frank, Miramontes, 1997)

- Health beliefs
- Trust in provider
- Cultural factors
- Disease factors
- Social support
- Economic factors
- Mental health status
- Substance use

Client Correlates of Non-adherence (Dunbar-Jacobs, 1997)

- Younger age
- Depressed mood
- Perceived stress
- Anxiety
- Pessimism about HIV disease
- Lower levels of coping efficacy

Strategies to Establish and Maintain Optimal Adherence

(Chesney, 1997)

- Clarify the regimen
- Tailor regimen to lifestyle
- Demonstrate use of medication diary
- Establish time to set out pills
- Establish set places for pill taking
- Plan any changes in routine in advance
- Make plans for holidays, weekends
- Lower barriers to care
- Refer to social services
- Followup

Adherence Interventions

- Environmental Strategies (Frank, 1997)
  - Transportation
  - Housing
  - Food
  - Drug treatment
  - Mental health service
  - Social network
  - Child care
  - Economic
  - Addressing cultural norms

Definition of Culture

(Randall-David, 1994)

An integrated system of learned behavior patterns that are characteristic of members of any particular group

Definition of Culture

(Hoopes & Pusch, 1981)

Culture is a sum total of ways of living; including values, beliefs, esthetic standards, linguistic expression, patterns of thinking, behavioral norms, and styles of communication which a group of people has developed to assure its survival in a particular physical and human environment

Cultural Competency

(Randall-David, 1994)

The ability to work effectively with culturally diverse clients and communities

Cultural Competency Includes Appropriate: (Randall-David, 1994)

- Attitudes
- Beliefs
- Behaviors
- Interventions
- Policies
- Advocacy

Culturally Competent Practitioner:

(Randall-David, 1994)

- Aware and sensitive to own cultural heritage
- Aware of own values and biases
  - **Impact on culturally diverse communities**
- Comfortable with differences
  - **terms of culture**
  - **effect on values, beliefs, attitudes**

Culturally Competent Practitioners

(Randall-David, 1994)

- Knowledgeable about the effect of:
  - **Oppression**
  - **Racism**
  - **Discrimination**
  - **Stereotyping**
    - **by the client**
    - **by the provider**

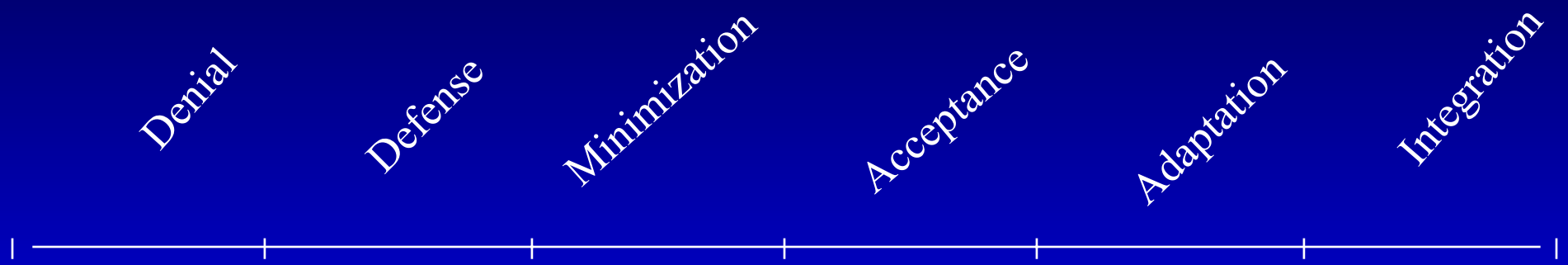
Culturally Competent Practitioner

(Randall-David, 1994)

- Understands historical events that have harmed particular cultural groups
- Understands the diversity within cultures is as important as diversity between cultures

Experience of Difference

Development of Intercultural Sensitivity



Ethnocentric Stages

Ethnorelative Stages

M. Bennett, 1986

The Culturally Competent Practitioner Recognizes that Differences May Exist in:

- Racial/Ethnic History
- Language
- Verbal & Nonverbal Communication
- Reading Ability
- Personal Space
- Eye Contact
- Touch
- Time Orientation

The Culturally Competent Practitioner Recognizes that Differences May Exist in:

- Beliefs about Sexuality and Gender
- Sexual Orientation
- Family Structures and Dynamics
- Activities of Daily Living and Self Care
- Clothing and Ornaments
- Food Preferences/Prohibitions
- Use of Chemical Substances
- Economics and Work

The Culturally Competent Practitioner Recognizes that Differences May Exist in:

- Social Values, Rituals, and Customs
- Religion/Spiritual Beliefs and Practices
- Birth and Death Rituals
- Illness Beliefs
- Health Beliefs and Practices
- Care Seeking
- Symptom Management
- Privacy and Confidentiality

The LEARN Model for Cultural Competency

L Listen with empathy and understanding to the person's perception of the situation

E Elicit culturally relevant information and Explain your perception of the situation

A Acknowledge the similarities & differences between your perceptions & their's

R Recommend options/alternatives and Respect the person and their choices

N Negotiate agreement