NEW DIRECTIONS IN HEALTHCARE FOR RESOURCE-LIMITED SETTINGS

Managing Chronic Conditions: Optimizing Health Throughout Life

The enormous burden currently posed by chronic disease in low-resource countries, and the realistic prospect that this burden will continue to increase, provide compelling reasons to rapidly address chronic illness from both a public health perspective and the impact on individual lives. This document is intended for FHI Country Office staff and other health program implementers in resource-limited areas and has two principal objectives:

1. To promote increased focus on chronic care and initiation of programmatic activities related to chronic conditions, including examination of needs and challenges related to the management of chronic illnesses within local contexts.
2. To describe technical approaches to assist in designing programs and interventions focusing on chronic conditions.

New Directions in Healthcare for Resource-Limited Settings

Family Health International recognizes the constantly changing reality of the science upon which quality healthcare is based. HIV/AIDS, tuberculosis, and chronic conditions are dynamic areas, both in terms of clinical practice and the delivery of health services that effectively manage and promote optimal health. New discoveries continue to emerge that have implications for health service delivery in resource-limited settings. To help health planners and implementers to access the most current knowledge and benefit individuals in these locations, FHI conceived this series to highlight important strategic approaches and state-of-the-science health delivery practices.

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MANAGING CHRONIC CONDITIONS: OPTIMIZING HEALTH THROUGHOUT LIFE — FAMILY HEALTH INTERNATIONAL

Managing Chronic Conditions

Optimizing Health Throughout Life

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Family Health
International

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MANAGING CHRONIC CONDITIONS: Optimizing Health Throughout Life

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Contents

Acknowledgments

Family Health International (FHI) is proud to present ***Managing Chronic Conditions: Optimizing Health Throughout Life.***

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Acronyms

ART	Antiretroviral therapy
ARV	Antiretroviral
ASW	Adherence support worker
(C)HBC	(Community) home-based care
DALY	Disability Adjusted Life Year
HCW	Healthcare worker
HMIS	Health management information system
M&E	Monitoring and evaluation
NGO	Nongovernmental organization
NPC	Non-physician clinician
OI	Opportunistic infection
PC	Palliative care
PEP	Post-exposure prophylaxis
PEPFAR	US President's Emergency Plan for AIDS Relief
PHC	Primary healthcare
PLHA	People living with HIV/AIDS
PMTCT	Prevention of mother-to-child transmission
QA/QI	Quality assurance/quality improvement
SOP	Standard operating procedure
STI	Sexually transmitted infection
TB	Tuberculosis
VCT	Voluntary counseling and testing
WHO	World Health Organization

Purpose

The enormous burden currently posed by chronic disease in low-resource countries, and the realistic prospect that this burden will continue to increase, provide compelling reasons to rapidly address chronic illness from both a public health perspective and the impact on individual lives. This document is intended for FHI Country Office staff and other health program implementers in resource-limited areas and has two principal objectives:

1. To promote increased focus on chronic care and initiation of programmatic activities related to chronic conditions, including examination of needs and challenges related to the management of chronic illnesses within local contexts.

2. To describe technical approaches to assist in designing programs and interventions focusing on chronic conditions.

FHI currently manages programs on HIV prevention, care, and treatment in more than 70 countries. This document selectively applies chronic care concepts and examples to HIV/AIDS (rather than other chronic conditions) to illustrate their relevance and to emphasize the pressing need to reframe HIV care within a chronic disease management context to ensure sustainable beneficial outcomes over the lifetime of those living with the condition.

The document begins by defining chronic disease and explaining how it differs from acute disease; identifying the key principles for effectively managing chronic conditions; and examining the implications these principles have for individuals, health systems, and communities. The next section presents strategies to enhance chronic care in resource-limited settings in terms of the following basic components of healthcare: patient, healthcare provider, health service delivery, community, and policy environment. Finally, key programmatic and research issues and needs are considered for advancing the care of people living with chronic conditions, including HIV/AIDS in resource-limited settings.

Chronic Disease

Introduction

Advances in biomedical science, behavioral health, and public health measures are radically impacting the management and outcomes of diseases that, because they lack a cure, have led to certain—and often premature—disability and death in the past (1). As these illnesses are transformed into chronic conditions, the primary benefit is the potential for individuals affected by them to live longer, more productively, and with higher quality of life. Whether this potential is realized rests largely on the capacity of health systems, working in concert with individuals living with chronic conditions, communities, and other societal sectors, to deliver patient-centered, science-based care for the duration of the individual's life.

Globally, chronic diseases account for 60 percent of all mortality, and twice the number of deaths from all infectious diseases (including HIV/AIDS, tuberculosis, and malaria), maternal and perinatal conditions, and nutritional deficiencies *combined* (2). In 2007, while 2.1 million deaths were attributable to HIV/AIDS worldwide, cardiovascular diseases claimed more than 17.5 million lives. Disability is another vital measure of disease burden; measured in terms of Disability Adjusted Life Year (DALY),[1] chronic diseases account for 48 percent of disability globally.[2]

Disability due to chronic conditions is also greater in low-resource countries than in all other income areas. Figure 1 and Figure 2 summarize available data on death and burden of disease (DALYs) respectively, described in terms of World Bank income groups and the following three categories of causes: (1) communicable diseases, maternal and perinatal conditions, and nutritional deficiencies; (2) chronic diseases; and (3) injuries. Although antiretroviral therapy (ART) has transformed HIV/AIDS into a chronic condition and the disease is most often defined that way in healthcare today, it should be noted that HIV is included in the category of "Communicable Diseases" in these figures rather than "Chronic Diseases."

The greatest burden of chronic disease resides in the poorest countries:

- 80 percent of deaths related to chronic diseases occur in low- and middle-income countries.
- Death rates for middle-aged individuals in their prime productive years in these settings are often higher than in high-income countries (3).

Chronic disease is not limited to noninfectious illnesses, but spans a wide spectrum of health conditions: noncommunicable diseases, long-term mental disorders, and persistent communicable diseases such as HIV/AIDS. For the individual living with an illness or condition that endures throughout life, ongoing, long-term healthcare supplants (though may include as required) the need for care to meet immediate, acute needs. For health systems, the management of long-term care requires inherently different approaches than care for acute problems.

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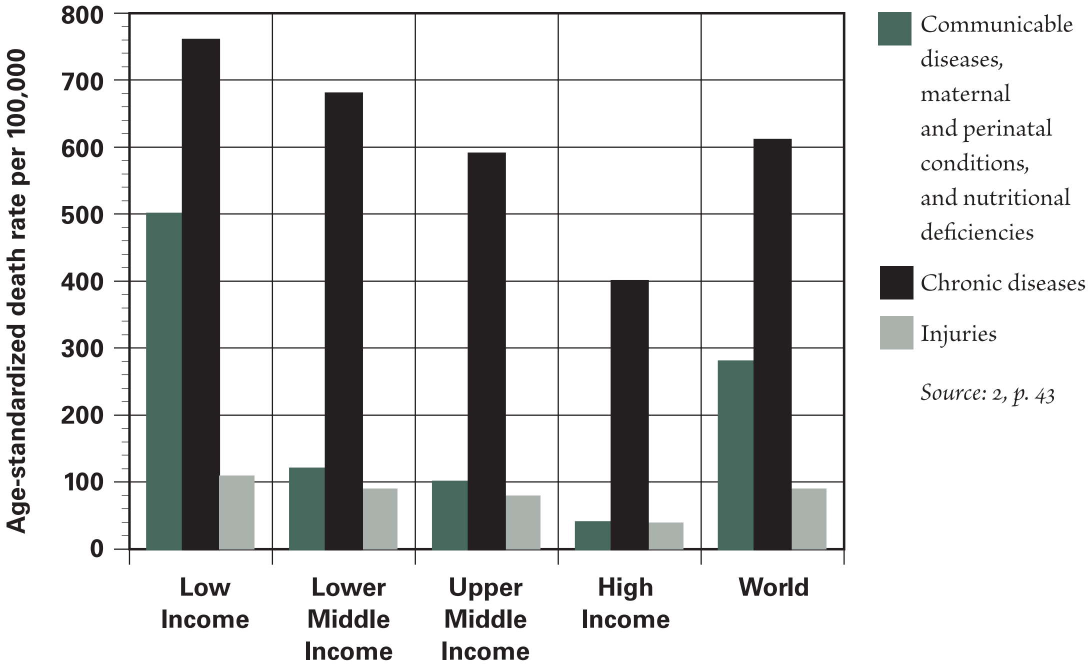
[1] Disability Adjusted Life Year (DALY) is a World Bank summary measure of the burden of disease that combines two components: "years of life lost due to premature mortality" and "years of life lived in a state of less than perfect health" (i.e., disability) (3, p. 493). "One DALY can be thought of as one lost healthy year of life" (2, p. 39).

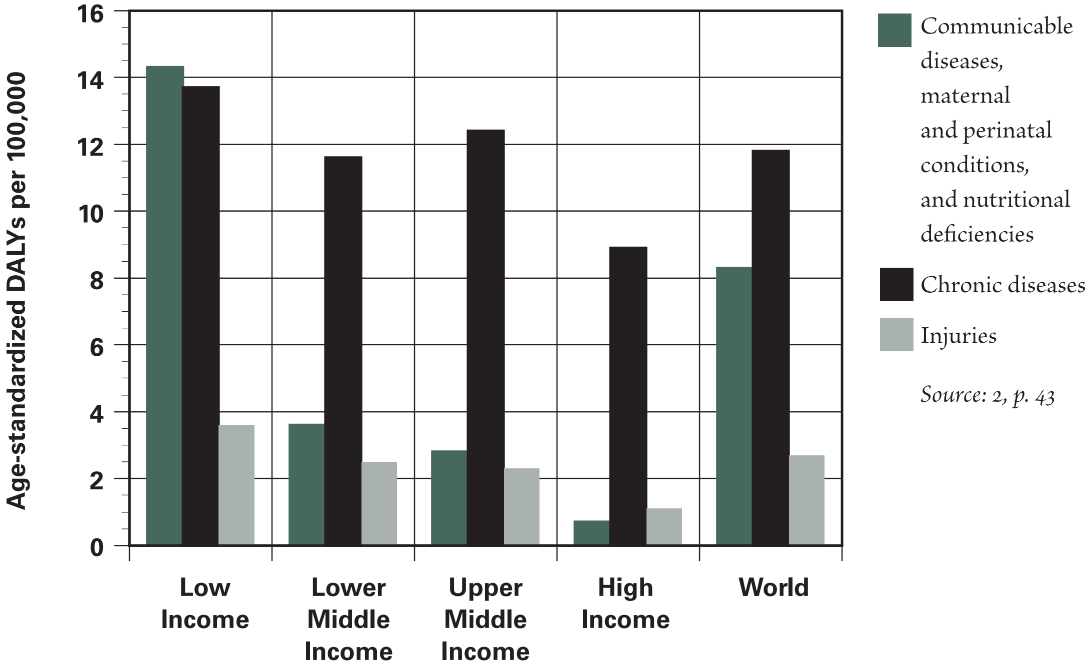
[2] The major causes of mortality in low-resource countries are presented in **Annex I.**

Figure 1: Projected main causes of death by World Bank income group (all ages, 2005)



Source: 2, p. 43

Figure 2: Projected main causes of burden of disease (DALYs) by World Bank income group (all ages, 2005)



Source: 2, p. 43

Chronic Disease Management

Introduction

Globally, the spectrum of "chronic" health conditions has vastly expanded (see **Table 1**). In resource-limited settings, an urgent need exists to address the growing challenges of these diseases and how current health delivery systems can more effectively respond to and manage the needs of those living with chronic conditions.

For healthcare providers, health program implementers, and community members, the lifelong reality of chronic illness requires a fundamental shift in perspective from the disease to the individual living with the condition.

The intrinsic relationship between the health sector and other societal sectors that impact chronic health conditions, including private healthcare, education, sanitation, agriculture, and transportation, must also be recognized. Extensive evidence suggests that these sectors contribute major elements of risk for chronic diseases that can be altered: for example, improved sanitation and waste management reduce the frequency of gastrointestinal diseases (2). Local production of affordable nutrient-rich foods that are consistently available contributes to well-nourished families. The growing impact of chronic disease upon society demands a broad multisectoral approach. While this document focuses on the health dimension of chronic disease, it simultaneously advocates for a comprehensive developmental approach that optimizes linkages with non-health sectors to reduce and mitigate the impact of chronic disease in resource-limited areas.

Chronic disease begins at all stages of life

An infant infected with HIV at birth will live into adolescence, adulthood, and old age when effective comprehensive healthcare is available that includes ART, psychosocial support, effective prevention behaviors, good nutrition, functional capacity to use income-generating skills as she matures, and other aspects of healthy living.

A 35-year-old nurse with hypertension will continue to actively perform her professional role and engage in other productive activities when standard health practices include ongoing health management by the patient in partnership with healthcare providers, health data recorded and maintained over time, and access to community resources that contribute to controlling risk factors to help maintain them within normal parameters (e.g., blood pressure, cholesterol and triglyceride levels, smoking cessation).

A 60-year-old farmer diagnosed with diabetes will continue to work productively to sustain his family and contribute to his community when he follows dietary, activity level, and medication protocols to control his glucose levels and is supported by healthcare providers and community resources to observe these health-enhancing practices on a daily basis and over time.

Table 1: Illustrative Chronic Conditions

Noncommunicable Conditions
- Cardiovascular diseases (e.g., ischemic heart disease)
- Diabetes
- Chronic respiratory diseases (e.g., asthma)
- Cancer (e.g., leukemia)
- Amyotrophic lateral sclerosis
- Multiple sclerosis
- Osteoporosis
- Uveitis
- Gastro-esophageal reflux disease

Infectious Conditions
- HIV/AIDS
- Hepatitis B
- Tuberculosis

Mental Health Conditions
- Depression
- Schizophrenia
- Substance addiction

Definitions: Acute and Chronic Disease

Chronic health conditions differ from acute illness primarily in duration, healthcare provider approach, treatments, and use of health system resources. By focusing on the disease—"disease care"—acute care neglects areas that are vital to the delivery of healthcare to optimize the wellbeing of the individual (see **Text Box 1**).

Bodenheimer et al. describe healthcare focused on responding to acute needs as the "tyranny of the urgent," which overshadows and assumes precedence over the needs of those with chronic conditions:

> *The acute symptoms and concerns of the patient crowd out the less urgent need to bring chronic illness under optimal management. . . . Under a system designed for acute rather than chronic care, patients are not adequately taught to care for their own illnesses. Visits are brief and little planning takes place to ensure that acute and chronic needs are addressed. . . . Too often, caring for chronic illness features an uninformed passive patient interacting with an unprepared practice team, resulting in frustrating, inadequate encounters (4, p. 1,775).*

While each chronic condition has disease-specific features that require appropriate interventions, certain elements are consistent across the spectrum of chronic diseases and define essential measures for effective management. Some pertain specifically to the patient and caregivers, while others focus on the healthcare system. Priorities for the **individual,** supported by caregivers, are as follows:

- interacting with the healthcare system on a regular basis, over time and for life
- incorporating responsibility for managing health and self-care into daily behavior
- sustaining behavior to achieve consistent adherence to medications and other relevant behaviors, such as healthy nutrition, at a high level to optimize health outcomes
- accessing viable mechanisms to deal with the emotional and social impact of adverse symptoms, disabilities, and the uncertainty of disease progression (5)

Text Box 1:
When Acute Care Predominates:

What doesn't get done

- Patient education (general health maintenance; disease-focused)
- Medication adherence support
- Prevention counseling
- Family planning
- Nutrition
- Stress reduction training
- Mental health
- STI screening
- Smoking cessation
- Substance use screening
- Vaccinations
- Cancer screening (e.g., Pap smears)

Source: 18

For **healthcare systems** to effectively manage chronic conditions, continuity of care must incorporate regular, sustained interaction with the patient (and caregivers as appropriate). Such interventions occur over an individual's life and strive to achieve the following goals:

- Fully engage the patient in care.
- Control the disease and manage symptoms and complications.
- Provide information to the patient and caregivers about the condition, including new therapies as they emerge.
- Engender skills and confidence in the patient, and provide ongoing motivation and support, to allow the patient to assume the primary role and responsibility in day-to-day management of the condition and their health.

Acute illness and chronic illness differ in the following ways:

Acute Illnesses

- Are characterized as episodic, time-limited events that treatment, or natural progression with supportive care, can cure or that result in death.
- Individuals seek health services when symptoms emerge that do not resolve without medical intervention.
- Healthcare providers react with medical interventions to cure or, if cure is not feasible, to control the cause and mitigate its adverse effects.
- Use the vast majority of resources of health systems in resource-limited countries today.

Chronic Health Conditions

- Insidious onset with a long duration; there is no cure.
- Occurrence at varying ages, from infancy to old age; some conditions (e.g., HIV/AIDS, diabetes, asthma) affect children early in life and exert substantial impact upon their developmental needs and potential.
- Fluctuating disease course includes complications and exacerbations that occur throughout the illness. Clinicians can anticipate many complications and their outcomes with some degree of accuracy, though specific complication type and onset vary among individuals.
- Healthcare goal is long-term (i.e., lifelong): to keep the individual as healthy as possible through prevention, early detection, and management of complications and exacerbations, thereby slowing disease progression and maintaining optimal functioning.
- Lifelong therapy must be systematic and sustainable to control the disease for conditions for which treatment is available (e.g., HIV/AIDS, diabetes, asthma). The treatment itself may produce complications that cause or contribute to chronic conditions.
- Addressing the needs of patients must be comprehensive. Diverse supportive therapies and life-enhancing resources must be accessible to meet the patient's needs, through linkages with health facility–based (e.g., physiotherapy, medication adherence support) and community-based (e.g., food support, home-based care) services.
- Patient self-care and day-to-day health management are essential.

Chronic Care, Comprehensive Care, and Palliative Care

The **chronic care** features described in the previous section distinguish it from other approaches to healthcare. However, chronic care overlaps in some respects, and is inextricably interrelated in other respects, with key approaches such as comprehensive care and palliative care.

Healthcare worldwide is widely perceived as fragmented and inefficient (1). In large measure, this can be attributed to the patterns that dominate individual care-seeking behaviors. Individuals access the health system primarily when an acute change occurs in their "normal" health, while health system providers focus on the presenting problem and not the individual during episodic events. To improve outcomes across all areas of health, a **comprehensive care** approach focuses on the individual as the frame of reference and seeks to address the holistic needs identified by the individual related to health and other interrelated dimensions of life.

The model of comprehensive care advocated by Family Health International embraces four interrelated life phases that span multiple domains: medical/health; psychological; socioeconomic; and human rights and legal. The comprehensive care approach addresses the needs of individuals, families, and communities in any and all of the four domains; it optimizes integrated care across the continuum of prevention, care, treatment, and support and connects the home and community to facility-based services and back. Chronic care and palliative care are integral components of comprehensive healthcare within this overarching framework.

The essence of **palliative care** is the relief of suffering, as it is defined by the individual and affected family and/or friends, through a wide range of interventions that address multiple dimensions of life, including the physical, mental, emotional, spiritual, and socioeconomic. Palliative care measures are most effective when enacted early in the disease course. They focus on quality of life rather than curing disease and feature a team approach to managing distressing symptoms. Palliative care is an integral component of both chronic care and comprehensive care, whereas the latter two are larger models of care.

These terms clearly overlap in many respects. While each also brings unique features to healthcare, what is important to recognize is that all three are interrelated and seek the same ultimate goal: the highest standard of health and quality of life for all people.

How Comprehensive, Palliative, and Chronic Care Differ:

- Comprehensive care employs a holistic approach, can be applied to both chronic and acute care, and includes palliative care.
- Palliative care focuses primarily on management of distressing symptoms.
- Chronic care is a larger model that includes the domains of comprehensive and palliative care.

Principles of Chronic Care

There is a vast literature on chronic disease, primarily from Western countries. Specific chronic conditions that are the focus of an extensive body of research, both as case studies and from randomized controlled trials, are diabetes, asthma, and cardiovascular diseases. To date, a paucity of research exists on chronic disease management in low-income countries and on the management of HIV/AIDS as a chronic condition in any setting. Though largely from high- and middle-income countries, existing research presents valuable insights and lessons to serve as a starting point for addressing issues of chronic disease management and for developing approaches and interventions related to chronic healthcare within the context of resource-constrained settings.

This research identified key principles for effectively managing chronic conditions applicable to diverse settings, including those with limited resources. For each principle listed, basic concepts and essential elements for effective chronic disease management follow, as well as issues that highlight key challenges for resource-limited settings.

1. An informed and engaged patient is an effective manager of her/his own health.

Fundamental Concepts: As chronic conditions are lifelong, the patient's participation in their own care is vital. Chronic disease transforms the individual's life, requiring that s/he create a new "normal" life that incorporates regular clinic visits, regular medication taking, regular monitoring for changes in health status (such as new symptoms, worsening of existing conditions, or functional deterioration), and adaptation to disabilities.

Extensive evidence exists to support the central role of patient self-management in chronic conditions (6, 7, 8). In a review of 39 studies of diabetes care programs, for example, Bodenheimer et al. reported that 19 out of 20 interventions using a patient self-management component improved a process or outcome measure (6). This review notes:

> *Patients with chronic conditions self-manage their illness. This fact is inescapable. Each day, patients decide what they are going to eat, whether they will exercise, and to what extent they will consume prescribed medications. . . . The question is not whether patients with chronic conditions manage their illness, but how they manage (6, p. 2470).*

Individuals with chronic illness must understand their illness and have the willingness and confidence to manage it on a day-to-day basis and in the medical, emotional, psychosocial, spiritual, and economic dimensions. This means proactively engaging in activities that promote health (such as good nutrition, maintaining social relationships, and avoiding harmful substances) and includes maintaining an ongoing relationship with healthcare providers on a routine as well as acute-need basis.

Key Challenges: In promoting a disease-focused rather than patient-focused approach, the current acute care model of service delivery in low-income countries creates passivity in patients that reinforces a dependent role in caring for their health. Most individuals thereby lack experience in self-advocacy, active engagement (in concert with healthcare providers as partners), and self-confidence in their ability to manage their own care. Structural and cultural barriers to healthcare also impact the individual's self-care capacity. For example, the paucity of health services in rural and hard-to-reach areas constrains access to meet even basic needs. For women who lack power to make many decisions about their healthcare, acquiring the knowledge and skills to self-manage a condition is a challenge requiring culturally sensitive and health evidence–based approaches and interventions.

Estimated age standardized death rates for chronic diseases in 2005 were 86 percent higher for women in low- and middle-income countries than for women in high-income countries (9).

2. The individual living with a chronic condition and his or her healthcare providers work in partnership, as a team.

Fundamental Concepts: Recognizing the patient's central role in and responsibility for the effective management of a chronic condition requires an essential shift in existing healthcare practices, particularly in resource-limited countries. From the current view of the patient as the passive recipient of care, healthcare providers must re-orient their approaches and practices to acknowledge and support the individual as a responsible and engaged co-manager (1, 10). For providers, this entails prioritizing information sharing, promoting beneficial health practices, and building the patient's skills in problem solving and confidence in their ability to care for themselves. Because of the extended duration of chronic illness, a plan of care developed collaboratively by patient and provider is a useful tool in defining objectives and essential elements of care (e.g., medication adherence and good nutrition, scheduling routine clinic visits, and laboratory tests) and thereby establishing a joint understanding of the respective roles and responsibilities of the patient and the provider.

Key Challenges: In health systems where the patient is traditionally viewed as the "recipient" of the healthcare provider's expert knowledge, cultural acceptance of an individual as a co-equal in care—with primary responsibility for and a central role in managing their health—requires a major shift in perception and practice on both sides of the relationship. Traditional patient education, based on didactic information acquisition, is inadequate for patients who require the knowledge and skills for lifetime self-care. Providers burdened by an existing high patient volume with acute needs are challenged for time, as well as the need to develop their own ability to work with the patient in developing self-management skills (10). Finally, providers lack not only the clinic time but also the communication skills to sensitively convey education and information messages to patients. Patient communication skills are traditionally overlooked in medical training (less so in nursing programs); many providers do not inherently possess the needed tools to assess, employ, and follow up on the most effective patient teaching without prior practice and feedback.

3. Evidence-based practices that incorporate routinely planned clinic encounters guide the effective management of chronic conditions by optimizing the ongoing follow-up of patients over time.

Fundamental Concepts: Effective management of chronic conditions requires clinical expertise based on current scientific evidence and best medical practices. The extensive burden of chronic disease, to be adequately addressed, calls for integrated networks of health services in which chronic care is oriented around regular, planned interaction with the patient (and caregiver as appropriate) and thereby includes capacity for continuous routine monitoring and early detection and treatment of emergent conditions; access is also needed to expert consultation and, as needed, patient referral through established relationships with specialists. Primary providers including physicians, nurses, nutritionists, lay counselors, and other health team members have updated knowledge and skills relevant to specific chronic conditions through regularly scheduled continuing education opportunities. Patients are educated on condition-related protocols that include the schedule of visits for routine care—and the rationale for routine care—and standard interventions to control disease progression. A clinic-based visit is not the only modality for routine care; alternative approaches include home visits by lay workers trained in basic health screening, health promotion, and adherence support.

Key Challenges: Health systems, particularly in resource-limited areas, are not organized for routine, long-term care of individuals. Systems for scheduling patient visits and long-term ongoing follow-up when a patient does not have an acute condition are generally lacking. Health facility staff are not oriented to planned, long-term care, and clinical information systems do not have procedures and tools for maintaining longitudinal patient databases and appointment schedules (see Principle 5.c.). Opportunities for ongoing clinical education updates for providers are also limited in most settings.

4. Prevention is a routine component of chronic care.

Fundamental Concepts: For an individual living with a chronic condition, one of the foremost objectives of care is to prevent disease-related or treatment-related complications and other co-morbid conditions that contribute to disease progression. Preventing the deterioration of health status and function is primarily related to the patient's integration of behaviors and lifestyle changes that optimize avoidance of risk factors contributing to disease complications and jeopardizing health. Patients must understand these factors and how they negatively impact health; providers must help patients develop the ability to avoid or, at minimum, reduce risk factors and promote skills and behaviors that contribute to good health.

Key Challenges: In general, prevention is not well integrated within healthcare regardless of whether the setting is a low-, middle-, or high-income country (2). Prevention support is one of the services that "does not get done" when the volume and urgency of acute care needs overwhelm healthcare providers (see **Text Box 1**). Multiple barriers prevent efforts to address the key modifiable risk factors for chronic conditions. For example, poverty impacts nutrition, alcohol use, and psychosocial stress; cultural beliefs and norms contribute to sexual practices and healthcare-seeking behaviors; and lack of regulatory mechanisms promote access to and use of tobacco.

Text Box 2:

Key Modifiable Risk Factors for Chronic Conditions

- Prolonged and unhealthy nutrition
- Unsafe sexual practices
- Tobacco use
- Physical inactivity
- Excessive alcohol use
- Unmanaged psychosocial stress
- Poor adherence to prescribed medications
- Non-routine episodic healthcare

Source: 1, p. 16

5. **Health facility–based care for chronic conditions is enhanced when the following elements are present:** (a) chronic care is integrated as a component of Primary Care;[3] (b) it is delivered by a multidisciplinary team of healthcare providers and community workers; (c) it utilizes a health information system with standardized and easily retrievable data; and (d) it has functional partnerships with community services to facilitate access to services across the continuum of care.

a. **Chronic care is delivered as a component of Primary Care:**

Fundamental Concepts: Primary Care is a standardized set of healthcare services centered on the ongoing promotion of optimal health for all individuals. **Annex II** presents the Core Components of Primary Care. Primary Care can be provided at any level of care, in the public sector and in the private sector. However, in most settings, it is a core activity of the primary or community level of care; there is evidence that Primary Care is most consistently and effectively delivered at the primary level of care (7, 11).

Basic care for all chronic diseases includes many of the components associated with Primary Care. Primary Care based in the community—and thereby delivered at primary-level health facilities—has the advantages of accessibility for patients, local staff known to residents of the area, and experience in caring for a broad range of health conditions with established referral networks linked to other levels of care. When complex presentations or complications of chronic conditions requiring specialty management occur, functional networks facilitate referral to the secondary or tertiary level, where most expert physicians are based.
In its comprehensive approach to service delivery and mechanisms for collaborating with other levels of healthcare and community-based resources, Primary Care embodies characteristics that contribute to service provision for individuals requiring a lifetime of care.

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[3] Primary Care refers to a package of essential health services that help an individual maintain optimal health and wellbeing (see Annex II: Core Components of Primary Care for a list of these services). This package is usually provided at the primary/community care level, but can also be provided at the secondary and tertiary levels. In this document, Primary Care is capitalized to assist in differentiating the term from primary level of care, i.e., care delivered at the community level as a component of the health system's levels of care.

Key Challenges: As previously noted (see **Definitions: Acute and Chronic Disease** and **Principle 4**, above), because of acute care needs, services that comprise standard Primary Care are often the ones that are not delivered. Moreover, the well-documented challenges in healthcare delivered at the primary level impact all services (1, 11). In some countries, not infrequently rural or distant areas, primary health sites are staffed by one or two healthcare workers, often nurses or workers from a lower cadre, who must address all medical and clinic management and administration needs. Poor facility infrastructure (e.g., lack of clean water, unsafe structural foundation, lack of basic commodities, and weak infection control practices) also impedes care delivery for both chronic and acute care patients. To improve effective practices of chronic care within care delivered at primary facilities requires a broad approach to health system strengthening at the primary healthcare (PHC) level.

b. A multidisciplinary team of healthcare providers and community members delivers care in partnership with the patient.

Fundamental Concepts: Providing care for chronic conditions as a planned, routine service exceeds the scope of any one healthcare provider. There is extensive evidence from middle- and high-income countries that a team of health workers with clear roles and responsibilities, and a regular mechanism for communication (such as weekly team meetings), can most effectively balance and deliver care for both large numbers of patients who live with chronic conditions and individuals requiring acute management (1, 7, 10). With training and tools, lay persons with specific responsibilities can add value to the team and reduce the workload of healthcare workers (HCWs); this is particularly relevant for facilities, such as PHCs, with one or few HCWs. For optimal health outcomes, ongoing coordination, documentation, and quality assurance/quality improvement (QA/QI) initiatives are requisite to ensure that all aspects of care (such as health screening, prevention counseling, patient self-management skills building, patient education and health promotion, and adherence support) are delivered by the person to whom each was delegated.

Key Challenges: Healthcare workers need skills that enable them to work cooperatively, as a team. As noted earlier, they also need training in communication skills that assist individuals with chronic conditions to develop self-confidence in managing their own care and sustaining health-enhancing behaviors over the course of the illness and their life (for example, adherence to prescribed medications and avoiding harmful risk factors). In addition to these specific skill sets, healthcare providers need systems and tools to follow up on patients living with chronic conditions through regular, planned interaction over time.

c. A health information system is available with standardized and easily retrievable data that contributes to effective healthcare for patients with chronic conditions over the long course of their illness.

Fundamental Concepts: Data processes and tools designed to maintain clinical information longitudinally are needed to follow and monitor patients who live with health conditions over lengthy periods. While computerized databases have the advantages of storage, easy retrieval, and report generation, paper-based systems can maintain the information to ensure a high standard of care (1, 12). Key components are patient registers; tracking systems for rapid follow-up (such as missed visits); a function that prompts HCWs to remind patients of scheduled visits, other services, or follow-up needs; and a reporting mechanism that quickly gives feedback to providers on key patient outcome measures as well as provider reminders of prevention/health maintenance activities (13).

Key Challenges: In most settings, health information systems lack the capacity for maintaining a large set of patient-level data over long periods of time. To effectively deliver care to individuals with any long-term chronic illness, however, multiple clinical parameters need to be tracked over time. Retrieving information from existing medical records is equally problematic. Since in acute care, patients seek services from healthcare providers as needed, systems are not in place for the regular, prescheduled interaction with providers that is a standard of care for chronic illness.

d. A functional partnership exists between health facility–based providers and community-based groups that facilitates access to services across the care continuum.

Fundamental Concepts: Chronic disease impacts all dimensions of an individual's life and the lives of family members or caregivers. The community within which the individual lives houses an array of resources that complement healthcare delivered within a facility: home-based care (HBC), spiritual support, food resources, and social relationships, for example, can support the patient's self-care and respond to needs as they change with disease fluctuations over time. Community lay workers can provide basic services for individuals, such as support for self-care, and can also raise awareness of risk factors for chronic illnesses and measures to promote good health. For continuity and coordination of care "that cuts across time, settings, and providers" (1, p. 43), integrated networks of services—inclusive of facility-based and community-based services—must be functional to optimize access and address care needs over time.

Key Challenges: In many settings, community members and groups actively engage in responding to the healthcare needs of residents and providing material and nonmaterial support according to individual needs. However, these services may not have the capacity to deliver resources and support over lengthy periods of time and in response to the fluctuations and often unpredictable course of chronic illnesses. For example, food support may be available for limited periods, but for a chronically disabled person unable to farm or obtain food on a regular basis, community-based mechanisms may not exist to address this need and other service gaps over weeks, months, or years. Finally, referral systems, where they exist, are frequently weak, with no standardized procedures, tools, or mechanisms to track whether individuals have access to needed services and whether their needs are met.

HIV/AIDS as a Chronic Condition

HIV/AIDS embodies all of the features that define an illness as a chronic condition, as presented in the table on page 5, ***Chronic Health Conditions***:

Chronic Health Conditions	HIV/AIDS
• Insidious onset with a long duration	• HIV/AIDS has a long latent period before the emergence of disease-specific symptoms.
• No cure	• Presently there is no cure.
• Occurrence at varying ages	• HIV can infect individuals of any age.
• Fluctuating disease course	• While the natural history of HIV/AIDS has been defined, the course of HIV disease varies among individuals, with complications, such as opportunistic infections (OIs), emerging at different times throughout the trajectory of the illness; however, the ultimate outcome of HIV disease is AIDS.
• Long-term healthcare goals	• The goal of healthcare is long-term (i.e., lifelong): to keep the individual as healthy as possible through health-promoting behaviors (such as good nutrition and ongoing prevention), cotrimoxazole preventive therapy, early detection and management of OIs and other HIV-related conditions, and prescription of antiretroviral therapy.
• Lifelong therapy must be systematic and sustainable to control the disease for conditions for which treatment is available.	• Treatment with ART is lifelong. It can control viral replication and disease progression with high levels of adherence, although not all regimens are equally effective for all patients, requiring frequent follow-up and monitoring.
• Daily patient self-care and health management	• Patient self-care and day-to-day health management are essential.
• Addressing the needs of patients must be comprehensive. Diverse supportive therapies and life-enhancing resources must be accessible to meet the patient's needs, through linkages with health facility–based services and community-based services.	• HIV/AIDS impacts all dimensions of life, and a comprehensive approach is essential to address the diverse needs of patients. For optimal health, those living with HIV require access to both health facility–based (e.g., medication adherence support, mental health counseling) and community-based (e.g., food support, home-based care) services when needs arise during the course of the illness.

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The principles of managing chronic disease are as relevant for HIV/AIDS as for other chronic conditions (14): for example, the HIV-infected patient has a central role in self-managing his or her health, including strengthening the immune system through basic health-promoting behaviors, adhering to prescribed drug regimens and monitoring protocols, and maintaining a viable partnership with healthcare providers. Prevention is an essential element, both to avoid re-infection and to prevent transmission of the virus to others.

However, certain features of HIV/AIDS distinguish it from other chronic illnesses, with implications for its management:

1. High levels of stigma continue to be associated with HIV/AIDS in many settings, and the discrimination experienced by those living with the disease can assume such life-altering forms as loss of jobs, loss of housing, and violence. While other chronic illnesses carry some stigma, HIV/AIDS bears a greater degree, in part because it is a communicable disease and also because some believe the individual is responsible for acquiring the disease (15, 16, 17).

2. ART remains a complex treatment in spite of recent enhancements (e.g., availability of fixed-dose combinations, reducing dosing frequency with newer drugs) and still requires rigid clinical and laboratory monitoring as well as strict treatment adherence.

    - Drugs for second line and salvage regimens are more complex to take, have more side effects and toxicities, generally have a higher pill burden, and may have specific food requirements.
    - In many settings the drugs are expensive and not widely available.
    - Adverse drug effects and toxicities are associated with most antiretrovirals (ARVs), particularly the older drugs.
    - Long-term toxicities from some of the ARV drugs include disfiguring effects (e.g., lipodystrophy) that impact adherence and long-term use.

3. Long-term complications from ARVs and aging include diabetes and cardiovascular disease, which produce additional chronic challenges to the HIV-infected patient.

4. HIV-infected patients lack a specific self-monitoring tool, such as blood sugar levels used by diabetics and peak flow levels by asthmatics, to provide feedback that can contribute to adjustments in health-related behaviors on a daily and ongoing basis[4] (18).

5. The potential for HIV to be transmitted to family members creates even broader implications for chronic care, extending the challenges to all infected with HIV.

These issues present particular challenges in the management of HIV as a chronic condition.

Chronic Care in Resource-Limited Settings

The high—and increasing—incidence of chronic disease in resource-limited countries has been widely documented (1, 11). In addition, communicable diseases place a concurrent burden on these societies, consuming vast resources and imposing great suffering on individuals. This "double burden of disease" in low- and middle-income settings is not widely acknowledged. External aid, for example, focuses primarily on infectious diseases, notably HIV/AIDS, tuberculosis, and malaria, while the larger—and growing—number of people with cardiovascular diseases, diabetes (some cases related to HIV/AIDS), and chronic pulmonary conditions receives scant attention (1). The imperative in these settings is to address both:

> *This is not a case of either-or, but of directing resources to cost-effective interventions to address both communicable and chronic disease burdens (3, p. 493).*

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[4] This feature is currently more relevant for high-income countries where the technology for self-monitoring these conditions is widely available.

There is increasing, though largely undocumented, recognition that internationally funded programs dedicated to HIV/AIDS, tuberculosis, and malaria strengthen health systems in ways that benefit the care of people with diverse health problems. Training health workers on best practice guidelines and standard operating clinical procedures, upgrading laboratories and pharmacies with functional equipment and procedures as well as facility infrastructure in general, and enhancing quality improvement processes contribute to health delivery improvement overall. For HIV/AIDS, a large portion of funding specifically supports the expansion of antiretroviral treatment, which provides the potential for HIV/AIDS to officially be classified as a chronic disease.

However, in health systems designed to deliver acute care, the transformation from acute disease management to chronic care management is uncertain—for HIV/AIDS and other protracted illnesses—without interventions that involve not only medications and infrastructural upgrades, but also broader systems change and a central role for the patient in managing their care. The next section considers strategic approaches and interventions to transform the principles of chronic disease management into operational practices that address the needs of people with chronic conditions, while continuing to care for those with acute needs, in resource-limited areas. Examples are drawn from FHI-supported programs in HIV/AIDS to illustrate applications.

Chronic Care Strategies

Several published studies report on interventions that improve health outcomes for patients with chronic illnesses. Summary findings follow from three articles with potential for informing strategic approaches for managing chronic conditions in resource-limited settings; two use data from middle- and high-income countries while the third draws upon data from low- as well as middle- and high-income countries:

- One meta-analysis of studies designed to test interventions to improve Primary Care for diabetes drew two major conclusions: first, that the more comprehensive and multifaceted approaches (i.e., those that target more than one component of care—patient-oriented, provider-oriented, care delivery organization and information systems) yielded greater improvement in the clinical criteria that define diabetic patient outcomes; second, that provider-targeted interventions do not change health outcomes unless interventions are concurrently directed at patients (7).
- Analyzing cost-effectiveness estimates for interventions to prevent or reduce major risk factors contributing to chronic disease, Gaziano et al. report findings supporting the scale-up of certain approaches in low-income countries that yielded favorable outcomes in middle- and high-income countries (e.g., tobacco taxation, salt reduction), but also observe that limited cost-effectiveness data exists on health system–based interventions required to address chronic disease equitably and effectively (19).
- One of the few studies available on chronic HIV care addresses the information, motivation, and behavioral skills for effective patient self-management, concluding that "[s]elf-management is a collaborative effort. Patients, providers, and the system of care all contribute, and the success or failure of self-management depends on how well the collaboration works" (20, p. S164).

These and other studies provide evidence for the design of interventions, and more broadly for program planning, to operationalize the principles of managing chronic conditions, including HIV/AIDS, in resource-limited settings. As a framework for transforming principles into practice, interventions are considered in the context of the five following essential elements of healthcare.

Principles into Practice:
Critical Healthcare Components

- Patient
- Provider
- Health delivery system
- Community
- Policy environment

1. Patient-Oriented Interventions

Chronic disease alters the life of individuals in profound ways. Extensive evidence demonstrates improved health outcomes when the individual living with a chronic illness assumes both a central role in reducing disease-related complications and symptoms and responsibility for the lifestyle changes that lead to this outcome (6, 10, 21, 22). **Text Box 3** presents key findings from one study as an example, reporting that changes in medication adherence self-efficacy and cognitive-behavioral self-efficacy among women living with HIV/AIDS are associated with positive clinical and cognitive-behavioral outcomes.

Summarized from the literature, the essential requirements for the individual's primary role in self-care follow:

a. disease-specific information about the condition and related technical skills to identify, treat, and monitor it (e.g., how to take prescribed medications).

b. problem-solving skills to effectively manage the condition, both to promote health and to avoid or reduce risk factors that exacerbate the condition.

c. confidence in managing the condition: increased self-efficacy in using the information and skills for positive health outcomes (8)

> *Regardless of age at onset, whether their etiology is known or whether their manifestations are primarily physical or psychosocial, essentially all chronic conditions present a common set of challenges to the sufferers and their families—dealing with symptoms, disability, emotional impacts, complex medication regimens, difficult lifestyle adjustments, and obtaining helpful medical care (10, p. 65).*

For patients and providers accustomed to a dependent relationship and to "as needed" healthcare-seeking behaviors, transforming patients into proactive, engaged co-managers of their illness with an increased self-care capacity requires a shift in existing attitudes and practices among all involved: patients, their families or caregivers, HCWs, and the broad health system, including professional organizations and health policymakers. Yet, apart from this fundamental culture shift, specific measures can prepare and support patients to assume a primary role in and responsibility for the management of their health. For example:

- **Health literacy** is the capacity to obtain information at a level and in terms understood by the patient, in relation to two broad spheres: first, basic areas contributing to general good health, including hygiene, nutrition, exercise, avoidance of harmful substances, and social support, and second, information specific to the disease with which the patient is living. Patient education is a fundamental responsibility of healthcare providers, although alternative sources can perform this role, thereby reducing the workload on clinicians (see below: **Lay supporters** and **"Expert patient"**). Patient-focused materials, such as videos and brochures, are important aids for conveying accurate health-related information.
- **Problem-solving skills:** Health literacy extends beyond access, to the ability to use information appropriately. It entails skills to extract and apply knowledge within given circumstances to address health needs or issues. The patient must understand
  - ➢ instructions in order to take drugs correctly
  - ➢ the importance of routine clinic visits in order to keep scheduled appointments
  - ➢ what action to take to manage a new symptom appropriately
  - ➢ the meaning of the consent form prior to undergoing a medical procedure

  Equally important is the ability of the patient to ask pertinent questions, verbalize health concerns, and accurately describe symptoms. Skills and self-confidence are built through practice and encouragement. While initially time-consuming for providers, consistent interaction aimed at patient involvement yields long-term benefits as the patient is able to assume more aspects of their own care. Integrating lay workers trained in patient education and counseling into healthcare teams comprises an evidence-based approach that builds patient skills while reducing the workload of professional health workers (23).

Primary Outcomes Reported in SMART/EST Women's Project Study

Increased medication adherence self-efficacy was significantly correlated with
- increase in CD4 count over time
- decrease in viral load over time

Increased cognitive-behavioral self-efficacy was associated with
- decreased viral load over time (but not changes in CD4 count)
- decreased depression
- decreased anxiety

Source: 22

- **Plan of care** reinforces the partnership between the patient and the care team members. Jointly developed by patient and provider, it identifies long-term and short-term goals of care and treatment specific to the patient and delineates action steps for achieving the expected outcomes. By defining the respective responsibilities of the patient and healthcare providers, the care plan establishes accountability of each with respect to the patient's optimal health.
- **"Expert patient"** embodies the self-confidence, skills, and knowledge for assuming the primary role in self-managing and living well with a long-term illness. Research conducted in high-income countries documents benefits associated with the capacity to perform the role of expert patient, including reduction in severity of symptoms experienced and improvement in resourcefulness in managing health-related events and life satisfaction (24, 25, 26). Training, mentoring, and consistent positive affirmation of self-worth contribute to heightened confidence and capacity as an expert patient.
- **Lay supporters** contribute to the capacity of patients to manage their chronic illness in multiple ways, such as through home-based care, treatment adherence support, peer education, support groups, and community service referrals. The benefits go beyond tangible assistance with preparing meals and providing medication reminders; as friends, peers, and fellow community members, lay workers help reduce the patient's isolation stemming from decreased functional capacity and/or stigma and are available to share emotions and spiritual doubts, helping to reaffirm the individual's self-worth and ability to manage the challenges created by their illness.

Examples from resource-limited countries exist of measures currently being implemented that build the self-management skills of patients. Within initiatives to expand ART and other HIV services, patients living with HIV are prepared in advance for their responsibilities in medication and clinic appointment adherence, as well as in changing risk behaviors, through ongoing education, counseling, and support. HIV-positive lay workers assume a major role in these interventions.

FHI-sponsored programs worldwide offer global success stories:

Kenya

Members of the Coast Organization of People Living with HIV/AIDS (COPE) in Mombasa apply skills acquired through ***training and mentoring to educate, counsel, and support their peers,*** *including: recently diagnosed HIV-positive individuals not yet in care, those in care but not on ART, and those started on ART. Comprehensive HIV care including ART started at FHI-supported health facilities in 2003.*

Cambodia

Practical and informative ***guidance developed in concert with people living with HIV/AIDS (PLHA)*** *provided for individuals living with HIV through a series of publications on self-care. Materials include "Living with Hope and Staying Healthy," "Living Peacefully with AIDS," and "Staying Healthy for Mothers with HIV."*

Zambia

HIV-positive Adherence Support Workers (ASWs) work alongside HCWs in health facilities in the Zambia Prevention, Care, and Treatment Partnership Project. Together they ***educate, counsel, and support individuals living with HIV as "expert patients"*** *knowledgeable about their condition, as advocates for quality care, and as role models for living a healthy lifestyle that includes primary responsibility for reducing harmful behaviors.*

2. Provider-Oriented Interventions

In addition to the broad commonalities shared by individuals with different chronic conditions, there is a wide range of factors specific to the individual, such as idiosyncratic health issues, economic circumstances, family and social relationships, and cognitive and mental functions. Standards dictate healthcare provided to effectively manage any condition to ensure all patients living with the illness receive optimal care. However, care must also be individualized to address the particular needs of the patient. Over a lifetime, as the patient's needs change, healthcare providers must be responsive and address each existing circumstance not as an episodic event, but as part of a continuum over the long-term course of the disease.

Chronic disease studies consistently reveal that when the interpersonal relationship between patient and provider evolves from the predominant dependent model between care recipient and sole expert manager to a co-manager partnership between patient and provider with clear roles and responsibilities, patient health outcomes improve (4, 12, 20, 27). Several measures illustrate how to support this transition for healthcare providers:

- **Plan of care:** As described in **Patient-Oriented Interventions,** a plan developed jointly with the patient provides a way to define respective roles and responsibilities of a patient and each provider on the healthcare team. The plan demonstrates collaborative goal setting and specific action planning and requires regular review and updates as needed.
- **Screening Guide:** Developed for each chronic condition, the guide helps ensure coverage of key care components at each patient encounter. It is based on the standard operating procedures (SOPs) used as the basis for service delivery and includes the Core Components of Primary Care as well as specific elements for managing the chronic condition.
- **Providers:** Providers are coached and mentored to strengthen skills in addressing the behavioral aspects of chronic care, including building the patient's capacity in problem solving and self-managing their illness. Such tools as the ICIC *Improving Your Practice Manual* focusing on chronic disease management can be adapted to specific countries and healthcare systems (28).
- **Prevention:** Incorporated within every patient encounter, prevention is promoted by the methodology presented in *Integrating HIV Prevention in the Care Setting: Health Manager's Guide,* published by FHI (29). While addressing HIV prevention specifically, the Guide describes an approach that can be adapted for integrating prevention within chronic care in general. Preventive healthcare also includes regular health maintenance activities, such as screenings (e.g., Pap smears, tuberculosis screening), family planning, and immunizations (e.g., hepatitis B vaccination).
- **National guidelines and facility-based SOPs:** Providers deliver evidence-based care for chronic conditions by adhering to these standards. Orientation to these materials promotes clinical practice compliant with the standards that are embedded in the guidelines. Job aids format the content of SOPs as a quick visual reference, assist healthcare workers by detailing procedures succinctly, and serve as a valuable memory cue for rapid decisionmaking. Established partnerships with specialists in chronic conditions facilitate access to expert consultation and patient referral as needed.
- **Continuing education updates:** Updates keep HCWs current with scientific findings and new and evolving clinical practices, and contribute to evidence-based care that supports positive health outcomes for patients.

The following illustrate current practices in the field.

Performance Checklist: HIV Counseling and Testing Skills Training Curriculum

- *A specific application of a screening or assessment tool is incorporated in FHI's VCT Toolkit.*
- *The checklist provides a practical tool to remind counselors and self-assess their observance of the essential counseling skills and steps in delivering HIV pre-test and post-test counseling. The VCT Toolkit is widely used in the 25 countries where FHI supports HIV counseling and testing services.*

SOPs for HIV Service Delivery (Including ART) for District- and Tertiary-Level Facilities

- *In Tanzania, the National AIDS Control Program (NACP) initiated the development of SOPs.*
- *Drafted collaboratively by the NACP and FHI, the SOPs and job aids summarize essential clinical care content guiding healthcare workers in the provision of safe and effective HIV care and treatment services despite limited HCW experience.*

ART Adherence Toolkit for Lay and Professional Health Workers

- *A toolkit has been developed in Vietnam to assist both lay and professional health workers in preparing clients for ART and supporting their ongoing adherence to treatment.*
- *Checklists for individual counseling sessions and a curriculum for group education sessions are included to guide adherence supporters in working effectively with ART clients for long-term beneficial outcomes.*

Adapting to a chronic and patient-centered model of care can create challenges for healthcare providers accustomed to acute care delivery and compliant patients. Their buy-in is crucial to success. However, considering the overflowing waiting rooms and pressing acute care demands in most resource-limited health facilities, is it realistic to advocate with and support providers to increase their focus on care for patients with chronic conditions? Several factors support an affirmative response:

- When providers recognize the benefits of a patient-provider partnership (for example, the provider is relieved of sole responsibility for the individual's complex, lifelong care needs, while the informed and engaged patient contributes substantially to their own care, saving the provider time over the long term), an important incentive exists for changing care practices.
- As suggested by illustrations from the field, strategic approaches and interventions currently implemented in these settings, in large measure due to ART expansion initiatives and other HIV-related services, can be adapted and enhanced to improve the management of chronic illnesses.
- With chronic diseases responsible for the greatest share of morbidity and mortality in resource-limited settings, creating the imperative previously cited—*This is not a case of either-or, but of directing resources to cost-effective interventions to address both communicable and chronic disease burden*—the appropriate question is: How can providers be prepared and supported to address chronic conditions effectively?

3. Healthcare Delivery–Oriented Interventions

Beneficial outcomes for patients with chronic conditions are associated with periodic assessment of clinical and psychosocial status, effective medical therapy, sustained follow-up, and greater patient confidence and skills in self-management (6, 13, 30). Transforming the organization of health delivery from episodic care to planned care across time can be advanced through interventions whose efficacy has been documented, including the following:

> ***Healthcare organizations should emphasize treating the patient who has HIV/AIDS, not treating the HIV/AIDS.***
>
> *Source: adapted from 1, p. 33*

- Health facility managers prioritize chronic care and work with staff to restructure service delivery to advance this priority (4).
- Systematized care delivery through regular, planned interactions between patients and providers over the course of the illness, with scheduled follow-up visits to promote continuity of care (7). Patients benefit from a "one-stop-shop" delivery system in which services are integrated at one service point (see **Annex II: Core Components of Primary Care**); however, if services are instead provided over a range of settings, functional coordination, such as a structured district-based referral network, is required to promote access (1).
- A team of providers with clearly demarcated roles and responsibilities can most effectively address the varied needs of patients with chronic conditions (4). At small primary health centers, a team may consist of one professional healthcare worker and one lay worker; at larger facilities, there may be a broader range of HCWs and lay workers. Regardless of the setting, team members need
    - ➢ skills to work cooperatively and a regular mechanism for communication, such as weekly scheduled meetings
    - ➢ skills in sharing responsibilities with patients, including skills in communication and behavioral interventions to promote patient self-management, adherence to care protocols, and changes in lifestyle
    - ➢ clear delegation of functions to optimize implementation of and responsibility for care practices
    - ➢ guidelines of care (such as national guidelines and SOPs) incorporating up-to-date evidence to inform their daily practice
    - ➢ essential drugs and other commodities relevant for each chronic illness
- An information management system that captures data and services over time is critical to ensure timely access to patient-level information throughout the lengthy course of the chronic illness, as well as population-level data to improve planning and service delivery in accordance with standards of care (1). For providers, important features of a health management information system (HMIS) that supports the management of chronic diseases are a routine reporting and feedback function that concisely lists prior diagnoses, medications, and laboratory results; and a reminder function, both to schedule follow-up visits and to address a patient's specific care needs (such as six-month CD4 count, specific prevention activities).

  According to the WHO, a simple, standardized paper-based register and standardized patient-held card can serve the needed functions (1); electronic-based systems have the additional advantages of retrieving larger data sets and rapidly producing reports, whether for an individual patient or a specific population.

Many care coordination interventions are currently implemented in some form and to varying degrees in different resource-limited settings as a result of activities to strengthen health systems in the expansion of HIV services. They create a basis for adaptation and expansion to improve outcomes for individuals with other chronic conditions. Following are a few examples from FHI-supported sites:

Cambodia: Comprehensive HIV Care Site (CCS)

- *Each healthcare team member has a clearly articulated and well understood scope of responsibilities.*
- *This facilitates care delivery of all essential services for each patient (e.g., registration, triage, assessment, medication dispensing, prevention counseling, adherence monitoring, referrals to community and for other health services, and documentation).*
- *Team members meet weekly to share information and discuss challenging issues.*

Zambia: ART Centers at ZPCT-Supported Health Facilities

- *Standardized clinical forms and registers are used.*
- *Data is managed by data clerks responsible for the quality of data collection and recording.*
- *ZPCT monitoring and evaluation (M&E) staff conducts regular data audits to ensure quality and sustainability of data maintenance methods over time. (While the paper-based HMIS is a functional system for a limited range of data elements, the data is currently being migrated into a nationwide software package to increase flexibility in data management for both patient care and population-level analysis.)*

Vietnam: HIV Outpatient Clinics

- *In some HIV outpatient clinics, the HIV team—including outpatient clinic staff, HBC team members, and PLHA peers—meet every morning for 30 minutes to discuss complex patients, review follow-up of clients who are hospitalized or with poor adherence, and raise general work-related issues.*
- *While each HIV team member has a different role on the team, they all share information and opinions that carry equal weight in the delivery of care services.*

4. Community-Oriented Interventions

An individual living with a well-managed chronic illness has the functional potential to participate in and contribute to family, work, and community life. Community resources serve several vital functions in supporting residents with chronic conditions. First, community organizations provide complementary services to health facility–based care, such as home-based care, food support, and peer support groups (10). Second, through local groups well-informed about chronic diseases, awareness can be raised about risk factors associated with chronic diseases and measures to promote healthy lifestyles. Communities can be mobilized to address risk factors such as polluted water, tobacco use, and the isolation in which individuals with chronically reduced function may be living. Stigma associated with HIV/AIDS is extensively documented; stigma also exists in varying degrees of intensity in relation to cancers, chronic depression, and other chronic diseases such as substance use. Community groups and members can disseminate accurate information and model behaviors that promote increased acceptance and tolerance; community leaders can advocate for increased resources to support people living with chronic conditions.

For accessibility to community resources and care to effectively span community and health sector services, coordination between providers is an essential and challenging prerequisite. Mechanisms to promote collaboration and communication, standardized processes and tools to optimize referrals, and continuous monitoring to support quality are necessary if individuals with chronic conditions are to meet their needs over the course of their illness.

As for the other essential elements of healthcare, existing programs to expand services for HIV/AIDS in resource-limited settings offer concrete examples of the vital role that communities assume in caring for those living with this condition. Such programs highlight valuable insights and lessons for adopting and adapting interventions related to the role of communities in addressing other chronic diseases.

Tanzania: TUNAJALI HIV Care and Treatment Program

- ***Capacity building*** *of community-based organizations and faith-based organizations to provide home-based care and orphan support.*
- ***Household visits*** *by trained community/home-based care (CHBC) workers help address basic nursing and social needs of those living with HIV and provide important opportunities for reinforcing prevention messages.*
- ***Lay workers accompany individuals*** *on hospital visits, promoting coordination of care, and follow up with patients on adherence to medications and attendance at their next clinic appointments.*

Vietnam: The Continuum of Care Coordination Committee (CoC-CC)

- ***Operationalizes collaboration*** *between health facility–based and community-based services.*
- ***Supports collaboration*** *between PLHA, PLHA groups, NGOs, CHBC teams, and faith-based organizations.*
- ***Identifies service gaps and mobilizes resources*** *to support initiatives to address these gaps.*
- ***Oversees referrals*** *to improve access to services.*

Zambia: ZPCT Project

- ***Supports the creation of district-based referral networks*** *that bring together community and health sector providers.*
- ***Strategy focuses on facilitating and supporting,*** *but not leading or managing, the referral networks' ongoing activities to optimize their sustainability.*
- *In each district, ZPCT-supported health facility and community partners* ***use the standardized district-based tools and processes, join other members in regular network meetings, conduct quality audits of referral data,*** *and as all network members, contribute minimal resources to sustain activities (e.g., providing a meeting venue, or a ream of paper to copy referral forms).*

5. Policy Environment–Oriented Interventions

The rising incidence of chronic diseases and high rates of associated morbidity and mortality in low-resource countries call for leadership to formulate policies and plans to mount an improved response at all levels—national, provincial, district, and local. Leaders and policymakers can be supported in developing policies and low-cost strategies to address chronic health needs when they are equipped with current, accurate information and the commitment to translate policies into urgent action to expand and improve chronic care. At the policy level, the following are priority areas:

- Integration of policies and integration of services—across health conditions, levels of healthcare, and health/community delivery systems—support effective management of chronic conditions and reduce fragmentation and waste of resources (12). Policies and plans can promote a comprehensive approach to chronic illness management by incorporating prevention, health promotion, and treatment across the continuum of care. To organize health systems on principles of service integration and chronic disease management, national guidelines that define standards and protocols are needed, as are standard operating procedures that adapt national guidelines for standardized, evidence-based clinical and community-based practices.
- Different sectors of society, including agriculture, labor, and education as well as private healthcare and private sector workplaces, impact health and contribute risk factors for chronic illnesses. A multisectoral approach designed to align the policies of these sectors into a coherent framework strengthens a coordinated response to comprehensively address the prevention, health promotion, and management of chronic conditions and promote partnerships between institutions and individuals working within these sectors (31).
- Interventions to prevent chronic conditions, to promote healthy lifestyles, and to manage chronic diseases over the lifetime of individuals require the long-term commitment of resources (12). While consistent financing is essential for basic systems that support the management of chronic conditions as well as other health issues (e.g., functional commodity management systems, health information management systems), resources are also needed to support evidence-based approaches to reducing risk factors for chronic conditions and supporting healthy behaviors (e.g., community-based anti-tobacco campaigns, lay workers to support adherence to medications and regular clinic follow-up). Potential approaches include multisectoral financing schemes and collaborative public/private partnerships.[5]

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[5] The *Innovative Care for Chronic Conditions Project* designed by WHO articulates a framework to guide decisionmakers in reorienting the healthcare system toward chronic illnesses (1).

The following describe interventions from FHI-supported programs in HIV care and treatment to illustrate potential approaches relevant to the policy environment domain:

India: SAMARTH Project

- *Technical assistance to the Indian National AIDS Control Program and the USAID Mission on evidence-based HIV policies and programs supports a comprehensive approach to HIV/AIDS.*
- *Initiative is managed by FHI in partnership with the Christian Medical Association of India, the Indian Network for People Living with HIV/AIDS, and Solidarity & Action Against the HIV Infection in India.*

Ghana and Côte d'Ivoire

- *Founded on a partnership between FHI, the World Cocoa Foundation, and the National Confectioners Association, this program focuses on the prevention of HIV/AIDS and malaria among cocoa farmers, their families, and agricultural communities in cocoa-growing regions.*
- *Key interventions include building awareness of and promoting safer sex practices as well as strengthening partnerships between cocoa-tree cooperatives, other workplace programs, and local community groups.*

Rwanda

- *The Ministry of Health inaugurated performance-based contracting/financing (PBF) as a strategy to strengthen the health sector and improve health outcomes.*
- *Using a phased approach based on nationally defined criteria for site eligibility, FHI/Rwanda provides PBF grants at primary health centers for indicators related to ART and other HIV-related services.*
- *Preparing the PHC staff on the national PBF methodology and tools and conducting joint visits with PBF supervisory staff to verify the quality of services delivered are two key activities in implementing the innovative financing scheme.*

Addressing Current Needs and Advancing into the Future

Chronic disease is responsible for tremendous burdens on individuals, communities, and societies worldwide. Most factors that cause or contribute to chronic health conditions are preventable. While the complexity of reducing these factors to prevent chronic illnesses and effectively managing chronic conditions over the lifespan of individuals must be acknowledged, there is much to learn from recent and ongoing programs to expand care and treatment for HIV/AIDS that are transforming the illness into a chronic condition in resource-limited settings. It is a place to begin a broader initiative focused on chronic diseases generally.

Programmatic Areas

Programs to scale up ART and other HIV-related services in resource-limited areas are placing more people on treatment and prophylaxis, improving the health and functional capacity of many living with the illness, averting new infections through prevention initiatives such as prevention of mother-to-child transmission (PMTCT), and assisting families and communities to support individuals with HIV, orphans, and vulnerable children. Formidable challenges remain, however, and point to areas in need of further assessment and intervention if HIV/AIDS is to be effectively managed as a chronic condition. As for any chronic condition, examining these needs and challenges must occur within the local context:

- What interventions work in preventing new infections? UNAIDS reports more new infections in 2007 than the number of deaths attributed to HIV/AIDS (32). As one key prevention strategy, are measures incorporated into routine clinical care to address prevention with positives?
- Once started, ART must continue for life. Are patients on treatment being retained in care? What interventions optimize adherence to ART and routine clinic appointments over time—three years, five years, 10 years? How can healthcare providers be better prepared for delivering care and outreach over years and decades?
- Patients diagnosed with HIV but not yet eligible for ART require intermittent clinical monitoring; they need skills to maintain healthy lifestyles and to effectively care for themselves while preventing further transmission. Are mechanisms available to healthcare providers to maintain communication with these patients over time and to track them if contact is lost?
- Most patients with chronic or acute illnesses need access to healthcare without such barriers as cost and long transport. Are ART and other HIV-related services available in their communities, along with the basic components of Primary Care that contribute to good health?
- Current international initiatives to expand HIV care focus almost exclusively on health sector–related interventions. Barriers to care and healthy lifestyles are frequently outside of this sector—for example, inadequate food resources for good nutrition; lack of clean water; and poor roads and lack of transport to healthcare sites. Individuals whose health has been improved with care and treatment need work opportunities to support themselves and their families. Are complementary, cross-sectoral interventions available to assist these individuals to restore or build new livelihoods?

Future experiences and lessons from programmatic efforts to support health systems in more effectively managing HIV/AIDS as a chronic condition in resource-limited settings can inform an expanded health agenda focusing on improving the management of all chronic conditions.

Research Areas

As interventions are implemented to adapt or develop systems and practices oriented to chronic care, a priority need is to examine their effectiveness in terms of the benefit in health outcomes, the impact on health delivery systems, and cost. For many chronic conditions, clinical outcomes can be defined in terms of biological indicators (e.g., CD4 and HIV viral load for HIV/AIDS; glycemic control for diabetes); research is needed to assess the impact of programmatic interventions on various health outcome measures and whether beneficial health outcomes are being sustained, including survival and retention in care over time in low-resource areas.

The perspective of HIV/AIDS as a chronic, manageable illness is not yet widespread in resource-limited settings. What impact will increased recognition of HIV/AIDS as a lifelong, chronic condition have upon the stigmatization of HIV-infected individuals and the discrimination they face in everyday life, and what type of research projects can demonstrate such a relationship? A few research question sets follow for key areas related to HIV/AIDS as a chronic illness.

a. Intervention Crossover Effectiveness

If evidence demonstrates that certain interventions work well to improve the management of HIV/AIDS as a chronic illness, do they work as well for managing other chronic conditions—for example, cardiovascular diseases and mental illnesses? As noted previously, certain measures implemented to support quality HIV care (e.g., upgrading the infrastructure and capacity of laboratories, improving commodity management) are benefiting the care provided for other health conditions in resource-limited areas. Can these benefits be sustained by local governments over time?

Regardless of the specific condition, do patients living with chronic diseases benefit from specific measures that should be the standard of care in all settings? In this document, various principles and components of care have been identified as essential for effective chronic care based on evidence primarily from middle- and high-income countries, including patient self-care skills, patient-provider partnership, routine clinic encounters, and a package of Primary Care services. Are these valid for and effective in resource-limited areas?

b. Patient-Level, Healthcare-Related Decisionmaking

Why do patients who take medications do so regularly? Why do they stop? Why do they take medications intermittently? Do interventions to increase skills in self-managing their condition produce beneficial outcomes for individuals over the course of their disease in resource-limited settings? For HIV/AIDS and other chronic conditions with lifetime treatment, high levels of drug adherence are required to achieve and sustain beneficial health outcomes. There is a need to better understand the impact of chronic illness upon the individual and their family—how changes in lifestyle are made and what factors enhance the capacity to live with and self-treat a fluctuating, progressive illness over time and for a lifetime.

c. Intervention Costs

What are the costs for enhancing patient self-care skills or for developing systems that can manage health-related data for large populations over lifetimes of care? If primary health centers are the principal setting for delivering Primary Care and managing chronic conditions over time, what investments are needed to strengthen service delivery at this level—in terms of increasing capacity and retention of staff, expanding services and service coverage, improving drug and other supplies, enhancing monitoring and evaluation of services, and improving coordination within the health sector and with community resources? Research is needed on the costs of interventions to strengthen health systems in delivering effective chronic care. In middle- and high-income countries, low-cost measures involving different sectors have been identified to reduce certain risk factors for chronic conditions. It is imperative to learn whether comparable interventions (for example, taxation on tobacco) yield effective health outcomes in resource-constrained settings.

Summary/Conclusion

This document defined chronic disease and how it differs from acute disease. It highlighted key principles and implications in managing chronic conditions for individuals, health systems, and communities. Strategies were examined relating to the special needs and interests of patients, healthcare providers, community members, the health service delivery system itself, and the policy environment. Finally, key questions and issues regarding programmatic and research issues and needs regarding HIV/AIDS as a chronic condition in resource-limited settings were addressed.

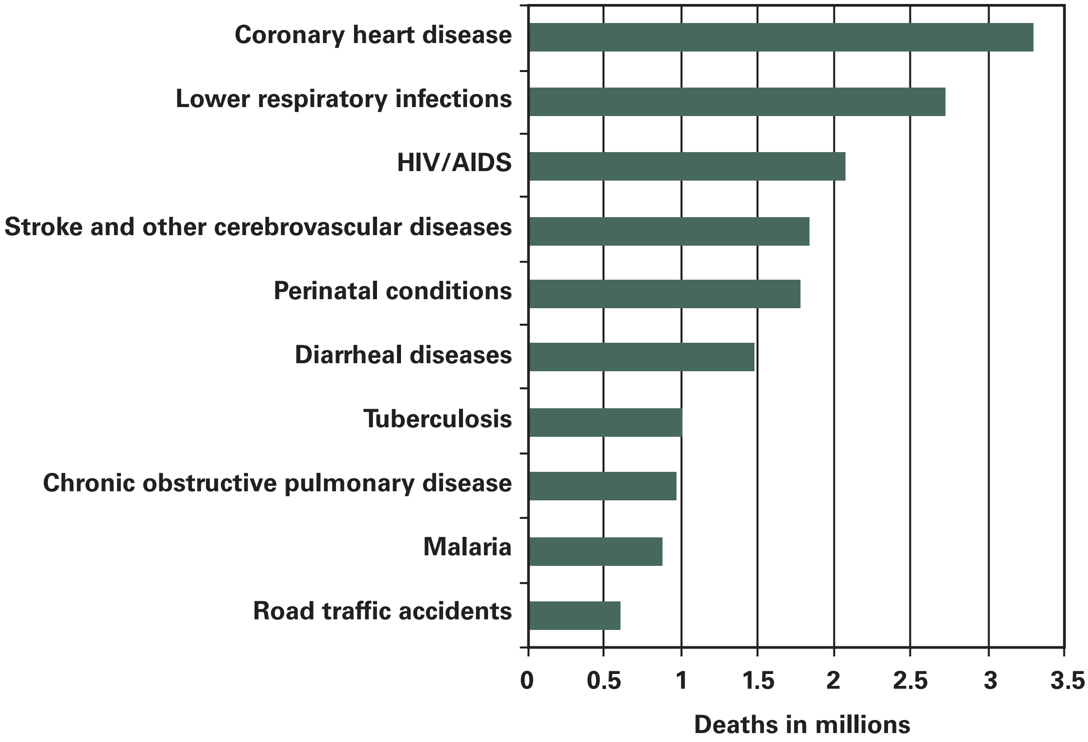
- For healthcare providers, health program implementers, and community members, the lifelong reality of chronic illness requires a fundamental shift in perspective from the disease to the individual living with the condition. **Healthcare organizations should emphasize treating the patient who has HIV/AIDS, not treating the HIV/AIDS.**
- For healthcare systems to effectively manage chronic conditions, continuity of care must incorporate regular, sustained interaction with the patient (and caregivers as appropriate).
- Health interventions need to develop patient skills and confidence in self-care and provide ongoing motivation and support to ensure a patient assumes the primary role and responsibility in day-to-day management of the condition and their health.
- Healthcare training needs to include provider communication skills to help clinicians sensitively convey education and information messages to patients over the lifetime of the chronic disease–based relationship.
- Improving effective practices of chronic care within care delivered at all care levels—primary, secondary, tertiary—requires a broad, comprehensive (e.g., holistic) approach to health system strengthening.
- Data processes and tools designed to maintain clinical information longitudinally are needed to follow and monitor patients who live with health conditions over lengthy periods.
- Research is needed to assess the impact of programmatic interventions on various health outcome measures and whether beneficial health outcomes are being sustained, including survival and retention in care over time in low-resource areas.

This document defined chronic disease management in terms of HIV/AIDS programs in resource-limited settings and described technical approaches to assist in designing programs and interventions focusing on chronic conditions. Many examples of HIV/AIDS programs and strategies featured chronic care concepts and integrated multidisciplinary principles from comprehensive and palliative care models as well. The diverse set of FHI-supported programs presented shows that FHI is well positioned to advance chronic care practice within its own global activities while advocating for the critical shift from acute to chronic care in resource-limited settings. Future research and documentation of current practices are needed to further improve health outcomes as chronic disease demands continue to press on resource-limited health systems. FHI is well poised to continue existing research and evidence-based initiatives and further contribute to the growing body of literature documenting the efficacy and need for chronic care programs worldwide.

ANNEX I: The 10 leading causes of death in low-income countries (2005 projections)

	Deaths in millions	% of deaths
Coronary heart disease	3.29	11.4
Lower respiratory infections	2.72	9.5
HIV/AIDS	2.06	7.2
Stroke and other cerebrovascular diseases	1.83	6.4
Perinatal conditions	1.78	6.2
Diarrheal diseases	1.48	5.2
Tuberculosis	1.01	3.5
Chronic obstructive pulmonary disease	0.97	3.4
Malaria	0.87	3.0
Road traffic accidents	0.60	2.1

Source: WHO, accessed at http://www.who.int/mediacentre/factsheets/fs310/en/index4.html



ANNEX II: Core Components of Primary Care

- Basic health screening and routine health maintenance, including mental health
- Education on staying healthy and promotion of good nutrition, exercise, adequate rest, and stress reduction
- Education on risk factors for alteration in health and promotion of smoking cessation, moderation in alcohol, safer sex, and substance use reduction
- Education specific to patient's illness
- Support for patient self-care
- Immunizations against major infectious diseases
- Maternal and child healthcare
- Family planning and reproductive health
- Promotion of safe water, good hygiene, and basic sanitation
- Diagnosis of and appropriate treatment for common diseases and injuries
- Prevention and control of locally endemic diseases
- Ongoing monitoring of chronic conditions, early detection, and management of complications and exacerbations
- Referral to specialist/advanced care for complex conditions and community resources for appropriate services

Sources: 11, 33, 34

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