

Section II

SECTION II

**Improving adherence rates: guidance
for countries**

Chapter IV

Lessons learned

1. Patients need to be supported, not blamed 36
2. The consequences of poor adherence to long-term therapies are poor health outcomes and increased health care costs 36
3. Improving adherence also enhances patient safety 38
4. Adherence is an important modifier of health system effectiveness 39
5. Improving adherence might be the best investment for tackling chronic conditions effectively 39
6. Health systems must evolve to meet new challenges 40
7. A multidisciplinary approach towards adherence is needed 41
8. References 42

Over the past 40 years, health, behavioural and social scientists have been accumulating knowledge concerning the prevalence of poor adherence, its determinants and interventions. This report is an attempt to integrate diverse findings across a number of diseases in order to stimulate intersectoral awareness of the magnitude and impact of poor adherence to therapies for chronic conditions, to catalyse discussion, and to identify specific targets for further research and intervention.

Several key lessons have emerged or have been reinforced by evidence from the reviews discussed in this report. These are described below.

1. Patients need to be supported, not blamed

Despite evidence to the contrary, there continues to be a tendency to focus on patient-related factors as the causes of problems with adherence, to the relative neglect of provider and health system-related determinants. These latter factors make up the health care environment in which patients receive care and have a considerable effect on adherence. Interventions that target the relevant factors in the health care environment are urgently required.

Patients may also become frustrated if their preferences in treatment-related decisions are not elicited and taken into account. For example, patients who felt less empowered in relation to treatment decisions had more negative attitudes towards prescribed antiretroviral therapy and reported lower rates of adherence (1).

Adherence is related to the way in which individuals judge personal need for a medication relative to their concerns about its potential adverse effects (2). Horne et al. proposed a simple necessity-concerns framework to help clinicians elicit and address some of the key beliefs that influence patients' adherence to medication. Necessity beliefs and concerns are evaluative summations of the personal salience of the potential costs and benefits or pros and cons of the treatment (3).

2. The consequences of poor adherence to long-term therapies are poor health outcomes and increased health care costs

Adherence is a primary determinant of the effectiveness of treatment (4,5) because poor adherence attenuates optimum clinical benefit (6,7). Good adherence improves the effectiveness of interventions aimed at promoting healthy lifestyles, such as diet modification, increased physical activity, non-smoking and safe sexual behaviour, (8-10) and of the pharmacological-based risk-reduction interventions (4,11-13). It also affects secondary prevention and disease treatment interventions.

For example, low adherence has been identified as the primary cause of unsatisfactory control of blood pressure (14). Good adherence has been shown to improve blood pressure control (15) and reduce the complications of hypertension (16-18). In Sudan, only 18% of non-adherent patients achieved good control of blood pressure compared to 96% of those who adhered to their prescribed treatment (19,20).

In studies on the prevention of diabetes type 2, adherence to a reduced-fat diet (21) and to regular physical exercise (22) has been effective in reducing the onset of the disease. For those already suffering the disease, good adherence to treatment, including suggested dietary modifications, physical activity, foot care and ophthalmological check-ups, has been shown to be effective in reducing complications and disability, while improving patients' quality of life and life expectancy (23).

Level of adherence has been positively correlated with treatment outcomes in depressed patients, independently of the anti-depressive drugs used (24). In communicable chronic conditions such as infection with HIV, good adherence to therapies has been correlated with slower clinical progression of the disease as well as lower virological markers (25-32).

In addition to their positive impact on the health status of patients with chronic illnesses, higher rates of adherence confer economic benefits. Examples of these mechanisms include direct savings generated by reduced use of the sophisticated and expensive health services needed in cases of disease exacerbation, crisis or relapse. Indirect savings may be attributable to enhancement of, or preservation of, quality of life and the social and vocational roles of the patients.

There is strong evidence to suggest that self-management programmes offered to patients with chronic diseases improve health status and reduce utilization and costs. When self-management and adherence programmes are combined with regular treatment and disease-specific education, significant improvements in health-promoting behaviours, cognitive symptom management, communication and disability management have been observed. In addition, such programmes appear to result in a reduction in the numbers of patients being hospitalized, days in hospital and outpatient visits. The data suggest a cost to savings ratio of approximately 1:10 in some cases, and these results persisted over 3 years (33). Other studies have found similarly positive results when evaluating the same or alternative interventions (28,34-47).

It has been suggested that good adherence to treatment with antiretroviral agents might have an important impact on public health by breaking the transmission of the virus because of the lower viral load found in highly adherent patients (12).

The development of resistance to therapies is another serious public health issue related to poor adherence, among other factors. In addition to years of life lost due to premature mortality and health care costs attributable to preventable morbidity, the economic consequences of poor adherence include stimulating the need for ongoing investment in research and development of new compounds to fight new resistant variants of the causative organisms.

In patients with HIV/AIDS, the resistance of the virus to antiretroviral agents has been linked to lower levels of adherence (29) by some researchers, while others have suggested that resistant virus is more likely to emerge at higher levels of adherence (48,49). Although they appear to be contradictory, both describe the same phenomenon from a different starting point. At the lower end of the spectrum of adherence, there is insufficient antiretroviral agent to produce selective pressure, so the more adherence rates increase the higher the likelihood that resistance will appear. At the higher levels of adherence, there is not enough virus to become resistant, thus the less adherent the patient, the greater the viral load and the likelihood of resistance. Some of the published research has suggested that when adherence rates are between 50% and 85%, drug resistance is more likely to develop (50,51). Unfortunately, a significant proportion of treated patients fall within this range (52). The “chronic” investment in research and development could be avoided if adherence rates were higher, and the resources could be better used in the development of more effective and safer drugs, or by being directed to the treatment of neglected conditions.

There is growing evidence to suggest that because of the alarmingly low rates of adherence, increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments (53).

We strongly support the recommendations of the Commission on Macroeconomics and Health on investing in operational research “at least 5% of each country proposal for evaluating health interventions in practice, including adherence as an important factor influencing the effectiveness of interventions” (12).

3. Improving adherence also enhances patient safety

Because most of the care needed for chronic conditions is based on patient self-management (usually requiring complex multi-therapies (54), the use of medical technology for monitoring and changes in the patient’s lifestyle (55), patients face several potentially life-threatening risks if health recommendations are not followed as they were prescribed.

Some of the risks faced by patients who adhere poorly to their therapies are listed below.

More intense relapses. Relapses related to poor adherence to prescribed medication can be more severe than relapses that occur while the patient is taking the medication as recommended, so persistent poor adherence can worsen the overall course of the illness and may eventually make the patients less likely to respond to treatment (56).

Increased risk of addiction. Many medications can produce severe addiction if taken inappropriately by patients. Good examples are diazepam (57) and opioid-related medications.

Increased risk of abstinence and bounce syndromes. Adverse effects and potential harm may occur when a medication is abruptly discontinued or interrupted. Good adherence plays an important role in avoiding problems of withdrawal (e.g. as seen in thyroid hormone replacement therapy) and bounce syndrome (e.g. in patients being treated for hypertension and depression), and consequently decreases the likelihood that a patient will experience adverse effects of discontinuation (58,59).

Increased risk of developing resistance to therapies. In patients with HIV/AIDS, the resistance to anti-retroviral agents has been linked to lower levels of adherence (48,60). Partial or poor adherence at levels less than 95% can lead to the resumption of rapid viral replication, reduced survival rates, and the mutation to treatment-resistant strains of HIV (61). The same happens in the treatment of tuberculosis where poor adherence is recognized as a major cause of treatment failure, relapse and drug resistance (62,63).

Increased risk of toxicity. In the case of over-use of medicines (a type of non-adherence), patients are at an increased risk of toxicity, especially from drugs with accumulative pharmacodynamics and/or a low toxicity threshold (e.g. lithium). This is particularly true for elderly patients (altered pharmacodynamics) and patients with mental disorders (e.g. schizophrenia).

Increased likelihood of accidents. Many medications need to be taken in conjunction with lifestyle changes that are a precautionary measure against the increased risk of accidents known to be a side-effect of certain medications. Good examples are medications requiring abstinence from alcohol (metronidazole) or special precautions while driving (sedatives and hypnotics).

4. Adherence is an important modifier of health system effectiveness

Health outcomes cannot be accurately assessed if they are measured predominantly by resource utilization indicators and efficacy of interventions.

The economic evaluation of nonadherence requires the identification of the associated costs and outcomes. It is logical that nonadherence entails a cost due to the occurrence of the undesired effects that the recommended regimen tries to minimize. In terms of outcomes, nonadherence results in increased clinical risk and therefore in increased morbidity and mortality.

For health professionals, policy-makers and donors, measuring the performance of their health programmes and systems using resource utilization end-points and the efficacy of interventions is easier than measuring the desired health outcomes. While such indicators are important, over-reliance on them can bias evaluation towards the process of *health care provision*, missing indicators of *health care uptake* which would make accurate estimates of *health outcomes* possible (64).

The population-health outcomes predicted by treatment efficacy data will not be achieved unless adherence rates are used to inform planning and project evaluation.

5. Improving adherence might be the best investment for tackling chronic conditions effectively

Studies consistently find significant cost-savings and increases in the effectiveness of health interventions that are attributable to low-cost interventions for improving adherence. In many cases investments in improving adherence are fully repaid with savings in health care utilization (33) and, in other instances, the improvement in health outcomes fully justified the investment. The time is ripe for large-scale, multidisciplinary field studies aimed at testing behaviourally sound, multi-focal interventions, across diseases and in different service-delivery environments.

Interventions for removing barriers to adherence must become a central component of efforts to improve population health worldwide. Decision-makers need not be concerned that an undesired increase in health budget will occur due to increasing consumption of medications, because adherence to those medicines already prescribed will result in a significant decrease in the overall health budget due to the reduction in the need for other more costly interventions. Rational use of medicines means good prescribing and full adherence to the prescriptions.

Interventions that promote adherence can help close the gap between the clinical efficacy of interventions and their effectiveness when used in the field, and thus increase the overall effectiveness and efficiency of the health system.

For outcomes to be improved, changes to health policy and health systems are essential. Effective treatment for chronic conditions requires a transfer of health care away from a system that is focused on episodic care in response to acute illness towards a system that is proactive and emphasizes health throughout a lifetime.

Without a system that addresses the determinants of adherence, advances in biomedical technology will fail to realize their potential to reduce the burden of chronic illness. Access to medications is necessary, but insufficient in itself to solve the problem (12).

Increasing the effectiveness of adherence interventions might have a far greater impact on the health of the population than any improvement in specific medical treatments (65).

6. Health systems must evolve to meet new challenges

In developed countries, the epidemiological shift in disease burden from acute to chronic diseases over the past 50 years has rendered acute care models of health service delivery inadequate to address the health needs of the population. In developing countries this shift is occurring at a much faster rate.

The health care delivery system has the potential to affect patients' adherence behaviour. Health care systems control access to care. For example, health systems control providers' schedules, length of appointments, allocation of resources, fee structures, communication and information systems, and organizational priorities. The following are examples of the ways in which systems influence patients' behaviour.

- Systems direct appointment length, and providers report that their schedules do not allow time to adequately address adherence behaviour (66).
- Systems determine fee structures, and in many systems (e.g. fee-for-service) the lack of financial reimbursement for patient counselling and education seriously threatens adherence-focused interventions.
- Systems allocate resources in a way that may result in high stress and increased demands upon providers which, in turn, have been associated with decreased adherence in their patients (67).
- Systems determine continuity of care. Patients demonstrate better adherence behaviour when they receive care from the same provider over time (68).
- Systems direct information sharing. The ability of clinics and pharmacies to share information on patients' behaviour regarding prescription refills has the potential to improve adherence.
- Systems determine the level of communication with patients. Ongoing communication efforts (e.g. telephone contacts) that keep the patient engaged in health care may be the simplest and most cost-effective strategy for improving adherence (69).

Few studies have evaluated programmes that have used such interventions, and this is a serious gap in the applied knowledge base. For an intervention to be truly multi-level, systemic barriers must be included. Unless variables such as these are addressed, it would be expected that the impact of the efforts of providers and patients would be limited by the external constraints.

The changing nature of disease prevalence also influences activities at the system level. Ongoing reliance on acute models has delayed the reforms necessary to address longer-term interventions for chronic conditions. In developing countries this shift is occurring at a much faster rate at a time when the battle against communicable diseases is still being fought.

In some countries, the attention of the policy-makers may remain focused on communicable diseases, for example HIV/AIDS and tuberculosis. However, these diseases are not effectively addressed by the acute care model. Even if it were to provide full and unrestricted access to appropriate drugs, the acute care model would lack impact because it does not address the broad determinants of adherence.

7. A multidisciplinary approach towards adherence is needed

The problem of nonadherence has been much discussed, but has been relatively neglected in the mainstream delivery of primary care health services. Despite an extensive knowledge base, efforts to address the problem have been fragmented, and with few exceptions have failed to harness the potential contributions of the diverse health disciplines. A stronger commitment to a multidisciplinary approach is needed in order to make progress in this area. This will require coordinated action from health professionals, researchers, health planners and policy-makers.

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Chapter V

CHAPTER V

The magnitude of the problem of poor adherence

1. Five interacting dimensions affect adherence 41
- 2 Intervening in the five dimensions 45
3. Reference 50

1. Five interacting dimensions affect adherence

Adherence is a multidimensional phenomenon determined by the interplay of five sets of factors, here termed “dimensions”, of which patient-related factors are just one determinant. The common belief that patients are solely responsible for taking their treatment is misleading and most often reflects a misunderstanding of how other factors affect people’s behaviour and capacity to adhere to their treatment.

The five dimensions are briefly discussed below. The length of the discussion on each dimension reflects the quantity of evidence available, which is biased by the traditional misconception that adherence is a patient-driven problem. Therefore, the size of the section does not reflect its importance.



Figure 3

A. Social and economic factors

Although socioeconomic status has not consistently been found to be an independent predictor of adherence, in developing countries low socioeconomic status may put patients in the position of having to choose between competing priorities. Such priorities frequently include demands to direct the limited resources available to meet the needs of other family members, such as children or parents for whom they care.

Some factors reported to have a significant affect on adherence are: poor socioeconomic status, poverty, illiteracy, low level of education, unemployment, lack of effective social support networks, unstable living conditions, long distance from treatment centre, high cost of transport, high cost of medication, changing environmental situations, culture and lay beliefs about illness and treatment, and family dysfunction. Various sociodemographic and economic variables are discussed in the course of this report (see also Annex 3).

Some studies have reported that organizational factors are more related to adherence than sociodemographic ones, but this might differ from one setting to another. An interesting study by Albaz in Saudi Arabia concluded that organizational variables (time spent with the doctor, continuity of care by the doctor, communication style of the doctor and interpersonal style of the doctor) are far more important than sociodemographic variables (gender, marital status, age, educational level and health status) in affecting patients' adherence (1).

Race has frequently been reported to be a predictor of adherence, regardless of whether the members of a particular race are living in their country of origin or elsewhere as immigrants. Often, cultural beliefs are the reason behind these racial differences (2), but, no less often, social inequalities confound these findings (3). For example, in the United Kingdom, HIV-positive black Africans have been found to have a different experience of treatment because of their fear of being experimented on, distrust of the medical profession and fears of discrimination (4). In the United States, African Americans have been reported to express significantly more doubt regarding their ability to use protease inhibitors and adhere to the treatment, and about the competence of their physicians than do the white population (5).

War has also been reported to have an influence on adherence to therapies, even after the war is over. This is mainly the result of former war experiences such as economic hardship, lack of medical control, fatalism and anarchy (6).

Age is a factor reported as affecting adherence, but inconsistently. It should be evaluated separately for each condition, and, if possible, by the characteristics of the patient and by developmental age group (i.e. children dependent on parent, adolescents, adults and elderly patients).

Adherence to treatment by *children and adolescents* ranges from 43% to 100%, with an average of 58% in developed countries (7). Several studies have suggested that adolescents are less adherent than younger children (8). The adherence of infants and toddlers to recommended treatment regimens is largely determined by the ability of the parent or guardian to understand and follow through with the recommended management. As age increases, children have the cognitive ability to carry out treatment tasks, but continue to need parental supervision.

School-age children engage in the developmental task of industry, learning to regulate their own behaviour and control the world around them. As children enter school, they spend less time at home with parents and are increasingly influenced by their peers and the social environment.

At the same time, increasing numbers of single and working parents have shifted more of the responsibility for disease management to the child. Assigning too much responsibility to a child for management of his or her treatment can lead to poor adherence. For example, studies indicate that, like adults, children exaggerate their adherence behaviours in their self-reports (9). Parents need to understand that inaccurate diary reporting may hinder appropriate disease management by clinicians. These findings

underscore the value of parental supervision and guidance of children in their health behaviours. Shared family responsibility for treatment tasks and continuous reinforcement appear to be important factors in the enhancement of adherence to prescribed treatment for the paediatric population. In addition to parental supervision, behavioural techniques designed to help children, such as goal-setting, cueing, and rewards or tokens, have been found to improve adherence in the school-aged population (10).

Adolescents, though capable of greater autonomy in following treatment recommendations, struggle with self-esteem, body image, social role definition and peer-related issues. Poor adherence in adolescents may reflect rebellion against the regimen's control over their lives. Most studies indicate that children and adolescents who assume early sole responsibility for their treatment regimen are less adherent and in poorer control of their disease management. Both sustaining parental involvement and minimizing conflict between adolescents and their parents are valuable in encouraging adherence to treatment regimens. Providing families with information on forming a partnership between the parent(s) and the adolescent is of considerable importance in promoting adherence to treatment for this age group. Educational efforts focusing on adolescents' attitudes towards their disease and its management, instead of predominantly on knowledge acquisition, may be beneficial.

Elderly people represent 6.4 % of the world's population and their numbers are increasing by 800 000 every month. They have become the fastest-growing segment of the population in many developing countries (11,12).

This demographic transition has led to an increased prevalence of chronic illnesses that are particularly common in the elderly. These include Alzheimer disease, Parkinson disease, depression, diabetes, congestive heart failure, coronary artery disease, glaucoma, osteoarthritis, osteoporosis and others.

Many elderly patients present with multiple chronic diseases, which require complex long-term treatment to prevent frailty and disability. Furthermore, the elderly are the greatest consumers of prescription drugs. In developed countries, people over 60 years old consume approximately 50% of all prescription medicines (as much as three times more per capita than the general population) and are responsible for 60% of medication-related costs even though they represent only 12% to 18% of the population in these countries (13).

Adherence to treatments is essential to the well-being of elderly patients, and is thus a critically important component of care. In the elderly, failure to adhere to medical recommendations and treatment has been found to increase the likelihood of therapeutic failure (14), and to be responsible for unnecessary complications, leading to increased spending on health care, as well as to disability and early death (15).

Poor adherence to prescribed regimens affects all age groups. However, the prevalence of cognitive and functional impairments in elderly patients (16) increase their risk of poor adherence. Multiple co-morbidities and complex medical regimens further compromise adherence. Age-related alterations in pharmacokinetics and pharmacodynamics make this population even more vulnerable to problems resulting from nonadherence.

B. Health care team and system-related factors

Relatively little research has been conducted on the effects of health care team and system-related factors on adherence. Whereas a good patient-provider relationship may improve adherence (17), there are many factors that have a negative effect. These include, poorly developed health services with inadequate or non-existent reimbursement by health insurance plans, poor medication distribution systems, lack of knowledge and training for health care providers on managing chronic diseases, overworked health care providers, lack of incentives and feedback on performance, short consultations, weak capacity of the system to educate patients and provide follow-up, inability to establish community support and self-management capacity, lack of knowledge on adherence and of effective interventions for improving it.

C. Condition-related factors

Condition related factors represent particular illness-related demands faced by the patient. Some strong determinants of adherence are those related to the severity of symptoms, level of disability (physical, psychological, social and vocational), rate of progression and severity of the disease, and the availability of effective treatments. Their impact depends on how they influence patients' risk perception, the importance of following treatment, and the priority placed on adherence. Co-morbidities, such as depression (18) (in diabetes or HIV/AIDS), and drug and alcohol abuse, are important modifiers of adherence behaviour.

D. Therapy-related factors

There are many therapy-related factors that affect adherence. Most notable are those related to the complexity of the medical regimen, duration of treatment, previous treatment failures, frequent changes in treatment, the immediacy of beneficial effects, side-effects, and the availability of medical support to deal with them.

Unique characteristics of diseases and/or therapies do not outweigh the common factors affecting adherence, but rather modify their influence. Adherence interventions should be tailored to the needs of the patient in order to achieve maximum impact.

E. Patient-related factors

Patient-related factors represent the resources, knowledge, attitudes, beliefs, perceptions and expectations of the patient.

Patients' knowledge and beliefs about their illness, motivation to manage it, confidence (self-efficacy) in their ability to engage in illness-management behaviours, and expectations regarding the outcome of treatment and the consequences of poor adherence, interact in ways not yet fully understood to influence adherence behaviour.

Some of the patient-related factors reported to affect adherence are: forgetfulness; psychosocial stress; anxieties about possible adverse effects; low motivation; inadequate knowledge and skill in managing the disease symptoms and treatment; lack of self-perceived need for treatment; lack of perceived effect of treatment; negative beliefs regarding the efficacy of the treatment; misunderstanding and non-acceptance of the disease; disbelief in the diagnosis; lack of perception of the health risk related to the disease; misunderstanding of treatment instructions; lack of acceptance of monitoring; low treatment expectations; low attendance at follow up, or at counselling, motivational, behavioural, or psychotherapy classes; hopelessness and negative feelings; frustration with health care providers; fear of dependence; anxiety over the complexity of the drug regimen, and feeling stigmatized by the disease.

Perceptions of personal need for medication are influenced by symptoms, expectations and experiences and by illness cognitions (19). Concerns about medication typically arise from beliefs about side-effects and disruption of lifestyle, and from more abstract worries about the long-term effects and dependence. They are related to negative views about medicines as a whole and suspicions that doctors over-prescribe medicines (20,21) as well as to a broader 'world view' characterized by suspicions of chemicals in food and the environment (22) and of science, medicine and technology (23).

A patient's motivation to adhere to prescribed treatment is influenced by the value that he or she places on following the regimen (cost-benefit ratio) and the degree of confidence in being able to follow it (24). Building on a patient's intrinsic motivation by increasing the perceived importance of adherence, and strengthening confidence by building self-management skills, are behavioural treatment targets that must be addressed concurrently with biomedical ones if overall adherence is to be improved.

2 Intervening in the five dimensions

The ability of patients to follow treatments in an optimal manner is frequently compromised by more than one barrier. Interventions to promote adherence require several components to target these barriers, and health professionals must follow a systematic process to assess all the potential barriers.

Adherence is a multidimensional issue where different health care actors' efforts meet.

Given that interventions are available, why has the adherence problem persisted? One answer concerns their implementation. There has been a tendency to focus on unidimensional factors, (primarily patient-related factors). All five dimensions, (social and economic factors, health care team and systems-related factors, therapy-related factors, condition-related factors and patient-related factors), should be considered in a systematic exploration of the factors affecting adherence and the interventions aimed at improving it.

While many interventions (e.g. education in self-management (25-34); pharmacy management programmes (35,36); nurse, pharmacist and other non-medical health professional intervention protocols (37-43); counselling (44,45); behavioural interventions (46,47); follow-up (48,49) and reminders, among others), have been shown to be effective in significantly improving adherence rates (50-54), they have tended to be used alone. A single-factor approach might be expected to have limited effectiveness, if the factors determining adherence interact and potentiate each other's influence as they are likely to do.

The most effective approaches have been shown to be multi-level – targeting more than one factor with more than one intervention. Several programmes have demonstrated good results using multi-level team approaches (55-57). Examples include the Multiple Risk Factor Intervention Trial Research Group, 1982 (58) and the Hypertension Detection and Follow-up Program Cooperative Group, 1979 (59). In fact, adequate evidence exists to support the use of innovative, modified health care system teams rather than traditional, independent physician practice and minimally structured systems (60,61).

Various interventions are already being implemented by many different health care actors. Although not all of these actors are directly responsible for providing health care, they nevertheless have an important role in improving adherence because they can influence one or more of the factors that determine adherence.

The work that is being done to improve adherence and the persons performing the work are described below.

A. Social and economic interventions

Policy-makers who have the major responsibility for designing and managing the health care environment need to understand the ways in which social and economic factors influence adherence.

The main economic and social concerns that should be addressed in relation to adherence are poverty (62), access to health care and medicines, illiteracy (62), provision of effective social support networks and mechanisms for the delivery of health services that are sensitive to cultural beliefs about illness and treatment. (For more information see Annex 4.)

The high cost of medicines and care is consistently reported as an important cause of non-adherence in developing countries. Universal and sustainable financing, affordable prices and reliable supply systems are required if good rates of adherence to therapies are to be achieved. Considerable efforts are being made by WHO and other partners to improve access to medicines and care worldwide.

Community-based organization, education of illiterate patients, assessment of social needs (63) and family preparedness have been reported to be effective social interventions for improving adherence (64).

Social support (i.e. informal or formal support received by patients from other members of their community), has been consistently reported as an important factor affecting health outcomes and behaviours (65,66). It has also been reported to improve adherence to prescribed recommendations for treating chronic conditions (67), such as diabetes (68-78), hypertension (79,80), epilepsy (81-86), asthma (87) and HIV/AIDS (88-92), and to some preventive interventions such as breast cancer screening guidelines (93) and follow-up for abnormal Pap smears (94,95). So far, social support has not been shown to affect adherence to smoking cessation therapies (96-98).

Good examples of successfully implemented community-based programmes are the medication groups (99) and the peer/community support groups. The objectives of these programmes are:

- to promote the exchange of experiences of dealing with a disease and its treatment;
- to provide comprehensive medical information; and
- to promote patients' responsibility for their own care.

There is substantial evidence that peer support among patients can improve adherence to therapy (88,100-107) while reducing the amount of time devoted by health professionals to the care of patients with chronic conditions (107-109). Many other community interventions have also been shown to result in economic and health benefits by improving patients' self-management capacities (110-117) and/or by the integration of the provision of care (57,118-121).

The participation of patients' organizations, with the support of community health professionals (122), has been shown to be effective in promoting the maintenance and motivation required for the self-management of chronic diseases, as well as keeping the patient active in the knowledge of his or her disease and in the acquisition of new habits (110,111,113-115,123,124).

There are three different types of patients' organization (PO):

- POs directly owned and managed by the health care provider (e.g. health maintenance organizations (HMOs) in the United States);
- POs directly owned by patients, but promoted, organized and supported by public health care providers (as in Mexico); and
- independent POs with no ties with health care providers.

Unfortunately, the POs that have no ties with health care providers usually lack the health care programmes required for supporting patients' self-management. Their effectiveness has not been evaluated and such organizations usually focus mainly on patient advocacy.

Although well-established group interventions do exist, few patients are informed by health professionals of the benefits of joining support groups for improving self-management of chronic conditions. Further evaluation is needed to assess the effectiveness and cost-effectiveness of these organizations in enhancing adherence.

WHO, ministries of health and development agencies have a major role in promoting and coordinating community-based efforts to tackle social and economic factors affecting adherence to therapies.

B. Health care team and health system interventions

The issue of non-adherence has caught the attention of front-line health service providers and health researchers for a long time. However, opinion leaders among policy-makers have yet to adopt the issue as a policy target. This report can be used to focus attention on the consequences of poor adherence not only for population health, but for the efficiency of the health care system and to demonstrate the key role that policy-makers have to play.

Adherence is a multidimensional issue where different health care actors' efforts meet.

Health leaders at many different levels contribute to shaping a health system to meet the needs of its constituents. The way that health systems operate, the types of services and resources that are available and accessible to the population, and the ways in which health providers deliver treatments are of primary concern here.

This review found five major barriers inextricably linked to health system and team factors:

- lack of awareness and knowledge about adherence;
- lack of clinical tools to assist health professionals in evaluating and intervening in adherence problems;
- lack of behavioural tools to help patients develop adaptive health behaviours or to change maladaptive ones;
- gaps in the provision of care for chronic conditions; and
- sub-optimal communication between patients and health professionals.

No single intervention or package of interventions has been shown to be effective across all patients, conditions and settings. Consequently, interventions that target adherence must be tailored to the particular illness-related demands experienced by the patient. To accomplish this, health systems and providers need to develop means of accurately assessing not only adherence, but also those factors that contribute to it.

Because health care providers could be expected to play a significant role in promoting adherence, designing and implementing interventions to influence what they do would seem a reasonable strategy. While there have been efforts in this area, it is possible that they have had less-than-optimal power because they have not conveyed a sufficiently powerful skill set and/or the skills have not been widely adopted in practice.

To make this way of practice a reality, practitioners must have access to specific training in adherence management, and the systems in which they work must design and support delivery systems that respect this objective. For empowering health professionals an “adherence counselling toolkit” adaptable to different socioeconomic settings is urgently needed that will systematically assess, suggest interventions and follow-up patients’ adherence.

Such training needs to address three main topics simultaneously.

The information on adherence. A summary of the factors that have been reported to affect adherence, the effective interventions available, the epidemiology and economics of adherence and behavioural mechanisms driving patient-related adherence.

A clinically useful way of using this information and thinking about adherence. This should encompass assessment tools and strategies to promote change. Any educational intervention should provide answers to the following questions: How should patients be interviewed to assess adherence? How can one learn from local factors and interventions? How should priorities be ranked and the best available interventions chosen? How should the patients' progress be followed up and assessed?

Behavioural tools for creating or maintaining habits. This component should be taught using "role-play" and other educational strategies to ensure that health professionals incorporate behavioural tools for enhancing adherence into their daily practice.

Some information is available on training health professionals to perform patient-tailored interventions effectively. Ockene et al. (125) reported the effectiveness of short patient-centred interventions in three different randomized clinical trials: the WATCH study (diet) (126,127), the Project Health (alcohol) (128), the Nurse-Delivery Diabetic Smoking Intervention Project (129) and the Physician-Delivered Smoking Intervention Project (smoking cessation) (130). The latter found a statistically significant improvement in smoking quitting rates associated with 5-9 minutes of intervention.

It is clear from these studies that good adherence requires a continuous and dynamic process. Practitioners (and other health enablers) often assume that the patient is, or should be, motivated to follow a best-practice protocol. However, recent research in the behavioural sciences reveals this to be an erroneous assumption. The patient population can be segmented according to level-of-readiness to follow health recommendations (131-133). The lack of a match between the patient's readiness and the practitioner's attempts at intervention means that treatments are frequently prescribed to patients who are not ready to follow them.

Although adherence interventions directed towards patients have typically focused on providing education to increase knowledge, the available evidence shows that knowledge alone is not enough. Roter et al., published a meta-analysis of adherence-enhancing interventions which concluded that "no single strategy or programmatic focus showed any clear advantage compared with another and that comprehensive interventions combining cognitive, behavioural, and affective [motivational] components were more effective than single-focus interventions" (134). Information alone is not enough for creating or maintaining good adherence habits. First-line interventions to optimize adherence must go beyond the provision of advice and prescriptions. If either the perceived value of adhering, or confidence, is low, the likelihood of adherence will also be low.

Health care providers can learn to assess the potential for non-adherence, and to detect non-adherence itself. They can then use this information to implement brief interventions to encourage and support progress towards adherence. A conceptual framework that explains how patients progress to adherence will help practitioners to tailor their interventions to the needs of the patient.

More research is required in this area. New, sustainable initiatives targeting providers could aim to impart knowledge about the broad determinants of the problem and of specific strategies for addressing them, in ways that can be systematically implemented in practice.

The evidence reviewed for this report suggests that it would be helpful to create a shift in provider perspective that supports tailoring of interventions to the needs of individual patients, and to teach specific strategies to address those needs. One of the problems in this area has been the relatively low levels of knowledge transfer. The results of effective studies have not been widely implemented in practice. This highlights the need for educational programmes that go beyond describing the problem, and that convey solutions to everyday problems in practice.

WHO and many ministries of health are working to improve the provision of health care, but a lot of work still needs to be done on the development of appropriate care for chronic conditions.

C. Therapy-related interventions

In studies of therapy-related interventions, the main barriers to adherence were found to be the dose frequency and the incidence of side-effects. Pharmaceutical companies in partnership with health professionals and researchers are addressing these problems. The health system has an important role in minimizing the impact of side-effects on patients.

D. Condition-related interventions

Disease-specific demands, symptoms and impairments are the targets of health professionals. These actors could provide optimal care by identifying and treating these problems, as well as identifying and treating co-morbidities that affect adherence. For example, because of the high prevalence of depression and its considerable effect on adherence, adherence counselling interventions should include systematic screening for depression.

E. Patient-related interventions

The major barriers to adherence described in the literature reviewed for this report were lack of information and skills as they pertain to self-management, difficulty with motivation and self-efficacy, and lack of support for behavioural changes.

These barriers were especially significant for those interventions intended to change habits and/or lifestyles, but also affected medication use. WHO acknowledges the necessity of supporting patients' efforts at self-management. Many researchers are working to develop or improve and disseminate self-management guidelines.

Global changes in the delivery of health services and shrinking health care budgets have also contributed to a need for patients to become more able to manage their own treatments. The development of self-management interventions aimed at improving motivation and adherence, based on the best available evidence, will help to fill this need. This work can support efforts by patients' organizations to engage and support their members.

Increasing the impact of interventions aimed at patient-related factors is essential. There is a wealth of data from the behavioural sciences demonstrating the efficacy of specific strategies. Although it is well known that education alone is a weak intervention, many interventions continue to rely on patient education to encourage patients to adhere to their treatment. Patients need to be informed, motivated and skilled in the use of cognitive and behavioural self-regulation strategies if they are to cope effectively with the treatment-related demands imposed by their illness. For the effective provision of care for chronic conditions it is necessary to activate the patient and the community who support him or her (135).

A continuous effort is being made to improve the provision of information to patients, but motivation, which drives sustainable good adherence, is one of the most difficult elements for the health care system to provide in the long term. Although health professionals have an important role in promoting optimism, providing enthusiasm, and encouraging maintenance of health behaviours among their patients (136), the health systems and health care teams experience difficulties in constantly motivating patients with chronic conditions. These difficulties have led to an increased interest during the past decade, in the role of community-based educational and/or self-management programmes aimed at the creation and maintenance of healthy habits, including adherence to health recommendations.

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Chapter VI

CHAPTER VI

How does poor adherence affect policy-makers and health managers?

1. Diabetes 53
2. Hypertension 54
3. Asthma 55
4. References 57

Many studies have reported institutional changes in costs following changes in adherence rates. Some studies have shown that initial investments in interventions to enhance adherence are fully recovered within a few years and recurrent costs are fully covered by savings. These “cost-saving interventions” are firmly linked to the prevention of disease relapses, crises and/or complications.

From a societal point of view, most interventions aimed at enhancing adherence have been shown to result in cost-savings, due to the improvement in patients’ quality of life, indirect costs avoided and increased productivity. Such savings are not reflected in economic studies with an institutional perspective.

1. Diabetes

Diabetes is a typical chronic disease that demonstrates the need for integrated and multifaceted approaches to achieve good control. Almost any intervention designed to improve metabolic control in diabetic patients, or to delay the onset of complications does so by supporting patients in developing appropriate self-management behaviours. Interventions to enhance adherence in patients with diabetes benefit from a comprehensive and multifactorial approach to providing better control of the disease.

For example, a systematic review by Cochrane (1), of interventions to improve the management of diabetes mellitus in primary care, conducted in outpatient and community settings, analysed 41 heterogeneous studies of multifaceted intervention strategies. Some of these studies were targeted at health professionals, others at the organization of care, but most of them targeted both. In 15 studies, patient education was added to the professional and organizational interventions. The reviewers concluded that multifaceted professional interventions can enhance the performance of health professionals in managing diabetic patients. Organizational interventions that improve regular prompted recall and review of patients can also improve diabetes management. In addition, the inclusion of patient-oriented interventions can lead to improved health outcomes for the patients. Nurses can play an important role in patient-oriented interventions, through patient education and facilitating adherence to treatment.

A recent meta-analysis has shown that education about self-management improves glycaemic levels at immediate follow-up, and increased contact time increases this effect. However, the benefit declines 1-3 months after the intervention ceases, suggesting that learned behaviours change over time (2), and that some additional interventions are needed for maintaining them.

In a study in Switzerland, Gozzoli et al. estimated the impact of several alternative interventions for improving the control of complications of diabetes (3). They concluded that the implementation of multifactorial interventions, including improved control of cardiovascular risk factors, combined with early diagnosis and treatment of complications of diabetes, could save both costs and lives.

Nurse case-management (4-6), disease management (7,8) and population-based management (9) have all resulted in better adherence to recommended standards of care, sometimes with impressive clinical and economic outcomes. Moreover, the Chronic Care Model (CCM), a systematic approach to improving the quality of care for persons with chronic diseases, has shown promising results (10,11).

Positive results have also been reported from the United States by the Diabetes Roadmap of Group Health Cooperative of Puget Sound (GHC), an HMO serving about 400 000 people in western Washington state, which uses the strategy of population-based management of care to improve care and outcomes for its 13 000 diabetic patients (9). Population-based care uses guidelines, and epidemiological data and techniques to plan, organize, deliver and monitor care in specific clinical sub-populations such as patients with diabetes. This support programme is aimed at helping primary care teams to improve their ability to deliver population-based diabetes care. Based on an integrated CCM, the programme includes an on-line registry of diabetic patients, evidence-based guidelines for routine diabetes care, improved support for patient self-management and practice re-design including group visits. Also, members of a decentralized, diabetes education team see patients jointly. Preliminary outcomes show that retinal screening rates have increased from 56% to 70%, renal screening rates from 18% to 68%, foot examination rates from 18% to 82% and patients being tested for glycosylated haemoglobin from 72% to 92%. The cost of care for the entire population of diabetic patients has decreased by 11%.

Most studies that reported cost-savings used a systematic approach to disease management (8,12). More research is needed to assess the cost-effectiveness of interventions aimed at improving adherence rates (13).

2. Hypertension

In patients with hypertension, adherence to treatment recommendations has a major impact on health outcomes and the costs of care. Some of the better recognized determinants of adherence to antihypertensive therapy are related to drug treatment such as drug tolerability and regimen complexity. Thus, reduced side-effects, fewer daily doses of antihypertensives, monotherapies and fewer changes in antihypertensive medications have all been associated with better adherence (14-16).

In a landmark study conducted by Morisky et al. (17), patients were assigned to three adherence-promoting interventions: physician counselling, family support for monitoring pill taking, group sessions with a social worker or to a control group. The 5-year analysis showed a continuing positive effect on appointment-keeping, weight control and blood-pressure control in the intervention groups. The all-cause life table mortality rate was 57.3% less for the experimental group than for the control group and the hypertension-related mortality rate was 53.2% less. The results from this longitudinal study provide evidence to support the use of adherence-enhancing interventions in patients with hypertension.

Another study used an educational programme to emphasize the importance of proper treatment. In the intervention groups, the systolic and diastolic blood pressure of both men and women decreased despite the 5-year increase in age; moreover, hypertension was better controlled after the programme

(24.8% baseline; 39.7% at the end of the study), and substantial decreases in deaths due to cardiovascular disease were reported (18).

Another intervention that has shown promising results is home recording of blood pressure. For example, one study showed that in patients who initially showed poor compliance, there was an increase in compliance from 0 to 70% after self-measuring of blood pressure was introduced. The authors concluded that self-recording of blood pressure may be of value in patients with unsatisfactory blood-pressure responses in whom poor compliance is suspected (19).

Other studies have shown that care of patients by specially trained nurses resulted in increased adherence (20-22) and compelling evidence for the efficacy of brief, nurse-administered behavioural counselling comes from a study of 883 patients of British physicians (21). Another study also showed that adherence to hypertension therapy would benefit from intervention by nurses (22).

Finally, Bogden et al. (23) tested the effect of physicians and pharmacists working together as a team on patients with uncontrolled hypertension. In a randomized, controlled trial, 95 adult patients with hypertension (more than twice as many patients in the intervention group as in the control group) attained blood pressure control.

3. Asthma

A systematic review by the Cochrane Airways Group has shown that training patients in asthma self-management which involves self-monitoring of either peak expiratory flow or symptoms, coupled with regular medical review and a written action plan appeared to improve health outcomes for adults with asthma. In addition, self-management education reduced hospitalizations, visits by the doctor, unscheduled visits to the doctor, days off work or school and nocturnal asthma. Finally, training programmes which enabled people to adjust their medication using a written action plan appeared to be more effective than other forms of asthma self-management and significant improvements in lung function were achieved (24).

The Cochrane Airways Group has also shown that non-comprehensive approaches such as the use of limited education about asthma (information only) do not appear to improve health outcomes in adults with asthma although perceived symptoms may improve (24).

Therefore, patient education and self-management should be integral components of any plan for long-term control of asthma. In particular, economic appraisals of asthma self-management programmes have shown them to be cost-effective both in terms of direct costs (mainly averted hospitalizations and reduced emergency department use) and in terms of indirect costs (e.g. productivity losses and missed school days). The cost-benefit ratios are between 1:2.5 and 1:7. Ratios are even better in programmes directed at high-risk groups and patients with severe asthma (25-27). Some examples of studies that reported net cost-savings are described below.

The Open Airways programme of six 1-hour monthly sessions instructed low-income parents of 310 urban children with asthma in the management steps to be taken both by the children and their parents. The programme found that 44 % of the parents lacked confidence in their ability to manage asthma attacks, believing they should take their children to the hospital emergency department for all episodes, whether mild or severe. Compared to a control group, participation in the Open Airways programme reduced emergency department visits and hospitalizations for asthma among those who had been hospitalized during the previous year by half, resulting in savings of \$11.22 for every dollar spent (28).

An Italian study evaluated two structured educational programmes on asthma. The study found that the savings per patient in terms of reduced morbidity were \$1894.70 (for the intensive programme (IP))

and \$1697.80 (for the brief programme (BP)). The net benefit was \$1181.50 for IP and \$1028.00 for BP and the cost-benefit ratio per dollar spent was 1:2.6 for IP and 1:2.5 for BP (29).

In a programme at Henry Ford Hospital in Detroit, Michigan, in 1986-1987 involving three, 1-hour, education sessions in small groups, a registered nurse taught patients about the importance of medication adherence, methods to control and prevent asthma attacks, relaxation exercises and smoking cessation. For just \$85 per person in annual programme costs, this intervention reduced the cost of emergency department visits by \$623 per person during the following year. The programme also reduced the number of days on which the activity of participants was limited because of asthma by 35% compared to a control group (30).

In Germany a structured intervention programme produced net benefits of DM12 850 (in 1991 DM (German marks)) per patient within 3 years. Within the health care sector, the net benefits were DM 5 900. Within 3 years, the paying bodies saved DM 2.70, and society as a whole saved DM 5.00 on each DM spent on the programme (cost-saving ratios 1:2.7 and 1:5). The authors concluded that the intervention produced net monetary benefits. This result was stable even when tested with different outcome measures. Such a programme is therefore worthwhile, not only for its demonstrated medical benefits, but also for its economic savings (31).

In a study in the United States, adult patients with asthma learned self-management skills in seven 90-minute, group sessions at Ohio University in Athens, Ohio. Participants were asked to keep a weekly record of peak flow rates and of any attacks they experienced. They also kept a workbook to record the information that was later used to calculate costs and benefits. At a programme cost of \$208 per patient, annual asthma-related costs for each patient were reduced by an average of nearly \$500 in the year following the programme, primarily from reductions in hospitalizations and work absences. The researchers have also adapted an individualized intervention for use in doctors' surgeries (32). The subsequent economic evaluation of this study showed that the programme was beneficial, reducing the cost of asthma to each patient by \$475.29. The benefit came primarily from reductions in hospital admissions (reduced from \$18 488 to \$1538) and income lost as a result of asthma (reduced from \$11 593 to \$4 589). The asthma self-management programme cost \$208.33 per patient. A comparison of the costs of the programme with the benefits produced a 1:2.28 cost-benefit ratio, demonstrating that the programme more than paid for itself (33).

The Harvard Community Health Plan, a large staff-model HMO, reduced the annual rate of paediatric emergency-room admissions related to asthma by 79% and hospital admissions by 86% using a single outreach nurse for 8 hours per week. In addition to instructing patients in asthma management, medications, triggers, and the use of inhalers and peak-flow meters, the nurse maintained regular telephone contact with the families to ensure compliance with individualized treatment plans. Patients participated for between 6 months and 2 years. At a cost of just \$11 115 per year, this intervention saved approximately \$87 000 in 1993 dollars (34).

In the Wee Wheezers programme, four small-group sessions of about 2 hours each were conducted to instruct parents of children under the age of 7 years how to help their children manage asthma attacks, communicate with health professionals, and promote the psychosocial well-being of the family unit. The last two sessions included 45 minutes of direct instruction for children aged 4-6 years. On average, the children reported 0.9 fewer sick days and 5.8 more symptom-free days, and their parents reported 4.4 more nights of uninterrupted sleep during the month preceding the follow-up questionnaire. The programme cost approximately \$26 per child (35).

To sum up, best practices in asthma control and in enhancement of adherence must include and reinforce the links between education and self-management. Not surprisingly, there is high quality evidence to support the efficacy and cost-effectiveness of guided self-management plans. Furthermore, most studies have reported net cost-savings.

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