

Annexes

Annex I

Behavioural mechanisms explaining adherence

What every health professional should know

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1. Introduction

Optimal outcomes in population health require both efficacious treatments and adherence to those treatments. Whether the treatment involves taking medication properly, making and keeping health care appointments, or self-managing other behaviours that influence the onset, course or prognosis of an illness; all other things being equal, success is determined by adherence behaviour. Patients, health care providers, researchers, funders and policy-makers, all have an interest in ensuring that effective bio-medical and behavioural therapies for chronic illnesses are “used as prescribed”. However, empirical studies have consistently found that levels of compliance or adherence are often far from optimal (1,2). Because the burden of illness in the population has shifted toward chronic diseases, the problem of poor adherence is of major concern to all stakeholders in the health care system. This is because the risk of poor adherence increases with the duration and complexity of treatment regimens and both long duration and complex treatment are inherent to chronic illnesses.

Across diseases, adherence is the single most important modifiable factor that compromises treatment outcome. The best treatment can be rendered ineffective by poor adherence. Our perspective is that an understanding of basic behavioural principles and models of behavioural change is relevant to adherence to treatment for all chronic medical conditions, and more helpful than a disease-specific approach to the issue.

Behavioural science offers useful theories, models and strategies that support best-practice approaches to delivering treatment. The effectiveness of adherence interventions based on behavioural principles has been demonstrated in many therapeutic areas. Examples include hypertension (3), headache (4), AIDS (5), cancer (6), heart transplantation (7,8), chronic asthma (9,10), diabetes (11), high cholesterol (12), obesity (13) and sun-protection behaviours (14) among others. Recent research has also evaluated interventions aimed at maintaining adherence to treatments targeting substance abuse in pregnancy (15); alcohol abuse (16); opioid addictions and methadone maintenance (17,18); substance dependence (19); cocaine abuse (20), and tobacco smoking (21).

Decades of behavioural research and practice have yielded proven strategies for changing people's behaviour. Such strategies can be used to help patients with diverse medical conditions (22,23), and can also be effective in changing the behaviour of health care providers (24) and health care systems (25).

Epidemiological research concerning the prevalence and correlates of poor adherence to treatment, and research on adherence to treatment for specific diseases is presented in the main text of this report. In this annex, the following are discussed from a behavioural perspective:

- the nature of poor adherence;
- a practical approach to conceptualizing and defining adherence;
- models to help explain determinants of adherence; and
- guidelines for assessment and intervention in clinical practice.

2. The nature of poor adherence

Treatment effectiveness is determined jointly by the efficacy of the treatment agent and the extent of adherence to the treatment. Despite the availability of efficacious interventions, nonadherence to treatment remains a problem across therapeutic areas.

Adherence is a complex behavioural process determined by several interacting factors. These include attributes of the patient, the patient's environment (which comprises social supports, characteristics of the health care system, functioning of the health care team, and the availability and accessibility of health care resources) and characteristics of the disease in question and its treatment.

There are many specific aspects of treatment to which a patient may not adhere, for example:

- health-seeking behaviours (such as appointment-keeping);
- obtaining inoculations;
- medication use (use of appropriate agents, correct dosing and timing, filling and refilling prescriptions, consistency of use, duration of use); and
- following protocols for changing behaviour (examples include modifying diet, increasing physical activity, quitting smoking, self-monitoring of symptoms, safe food handling, dental hygiene, safer sex behaviours and safer injection practices).

The most frequently cited conceptual definition of adherence is "the extent to which a person's behaviour – taking medication, following a diet, executing lifestyle changes – follows medical advice" (26). Adherence has also been defined as "the extent to which patient behaviour corresponds with recommendations from a health care provider" (27,28). It has also been suggested that a more practical approach is to define adherence as "following treatment at a level above which treatment goals are likely to be met". However, these broad definitions belie the complexity of the issue.

In research, adherence has been operationalized in many different ways: as the degree to which a regimen is followed expressed as a percentage or ratio, a categorical phenomenon (e.g. good versus poor adherence), or as an index score synthesizing multiple behaviours. However, for clinical purposes, these definitions lack specificity, and give no clear direction for assessment and intervention.

The treatments that patients are asked to follow vary according to the nature of the demands they impose. They range from requiring relatively simple and familiar behaviours, to more complex and novel ones. Some treatments involve one behaviour, while others carry multiple behavioural requirements. Protocols also vary in terms of the length of time for which they must be followed. This means that the nature and meaning of adherence change according to the specific treatment demands of a particular protocol. Assessment and intervention strategies will differ according to *the circumstances and/or intensity of the recommendations*. All treatments make demands of one type or another on patients. Patients differ in their ability to meet those demands, and the resources available and the environmental contexts outlined earlier also differ. Perhaps adherence might be better understood as reflecting the process of efforts, occurring over the course of an illness, to meet the treatment-related behavioural demands imposed by that illness. This behavioural conceptualization allows us to define adherence more explicitly according to the type of behaviour, an acceptable frequency, consistency, intensity and/or accuracy.

3. Determinants of adherence

A considerable amount of empirical, descriptive, research has identified correlates and predictors of adherence and nonadherence. These include aspects of the complexity and duration of treatment, characteristics of the illness, iatrogenic effects of treatment, costs of treatment, characteristics of health service provision, interaction between practitioner and patient, and sociodemographic variables. Many of these variables are static, and may not be amenable to intervention. They have been well described in the main text of this report and will not be discussed further here. While such findings help to identify risk factors, they tend to be discrete and atheoretical, and not very helpful in guiding a clinical approach to this problem.

This section describes several important variables that are behavioural in nature and are also dynamic, and therefore amenable to intervention. First we identify key behaviours of health care providers, health system factors and attributes of patients. Then we discuss promising behavioural science theories and models that help to explain behavioural change. These serve as helpful heuristics both for understanding nonadherence and for addressing it.

A. Provider behaviours

Variables related to how health care providers interact and communicate with their patients are key determinants of adherence and patient health outcomes (4,6,17,29,30). The health care providers prescribe the medical regimen, interpret it, monitor clinical outcomes and provide feedback to patients (31).

Correlational studies have revealed positive relationships between adherence of patients to their treatment and provider communication styles characterized by, providing information, “positive talk” and asking patients specific questions about adherence (32). The clarity of diagnostic and treatment advice has been correlated with adherence to short-term but not to long-term regimens and chronic illnesses. Continuity of care (follow-up) is a positive correlate of adherence. Patients who view themselves as partners in the treatment process and who are actively engaged in the care process have better adherence behaviour and health outcomes (33). Warmth and empathy of the clinician emerge time and again as being central factors (34). Their patients of providers who share information, build partnerships, and provide emotional support have better outcomes than the patients of providers who do not interact in this manner (35). Patients who are satisfied with their provider and medical regimen adhere more dili-

gently to treatment recommendations (36). Findings such as these can guide providers to create a treatment relationship that reflects a partnership with their patients and supports the discussion of therapeutic options, the negotiation of the regimen and clear discussion of adherence.

Health care providers often try to supply information to patients and to motivate them, and recognize the importance of behavioural skills in improving health. However, there is evidence that, in practice, they give limited information (37), lack skills in motivational enhancement (38), and lack knowledge and experience frustration in teaching patients behavioural skills (39). More structured, thoughtful and sophisticated interactions between provider and patient are essential if improvements in adherence are to be realized.

B. Health system factors

The health care delivery system has great potential to influence the adherence behaviour of patients. The policies and procedures of the health system itself control access to, and quality of, care. System variables include the availability and accessibility of services, support for education of patients, data collection and information management, provision of feedback to patients and health care providers, community supports available to patients, and the training provided to health service providers. Systems direct providers' schedules, dictate appointment lengths, allocate resources, set fee structures and establish organizational priorities. The functioning of the health system influences patients' behaviour in many ways.

- *Systems direct appointment length and duration of treatment*, and providers often report that their schedules allow insufficient time to address adherence behaviour adequately (40).
- *Health systems determine reimbursements and/or fee structures*, and many health systems lack financial coverage for patient counselling and education: this threatens or precludes many adherence-focused interventions.
- *Systems allocate resources* in ways that may result in heightened stress for, and increased demands upon, providers and that have, in turn, been associated with decreased patient adherence (41).
- *Systems determine continuity of care* and patients demonstrate better adherence when they receive care from the same provider over time (42).
- *Systems direct information sharing* – the ability of clinics and pharmacies to share information regarding patients' behaviour towards 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 (43).

C. Patient attributes

Patient characteristics have been the focus of numerous investigations of adherence. However, age, sex, education, occupation, income, marital status, race, religion, ethnic background, and urban versus rural living have not been definitely associated with adherence (26,44). Similarly, the search for the stable personality traits of a typical nonadherent patient has been futile – there is no one pattern of patient characteristics predictive of nonadherence (34,42). With the exception of extreme disturbances of functioning and motivation, personality variables have not emerged as significant predictors. Recent studies of patients with mental health problems have provided evidence that depression and anxiety are pre-

dictive of adherence to medical recommendations (45–48). Almost everyone has difficulty adhering to medical recommendations, especially when the advice entails self-administered care.

Illness-relevant cognitions, perceptions of disease factors, and beliefs about treatment have stronger relationships to adherence. In particular, factors such as perceived susceptibility to illness, perceived severity of illness, self-efficacy and perceived control over health behaviours appear to be correlates (26,49). For adherence to occur, symptoms must be sufficiently severe to arouse the need for adherence, be perceived as being resolvable and acute, and remedial action must effect a rapid and noticeable reduction in symptoms (50).

Knowledge about an illness is not a correlate of nonadherence, but specific knowledge about elements of a medication regimen is, although apparently only for short-term, acute illnesses (51). Some of the above variables, and several others, form the basis of various theories and models of behaviour change and we now turn our attention to these.

4. Models

Leventhal & Cameron (52) provided a very useful overview of the history of adherence research. They outlined five general theoretical perspectives on adherence:

- biomedical perspective;
- behavioural perspective;
- communication perspective;
- cognitive perspective; and
- self-regulatory perspective.

The **biomedical model of health and illness** remains a dominant perspective in many health care settings and organizations. The biomedical approach to adherence assumes that patients are more-or-less passive followers of their doctor's orders, further to a diagnosis and prescribed therapy (52,53). Non-adherence is understood in terms of characteristics of the patient (personality traits, sociodemographic background), and patient factors are seen as the targets of efforts to improve adherence. This approach has helped to elucidate the relationships between disease and treatment characteristics on the one hand, and adherence on the other. Technological innovations (e.g. assessing levels of adherence using biochemical measures, developing new devices to administer medications) have had this as their impetus. However, other important factors, such as patients' views about their symptoms or their medications have been largely ignored.

Behavioural (learning) theory emphasizes the importance of positive and negative reinforcement as a mechanism for influencing behaviour, and this has immediate relevance for adherence.

- The most basic, but powerful, principle is that of antecedents and consequences and their influence on behaviour (i.e. operant learning) (54,55).
- Antecedents, or preceding events, are internal (thoughts) or external (environmental cues) circumstances that elicit a behaviour.
- Consequences, or expected consequences, that can be conceptualized as rewards or punishments, also influence behaviour.
- The probability of a patient, provider, or health care system initiating or continuing a behaviour partially depends on what happens before and after the behaviour occurs.

- From a theoretical standpoint it would be possible to “control” the behaviour of patients, providers and health care systems if one could control the events preceding and following a specific behaviour. From a practical standpoint, behavioural principles can be used to design interventions that have the potential to incrementally shape behaviour at each level of influence (i.e. patient, provider and system) to address adherence problems.

Communication perspectives that emerged in the 1970s encouraged health care providers to try to improve their skills in communicating with their patients. This led to emphasis being placed on the importance of developing rapport, educating patients, employing good communication skills and stressing the desirability of a more equal relationship between patient and health professional. Although this approach has been shown to influence satisfaction with medical care, convincing data about its positive effects on compliance are scarce (56). Adopting a warm and kind style of interaction with a patient is necessary, but is insufficient in itself to effect changes in the adherence behaviours of patients.

Various models emphasizing **cognitive variables** and processes have been applied to adherence behaviour (53). Examples of these include the **health belief model** (57), **social-cognitive theory** (58), the **theory of planned behaviour** (and its precursor, the theory of reasoned action) (59), and the **protection-motivation theory** (60). Although these approaches have directed attention to the ways in which patients conceptualize health threats and appraise factors that may be barriers to, or facilitate, adherence they do not always address behavioural coping skills well.

Self-regulation perspectives attempt to integrate environmental variables and the cognitive responses of individuals to health threats into the self-regulatory model (61,62). The essence of the model pertains to the central importance of the cognitive conceptualization of a patient (or a patient-to-be (63) of a health threat or an illness. Illness representations (the ideas patients have about the diseases they suffer) and coping are seen as mediating between the health threat and the action taken. Recent empirical studies seem to lend support to the importance of illness cognitions in predicting adherence (64–66). Patients create personal representations of health threats and models of the illness and its treatment, and it is these that guide their decision-making and behaviour. Thus, adherence requires an appropriate model and the belief that one can manage one’s own environment and behaviour, specific coping skills, and a belief that the issue requires one’s attention and the modification of one’s behaviour.

Although these theories and models provide a conceptual framework for organizing thoughts about adherence and other health behaviours, each has its advantages and disadvantages and no single approach may be readily translated into a comprehensive understanding of, and intervention for, adherence. More recent approaches that are more specific to health behaviours and the demands of following recommended health practices may provide more helpful frameworks.

Meichenbaum & Turk (42) suggested that four interdependent factors operate on adherence behaviour and that a deficit in any one contributes to risk of nonadherence.

- knowledge and skills: about the health problem and self-regulation behaviours required, their mechanisms of action, and the importance of adherence;
- beliefs: perceived severity and susceptibility (relevance), self-efficacy, outcome expectations, and response costs;
- motivation: value and reinforcement, internal attribution of success (positive outcomes are reinforcing, negative results seen not as failure, but rather as an indication to reflect on and modify behaviour);
- action: stimulated by relevant cues, driven by information recall, evaluation and selection of behavioural options and available resources.

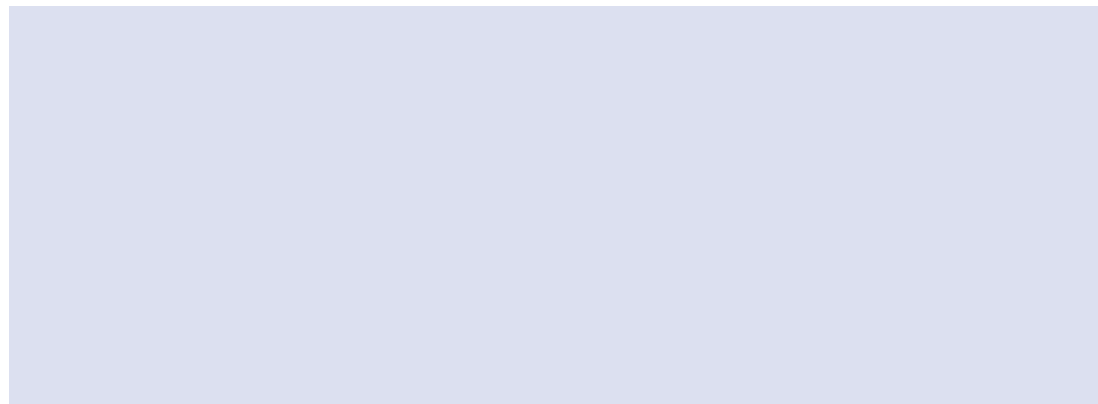
The recently developed **information–motivation–behavioural skills model (IMB model)** (67,68), borrowed elements from earlier work to construct a conceptually based, generalizable, and simple model to guide thinking about complex health behaviours. The IMB constructs, and how they pertain to patient adherence, are outlined below.

- Information is the basic knowledge about a medical condition that might include how the disease develops, its expected course and effective strategies for its management.
- Motivation encompasses personal attitudes towards the adherence behaviour, perceived social support for such behaviour, and the patients' subjective norm or perception of how others with this medical condition might behave.
- Behavioural skills include ensuring that the patient has the specific behavioural tools or strategies necessary to perform the adherence behaviour such as enlisting social support and other self-regulation strategies.

Note that information, motivation and behavioural skills must directly pertain to the desired behavioural outcome; they have to be specific.

Interventions based on this model have been effective in influencing behavioural change across a variety of clinical applications (67–69). In both prospective and correlational studies, the information, motivation and behavioural skills constructs have accounted for an average of 33% of the variance in behaviour change (68).

Figure 1 Information-motivation-behavioural skills model



The IMB model demonstrates that information is a prerequisite for changing behaviour, but in itself is insufficient to achieve this change (70). Motivation and behavioural skills are critical determinants and are independent of behaviour change (67,68). Information and motivation work largely through behavioural skills to affect behaviour; however, when the behavioural skills are familiar or uncomplicated, information and motivation can have direct effects on behaviour (see diagram). In this case, a patient might fill a prescription (a simple, familiar behaviour) based on information given by the provider. The relationship between the information and motivation constructs is weak. In practical terms, a highly motivated person may have little information, or a highly informed person may have low motivation. However, in the IMB model, the presence of both information and motivation increase the likelihood of adherence.

The **stages-of-change model** (SOC – also referred to as the transtheoretical model) identifies five stages through which individuals progress as they change behaviours, and stage-matched strategies that predict progress to each subsequent stage of change (71,72). The stages of change are: precontemplation (not considering changing behaviour in the next 6 months), contemplation (considering changing behaviour in the next 6 months), preparation (planning to change behaviour during the next 30 days), action (currently changing behaviour) and maintenance (successful behaviour change for at least 6 months). Stages of change describe an individual's motivational readiness to change.

The SOC model is useful for understanding and predicting intentional behaviour change. Most patients at one time or another make unintentional errors in taking their medication because of forgetfulness or misunderstanding of instructions. However, *intentional* non-adherence is a significant problem, particularly among patients with conditions requiring long-term therapy such as asthma, hypertension and diabetes.

Stage of change is an indicator of an individual's motivation to change, and is a powerful predictor of behaviour (73–75), but variables that explain behavioural change are needed to develop actionable, effective strategies to help people change. The SOC model has proven useful in this regard because it utilizes key psychological constructs to characterize individuals at different levels of readiness for change. Some of these constructs are: decisional balance, temptation to relapse, and processes or strategies for change (76). These constructs are briefly summarized below.

Decisional balance. Decisional balance consists of the pros and cons of behaviour change. Longitudinal research has established a characteristic relationship between stage of change and the pros and cons (77,78). The pros of healthy behaviour are low in the early stages of change and increase as stage of change increases. Conversely, the cons of the healthy behaviour are high in the early stages of change and decrease as stage of change increases. The positive aspects of changing behaviour begin to outweigh the negative aspects of change late in the contemplation stage or early in the preparation stage. Scales measuring pros and cons are particularly useful when intervening with individuals in early stages of change (precontemplation, contemplation and preparation) because decisional balance is an excellent indicator of an individual's readiness to move out of the precontemplation stage (74,78,79).

Temptation to relapse. The degree of temptation associated with situations that present a challenge for maintaining behavioural change is a concept based upon the coping models of relapse and maintenance. Situational temptation to engage in unhealthy behaviour is often viewed as an important companion construct to measures of confidence or self-efficacy. Confidence and temptation function inversely across stages of change (80), and temptation predicts relapse better (81). Scores on temptation are generally highest in the precontemplation stage, decreasing linearly from the precontemplation to maintenance stages (81).

Strategies for change. The SOC model identifies specific strategies or processes of change that are associated with successful movement from one stage to the next. The strategies for change outlined in the SOC theory are based upon components of several theoretical models in behavioural science. Each of the strategies for change is categorized as either experiential or behavioural in nature (82). Experiential strategies reflect cognitive, evaluative and affective planning for change whereas behavioural strategies reflect observable change strategies such as using reminders or rewards (73).

Specific strategies for change are useful for intervening with individuals in particular stages of change; individuals who are thinking about change need different strategies from those who are actively involved in change.

Tailored interventions provide individualized information based upon a specific theoretical framework, demographic characteristics or a combination of variables. There is evidence that tailored communications are more effective for influencing health behaviours than non-tailored materials (83), and comparisons of stage-tailored versus non-tailored interventions have shown that tailoring resulted in increased efficacy in influencing health behaviours (84).

A recent review found that interventions to improve adherence to medication were more effective when they included multiple components such as more convenient care, information, counselling, reminders, self-monitoring, reinforcement or family therapy (43). SOC tailoring may be a useful strategy for implementing complex, multi-component interventions in a cost-effective manner. Identification of stage of change can help determine the most relevant intervention components for each person, thus eliminating the need to deliver all intervention components to all patients. The availability of valid measures to assess stage of change provides a foundation for the development of stage-matched interventions for the promotion of adherence to medication. Stage-tailored communication has been shown to be an effective method for changing health behaviour, but has yet to be applied to the problem of nonadherence with medication.

5. Interventions

The “state-of-the-art” adherence interventions target the patient, the provider, and the health care system. Several programmes have demonstrated good results using multilevel team approaches (85–87). Adequate evidence exists to support the utility of innovative, modified health care system teams in addressing the problem (25,88).

However, research on interventions to promote adherence has focused largely on modifying patient behaviour. According to several published reviews on adherence, no single intervention targeting patient behaviour is effective, and the most promising methods of improving adherence behaviour use a combination of the strategies listed below (89–91):

- patient education (92);
- behavioural skills (93,94);
- self-rewards (95);
- social support (96); and
- telephone follow-up (97).

Various combinations of these techniques have been shown to increase adherence and improve treatment outcomes. However, even the most efficacious patient-focused interventions have no substantial effects on adherence behaviour over the long term (43) and few randomized controlled trials targeting patient adherence behaviour have been reported (91).

A. Patient interventions

The most effective adherence-enhancing interventions directed at patients aim to enhance self-regulation or self-management capabilities. Self-management programmes offered to patients with chronic diseases can improve health status and reduce health care utilization and costs. Some data suggest a cost-to-savings ratio of 1:10 (98). Such approaches are grounded in basic principles of learning (99,100). This is critical in the management of patients with chronic illness, as over the long term patients must rely on unassisted effort and self-regulation to maintain their behaviour. Several strategies appear to be effective, at least in the short term. These include:

- self-monitoring;
- goal-setting;
- stimulus control;
- behavioural rehearsal;
- corrective feedback;

- behavioural contracting;
- commitment enhancement;
- creating social support;
- reinforcement; and
- relapse prevention.

Since the early 1980s there has been sufficient evidence to support the use of these strategies. These are most effective when used as components of multi-modal programmes and implemented in an individualized tailored manner, including creating social support, reorganization of the service-delivery environment, increasing accessibility of services, and a collaborative treatment relationship.

A meta-analysis of 28 studies revealed that the key intervention components were providing reinforcement for patients' efforts to change, providing feedback on progress, tailoring education to patients' needs and circumstances, teaching skills and providing access to resources, and continuity of care (proactive) (101). An earlier review, Garrity & Garrity (102) identified four intervention themes associated with successful outcomes: active patient theme (promote self-care), social support theme (help in meeting illness-related demands), fear arousal theme (increase concern about the consequences of the disease), and patient instruction theme. The self-care (contingency contracting element) and social support themes were associated with the strongest effects on treatment outcome.

There has been little research on the most effective methods for improving adherence to recommended treatment in children. Education alone does not promote the desired patient outcomes and the format of the educational programme may be less important than the actual presentation and understanding of the information (103). However, when behavioural strategies were used in conjunction with patient education, adherence to recommended treatment improved by an average of 25% (104). Multi-component behavioural strategies that have been found to be successful in promoting adherence include self-monitoring, contingency contracting, reinforcing, tailoring and cueing. In addition, individual rather than group educational sessions can be better adapted to the specific needs of a child and his or her family, and are therefore anticipated to have a greater impact on outcomes (105). There is a need for research to identify and test developmentally-appropriate interventions to remedy the problem of paediatric nonadherence and improve health care outcomes for children.

The need for research to further our understanding of the differences in adherence behaviour at different stages of development has been only partially met. While some progress has been made in understanding and modifying adherence among paediatric populations there remains much to be learned. The research to date has suffered from a lack of methodological rigour and attention to theoretically-based investigations, particularly the utilization of developmentally-based theory to guide adherence interventions. Children are not small adults; children and adolescents have specific needs that differ from those of their adult counterparts. Advances in the area of adherence will be dependent upon:

- designing and testing tools for objectively measuring adherence that are non-intrusive (e.g. electronic monitoring), and that children and adolescents are willing and able to use;
- addressing psychosocial and family factors that modify adherence in children and adolescents;
- designing and testing age- and disease-specific quality-of-life scales for children and adolescents; and
- designing and testing educational and behavioural strategies appropriate for children and adolescents.

The desired outcome is for practitioners to tailor scientifically-based adherence interventions to the developmental stage of the patient. As interdisciplinary expertise is brought to bear on developing scientifically-based policy for addressing the developmental aspects of adherence and managing care, the gaps in the understanding of nonadherence should begin to close.

B. Interventions directed to providers

Because providers have such a significant role in adherence, designing interventions to influence their behaviour seems a reasonable strategy. However, few investigations on this subject have been reported in the literature. Training providers in patient-centred methods of care may be effective, but the strongest effects of such training appear to be on patient satisfaction with treatment. Some recent studies suggest that adherence interventions based on behavioural principles can be successfully implemented by social workers and nurses (106,107). Studies of physicians trained to use goal-setting, feedback and ongoing education reveal better patient outcomes, though such studies have seldom measured adherence as an outcome.

C. Health system

Interventions in the health system are higher order interventions affecting health policy; organization and financing of care and quality of care programmes. One example is the creation and adoption of chronic care models of service delivery, which, at least in patients with diabetes and asthma, have been shown to result in better patient outcomes. However the extent to which these models are related to adherence is not yet clear.

6. Conclusions

Nonadherence to treatment is a problem of increasing concern to all stakeholders in the health system. Since the early 1970s, the extent and consequences of poor adherence have been well documented in terms of impact on population health and health expenditure. Poor adherence limits the potential of efficacious treatments to improve patients' health and quality of life. This is a particular problem in the context of the chronic conditions that currently dominate the burden of illness in our society. Across health disciplines, providers experience considerable frustration over the high proportion of their patients who fail to follow treatment recommendations.

Adherence is a behavioural problem observed in patients, but with causes beyond the patient. It occurs in the context of treatment-related demands that the patient must attempt to cope with. These demands are characterized by the requirement to learn new behaviours, alter daily routines, tolerate discomforts and inconveniences, and persist in doing so while trying to function effectively in their various life-roles (108–110). While there is no behavioural magic bullet, there is substantial evidence identifying effective strategies for changing behaviour.

Practitioners (and other health enablers) often assume that the patient is, or should be, motivated by his or her illness to follow a treatment protocol. However, recent research in the behavioural sciences reveals this assumption to be erroneous. In fact, the patient population can be segmented according to level-of-readiness to follow health recommendations. The lack of concordance between patient readiness and practitioner behaviour means that treatments are frequently offered to patients who are not ready to follow them. This reflects an understandable bias towards treating the biomedical problem and an under-emphasis on addressing the behavioural requirements of the treatment protocol.

Prochaska (71) argued that people move through stages of increasing readiness to follow recommendations as they develop the motivation and skills required to change their behaviour. The SOC model provides a sensible and clear framework upon which to tailor treatment to patients' needs, and organize the delivery of the range of cognitive and behavioural interventions that are supported by the evidence

base. Miller and Rollnick (111) noted that motivation to adhere to treatment is influenced by the value that a person places on following the regimen (cost–benefit ratio) and their degree of confidence in being able to follow it. If either the perceived value of adhering, or confidence, is low the likelihood of adherence will also be low.

First-line interventions to optimize adherence can go beyond the provision of advice. Building on a patient's intrinsic motivation by increasing the perceived importance of adherence, and strengthening confidence by intervening at the level of self-management skills are behavioural treatment targets that must be addressed concurrently with biomedical ones if overall effectiveness of treatment is to be improved. This approach offers a way of increasing the sophistication of the adherence interventions offered to patients. Pharmacists, case managers, health educators and others involved in patient care should be made familiar with these basic concepts. Non-physician providers have an important role to play and an opportunity to dramatically improve health by specifically targeting issues of patient adherence.

In every situation in which patients are required to administer their own treatment, nonadherence is likely. Consequently, the risk for nonadherence for all patients should be assessed as part of the treatment-planning process and their adherence should be monitored as part of treatment follow-up. The traditional approach has been to wait to identify those patients who demonstrate nonadherence and then try to “fix” the problem. The risk for nonadherence is ever present. Interventions based on non-adherence risk-stratification should be offered from the start, as opposed to using a stepped-care approach.

Poor adherence persists largely because it is a complex problem and is resistant to generic approaches to dealing with it. Adherence-promoting interventions are not consistently implemented in practice; practitioners report lack of time, lack of knowledge, lack of incentives and lack of feedback on performance as barriers. Clearly, non-adherence is not simply a “patient” problem. At the points of initial contact and follow-up, providers can have a significant impact by assessing risk and delivering interventions to optimize adherence. 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. Health care providers can learn to assess the potential for nonadherence, and to detect in their patients. They can then use this information to implement brief interventions to encourage and support progress towards adherence.

Interventions aimed at particular diseases need to target the most influential and core determinants among the various factors. Given available resources, these targets will invariably be the patient and provider, at least in the immediate term. Disease-specific protocols for patients can be tailored to their needs. Practitioner protocols can convey the key requirements for the creation of optimal treatment relationships and behaviour assessment and management skills. Beyond this, the system in which providers work must be organized in such a way as to enable a consistent and systematic focus on adherence. A major focus for future research should be the clarification of the best mode, or modes, of delivering adherence interventions. There are many points of contact with patients and times at which such interventions are required, and delivering them outside the traditional health system may enhance their overall effectiveness.

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Annex II

Statements by stakeholders

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All statements expressed here are the sole responsibility of each individual or organization. None of these statements reflects the views of the World Health Organization on the topic discussed, or those of any other person or organization mentioned in this report.

The stakeholders are listed in alphabetical order, with the exception of patients, who should always come first.

1. Family, community and patients' organizations

Helping people with diabetes

By P. Lefebvre, President-Elect, The International Diabetes Federation (IDF)

Diabetes today represents an unprecedented epidemic. The number of people with diabetes worldwide is estimated to be more than 180 million, a figure likely to double in the next 20–25 years. Diabetes is currently a disease that can be treated, but unfortunately not cured.

The International Diabetes Federation (IDF) is the global advocate for people with diabetes. It comprises 182 patients' associations in more than 140 countries. The current mission of the IDF is to work with its member associations to enhance the lives of people with diabetes through awareness, education and improvement of health and well-being.

Several studies have shown that a gap presently exists between the goals recommended for diabetes care and the care that patients actually receive. Achieving the recommended targets for diabetes control requires informed patients who are motivated to work with their health care providers. The IDF stresses the importance of:

- helping people with diabetes, their families and communities to achieve better control of the condition; and
- helping to train health care professionals, people with diabetes and their families to improve management of the condition.

In this respect, the IDF fully endorses the recommendations of the [WHO Adherence Report](#). The strategy of the IDF for helping to improve adherence includes the identification of core strategic messages and definition of communication objectives targeted at people with diabetes, their families and health care professionals. Specific programmes include the development of standardized and reliable measurement tools. Special emphasis is put on helping patients in developing countries and minority groups.

The IDF also stresses the need for making essential drugs, such as insulin, and monitoring material, such as home blood-glucose monitoring, available and affordable to all people with diabetes in all countries.

The Work of the South African Depression and Anxiety Support Group

By Linda Woods, General Manager, South African Depression and Anxiety Support Group (SADASG)

Seven years have given the SADASG a long time to work on the issues of depression and anxiety and to fulfil our goals, which have been:

Getting patients to treatment. By having a voice on the line, which is often that of someone who has been through the feelings and emotions the patient is currently experiencing, and by being independent and trustworthy listeners we are able to give the caller the confidence to take the next step which is to visit a professional psychiatrist or psychologist. Our referral list includes not only psychiatrists and psychologists, but also general practitioners with the special skills needed to help patients to find the right answers to becoming well again.

Screening. Through our counselling line which is operated from 8 a.m. to 7 p.m. on six days a week, we have been able to give callers advice on their symptoms, whether caused by depression, bipolar disorder, obsessive–compulsive disorder, social phobia, panic disorder, generalized anxiety disorder or post-traumatic stress disorder. Our counsellors have been trained to ask pertinent questions, to help the caller to understand that their symptoms could be those of a real illness and to tell them what it could possibly be.

Adherence. A voice with the time to listen to patients' concerns, their side-effects, their self-doubt, and that can reassure them – often from first-hand experience, for example, that the side-effects they are experiencing are transient, normal and non-threatening and will usually disappear in time. That even though they are feeling so much better after 3 months, we would encourage them to stay on their medication for 6 to 12 months, as recommended by WHO guidelines.

Destigmatization. Through a concerted and targeted effort we currently send out a press article *every single week*. These articles include statistics and quotes from local South African experts, and guidelines on how to get the help that patients may need. They emphasize that treatment is nothing to be ashamed of these days. They feature patients with names, jobs, business men, and women and media personalities who are not ashamed and who can confirm that mental illness is an illness just like diabetes, or

heart disease, or asthma, and patients can be helped. Radio programmes, television shows and the screening of 30-second public service advertisements as well as magazine and newspaper articles help to get our message out. Through corporate education programmes that address a diversity of companies we are able to achieve a more caring and open atmosphere in which to tackle these disorders.

Our sponsors, local and national government, industry and certain foundations have helped us play a huge role in opening up this critical field for patients with depression and anxiety disorders throughout South Africa. We look forward to having the continued understanding and support of local government, with whom we could combine efforts to help patients at the community level.

Through our continued efforts, we can bring more people to treatment and improve levels of adherence. Thereby we can try to prevent some of the repercussions of depression becoming the number one illness causing death and disability in the world by 2020 as predicted by the World Bank and the World Health Organization.

2. Behavioural medicine

Health promotion, human behaviour and adherence to therapies

By Dr Aro Arja, Director, Education and Training Committee, International Society of Behavioural Medicine (ISBM)

Most long-term therapies combine medication with simultaneous instructions on health habits and lifestyle changes such as diet, physical activity and smoking cessation. Adherence to such lifestyle changes is often as important to optimal treatment outcome as adherence to medication. Furthermore, through lifestyle change, health promotion and disease prevention interventions can have a far-reaching impact in [enhancing health](#) beyond the specific condition being treated¹.

In comparison to the way in which adherence to medication has historically been addressed (in which the target behaviour is somewhat less multidimensional, but perhaps equally broadly determined), adherence to health-promoting or disease-preventing lifestyle changes now requires a different perspective. This perspective is quite broad in terms of the contexts or circumstances that directly influence these target behaviours; it requires a longer time horizon in which to evaluate benefits, consideration of a wider range of multi-level interventions, and a more varied theory-base.

The [context](#) extends beyond the person to the wider society, arrangement of working conditions and social processes. In practical terms it means that many factors outside the person, and perhaps beyond their volitional control must be considered. The *time horizon* means that the availability of data having a bearing on the effectiveness of programmes or procedures, in terms of recognizable health benefits, is often delayed by years or decades (as in the benefits of smoking cessation). This provides a challenge for motivation to adopt and maintain changes, especially in the absence of imminent threats to health.

The [interventions](#) needed are not only those that target the individual, but also those that act at the level of a society, community or group, and which are conveyed through a host of different channels of influence. For example using mass media, creating environmental changes, and regulations and laws such as smoking bans. Thus, multi-level approaches apply here too, but their range is wider than in compliance to medication.

¹ Tuomilehto J et al. Prevention of type 2 diabetes mellitus by changes in lifestyle among subjects with impaired glucose tolerance. *New England Journal of Medicine*, 2001, 344:1343–1350.

The [theoretical basis for surveillance, monitoring and intervention](#) also requires the adoption of a wider social and cultural framework (e.g. social marketing and communication theory) outside the individual, family and patient–clinician relationship². Models explaining the inter-relationships between different health-relevant behaviours, the factors that influence them, and the causal pathways of change in different contexts and over the life-course are needed.

Studying and enhancing adherence to preventive therapy and change towards a healthy lifestyle require building a bridge from the person-centred approaches to adherence to medical regimens with their traditional emphasis on individual volition and behavioural control, to the tools and concepts of health promotion which attempt to understand and intervene in a more systemic manner. This involves targeting causes at many levels of the processes that determine human behaviour, not just the behaviour of the individual.

3. General practitioners/family physicians

General practice/family medicine – our role in improving adherence

By Bjorn Gjelsvik, Hon. Secretary, World Organization of Family Doctors (Wonca), Europe Region

The general practitioner (GP) meets the patient in the first line. In many countries, the GP is the first point of contact with the health system.

One of the main goals of a GP is to follow the chronic ill “from birth to the grave,” through his or her illnesses. This is in contrast with second-line or hospital medicine, where the patient is seen seldom and arbitrarily. “In hospitals patients come and go; the diseases persist. In general practice, the patients persist and diseases come and go.”

Wonca is working very hard to improve quality of care. Every year, there are several Regional Conferences where thousands of GPs meet to discuss this issue. One of the items is, of course, adherence to therapy and the rational use of resources.

During the past 10 years, there has been a great wave of production of guidelines and treatment regimens for chronic diseases and risk conditions. These guidelines should be based on the best available evidence, but it is also necessary to assess their socioeconomic, ethical and political implications, and also what impact they will have on the corps of doctors working in the field.

Important principles to improve adherence are:

- maintaining and building good doctor–patient relationships;
- in consultations, emphasizing the concept of patient-centred method through education and research;
- strengthening the collaboration with home nurses and other services in the care of elderly patients; and
- developing better information technology and filing services for general practices to minimize the risk of failure.

Wonca is the most important international organization for General Practice/Family Medicine. There are member organizations in 66 countries and Wonca is divided into Regions, covering countries connected by geography, language and culture.

4. Industry

How better labels and package inserts could help people increase their adherence to therapies

By Jerome Reinstein, Director-General, World Self-Medication Industry (WSMI)

The literature on adherence to therapy has concentrated on specific therapies. There is at least one area, however, which is applicable to adherence to all therapies: improving the usability of medicine labels and package inserts. Along with all the specific interventions to improve adherence to therapy, the use of written information for the patient, which has been proven to result in appropriate behaviour with the medicine, is one that needs additional research and the application of what is already known about medicine information design.

WHO has stated on a number of occasions that about half of medicines are not used according to best practice. One of the reasons for this is that labels and leaflets are often not as useable as they should be. Currently, labelling regulations are content-based. That is to say, regulators in individual countries or the European Union decide on what should be on a label and what should be in a leaflet. Sometimes, the regulations even state that the information should be “in consumer-understandable language”. However, no regulations currently require testing of labels and leaflets to determine their performance in real-life use. That is to say the labels and leaflets are not tested by members of the public to determine whether an acceptable standard of performance has been reached. One exception to this is in Australia where Consumer Medicines Information is performance-tested and where the contents of labels and leaflets are in the process of being regulated on a performance-test basis.

There are universal principles for producing usable medicines information, but in practice they are not followed by regulatory authorities. Information design principles can be used to produce labels that can be shown to be usable by people. The steps required are:

- *Scoping* – defining the problem to be solved.
- *Bench-marking* – setting performance requirements for the design.
- *Prototype development* – using the best writing and layout skills to develop a prototype.
- *Testing and refinement* – changing the prototype to meet performance requirements (this process may have to be repeated several times in iterative testing to reach the agreed standard).
- *Specification and production* – implementing the design for production and distribution.
- *Monitoring* – measuring the design's performance in use.

The application of these principles is not obvious and must be taught as a discipline. However, the principles can be learned in a short time and can then be applied and tested in any cultural environment, even in environments in which many people are illiterate, where communication agents such as children or village elders can be used to transmit the information on medicines.

How the pharmaceutical industry can help in enhancing adherence to long-term therapies

By H. Bale, Director-General, International Federation of Pharmaceutical Manufacturers Associations (IFPMA).

Medicines won't work if you don't take them. Even the best treatment plan will fail if it isn't followed. The most obvious consequence of nonadherence is that a person's illness may not be relieved or cured.

According to an estimate from the Office of the United States Inspector General, every year nonadherence to drug treatment results in 125 000 deaths from cardiovascular diseases such as heart attack and stroke. In addition, up to 23% of admissions to nursing homes, 10% of hospital admissions, many visits to doctors, many diagnostic tests and many unnecessary treatments could be avoided if people took their drugs as directed.

Unfortunately, people often don't take their medicines as prescribed. This nonadherence has serious and wide-reaching outcomes, ranging from the extra cost to whoever pays for the wasted medicines and additional treatment, to the cost to patients who will suffer avoidable illness and in serious cases, even death. For example, missed doses of a glaucoma drug can lead to damage to the optic nerve and blindness; missed doses of a heart drug may lead to an erratic heart rhythm and cardiac arrest; missed doses of a high blood-pressure drug can lead to stroke; and failure to take prescribed doses of an antibiotic can cause an infection to flare up again and can lead to the emergence of drug-resistant bacteria.

Studies of patient behaviour show that some 50% of medicines are not taken as prescribed. There are many reasons for this, and among the many reasons that patients give for not adhering to a treatment plan, forgetfulness is the most common. A key question is: why do people forget? The psychological mechanism of denial is often a reason, and sometimes something about the treatment may greatly concern the patient, resulting in a repression of the desire to follow the prescribed treatment. Illness in itself is a concern, and having to take medication is a constant reminder that you're ill. Other reasons for not adhering to a treatment plan include the cost of treatment, inconvenience and possible adverse effects.

Studies have shown that patients are more likely to be motivated to take their medicines correctly as prescribed when they:

- understand and accept the diagnosis;
- agree with the treatment proposed; and
- have been able to address and discuss seriously their concerns about the specific medicines.

Ways to improve adherence. Dr Joanne Shaw, director of the Medicines Partnership project (UK), points out that being part of the decision-making process involved in buying a home, household goods or a new car is obvious to most people, but this may not be as obvious when getting treatment for their illness. It has been shown that people normally adhere better to their prescribed treatment if they have a good relationship with their prescribing doctor. One reason for this is that when people participate in their health care planning, they also assume responsibility for it and are therefore more likely to stay with the plan. Getting clear explanations in a language they understand and understanding the rationale for the treatment also help to increase adherence.

A further important issue identified by the Medicines Partnership project, is that people are more likely to adhere if they believe that their doctor, nurse, physician assistant or pharmacist cares whether or not they stick with the plan. Studies show that people who receive explanations from a concerned doctor are more satisfied with the help they receive and like the doctor more; the more they like the doctor, the better they follow a treatment plan. Written instructions help people to avoid mistakes caused by poor recall of what the doctor said.

Creating a two-way relationship between patient and doctor can start with an information exchange. By asking questions, a patient can come to terms with the severity of his or her illness and intelligently weigh the advantages and disadvantages of a treatment plan. Misunderstandings can often be clarified simply by talking to an informed professional. Good communication also ensures that all caregivers can understand plans prescribed by other health care practitioners.

Patients who take responsibility for helping to monitor the good and bad effects of their treatment and discussing concerns with health care practitioners are likely have better results from a treatment plan. They should inform the doctor, pharmacist or nurse about unwanted or unexpected effects before adjusting or stopping the treatment on their own. A patient often has good reasons for not following a plan, and a doctor can make an appropriate adjustment after a frank discussion of the problem.

Patients may also form support groups for people suffering from similar conditions. Often the fact that there are other patients trying to cope with the same problems can be helpful, and the patient support groups can provide suggestions for coping with problems, building on the experiences of other patients.

Reasons for not adhering to a treatment plan. It is also important to try to understand the reasons for not adhering to a prescribed treatment. The patient could be misunderstanding or misinterpreting the instructions. Forgetting to take a medication is common, and experiencing adverse effects may be perceived as worse than the disease itself, especially if the disease is asymptomatic – the treatment of high blood pressure is a classic example of this. What may be represented as “misunderstanding or misinterpreting or forgetting”, could be the expression of underlying beliefs and priorities about medicines in general, and the patient’s regimen in particular. Denying the diagnosis and the illness, and not believing that the medicine will help are other factors. Patients may also fear adverse effects or becoming dependent on the drug (which may lead the patient to take a “medication holiday”). Sometimes patients may believe mistakenly – that the disease has been sufficiently treated, as is often the case when people take antibiotics for an infection, and the symptoms disappear before all the bacteria are eradicated. Other factors may be worries about the costs, or the patient experiences problems, for example, difficulty swallowing tablets, opening the medicine container, or following a cumbersome treatment plan.

For older people adherence may be a particular challenge, as they are often taking several drugs concurrently, making it harder for them to remember when to take each of them. It is also not unlikely that they could experience an adverse drug interaction. Doctors should take care to obtain information about all the drugs a person is taking, not only prescription medications, but also over-the-counter preparations.

A role for industry. The main role of the pharmaceutical industry is to develop safe and efficacious treatments. The development of drugs with few side-effects and easy or easier administration would promote adherence. Because medicines are for patients and their optimal use, the industry’s role should go beyond the traditional one of bringing the medicines to the market. Industry also has a necessary role in helping to inform patients about their products. This should be in such a way that broader and increased knowledge and understanding can support the patient’s relation to, and dialogue with, the prescribing doctor and the other health professionals involved, such as nurses and pharmacists, in following the prescribed treatment to achieve the best outcome for both the patient and the health care system.

5. Nurses

The role of the nurse in improving adherence

By Tesfamicael Ghebrehwet, Nursing and Health Policy Consultant, International Council of Nurses (ICN)

Nonadherence to treatment regimens is a persistent challenge to nurses and other health professionals. It is estimated that the percentage of patients who fail to adhere to prescribed regimens ranges from 20 to 80%^{1,2}. Nurses are aware of the consequences of nonadherence and its high cost to the patient, the community and the health care system. In addition, nurses are all too familiar with the frustrations about treatment failures, poor health outcomes and patient dissatisfaction that accompany poor adherence.

The International Council of Nurses (ICN) estimates that there are about 12 million nurses worldwide. And with a proper understanding of the dynamics of adherence, and techniques in assessing and monitoring the problems of nonadherence, these millions of nurses represent a formidable force in improving adherence and care outcomes. Their presence in all health care settings, their closeness to people and their large numbers combine to position nurses for sustained strategies to improve adherence.

Nursing interventions to scale up adherence need to be based on innovative approaches that involve nurse-prescribing, patient participation in self-care, and continuous assessment and monitoring of treatment regimens. Such approaches should foster therapeutic partnerships between patients and nurses that are respectful of the beliefs and choices of the patient in determining when and how treatment regimens are to be followed. Because much of the treatment for chronic conditions takes place in the home and community setting, nurses can provide a link and support through home visits, telephone and other reminders that facilitate adherence. Through sustained contact, nurses can form a therapeutic alliance with patients and their families and provide ongoing support for taking the recommended medications. Some techniques of monitoring adherence include directly observed therapy (DOT), pill counting, thoughtful and non-judgemental interviews, and reviewing medication cabinets³.

Nursing strategies to improve adherence include:

- assessing the extent of adherence using non-threatening questions;
- asking about side-effects of medication and their effect on patient's quality of life;
- educating patients on their illness, the importance of adherence, how the treatment will help, possible side-effects and how deal with them;
- suggesting cues and reminders such as detailed schedules, integrating medication times with daily habits, using medication boxes and timers, alarms, beepers, etc;
- rewarding and reinforcing adherence behaviour, for example, through charts and graphics that show the impact of medication on clinical markers of disease: e.g. lower blood pressure, lower blood sugar, lower viral load, etc;
- encouraging the patient to cultivate therapeutic relationships with health professionals, and to talk with peer groups and family members.

Ensuring that treatment regimens are followed and administering medications and other treatments are some of the key roles in nursing. Nurses have diverse skills that must be tapped in improving adherence and care outcome. Continuing education programmes for nurses and other health professionals can improve their competence and awareness about the importance of adherence in health care.

^{1,2} Cramer JA et al. How often is medication taken as prescribed? A novel assessment technique. *Journal of the American Medical Association*, 1989, 261:3273–3277 [erratum published in *Journal of the American Medical Association*, 1989, 262:1472].
Wright EC. Non-compliance – or how many aunts has Matilda? *Lancet*, 1993, 342:909–913.

³ Williams AB. Adherence to HIV regimens: 10 vital lessons. *American Journal of Nursing*, 2001, 101:37–43.

6. Pharmacists

The role of the pharmacist in improving adherence

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Medicines are an integral part of most courses of therapy, and their safe and appropriate use is an important aspect of optimizing health care outcomes. Medicines can be used effectively to prevent disease or the negative consequences of long-term chronic illness, but more needs to be done to improve the overall quality of their use. Pharmacists have a key role to play by providing assistance, information and advice to the public about medicines, as well as by monitoring treatment and identifying problems in close cooperation with other health care providers and the patients.

Pharmacists are well-positioned to play a primary role in improving adherence to long-term therapy because they are the most accessible health care professionals and they have extensive training in pharmaceuticals. Part of the professional responsibility of pharmacists is to provide sound, unbiased advice and a comprehensive pharmacy service that includes activities both to secure good health and quality of life, and to avoid ill-health.

Pharmaceutical care is a relatively new philosophy of practice, the goal of which is to optimize the patient's health-related quality of life and to achieve positive clinical outcomes.

Pharmaceutical care includes:

- educating the patient or the person caring for the patient about their medications and the conditions for which they are prescribed to ensure maximum therapeutic benefit and safety;
- reviewing the patient's medication history;
- continuous monitoring of the patient's therapy;
- screening for potential adverse effects; and
- monitoring the patient's ability to take his or her medications correctly and to adhere to the prescribed therapies.

Pharmacists, through the practice of pharmaceutical care, can prevent or stop interactions, monitor and prevent or minimize adverse drug reactions and monitor the cost and effectiveness of drug therapy as well as provide lifestyle counselling to optimize the therapeutic effects of a medication regimen. The concept of pharmaceutical care is particularly relevant to special groups of patients such as the elderly and chronically ill.

Intervention by the pharmacist and pharmaceutical care are effective approaches to improving adherence to long-term therapies. Adherence to immunosuppressive medications in renal transplant patients ranges from 50 to 95% and nonadherence can result in organ rejection¹. Intervention by pharmacists has been demonstrated to improve average monthly compliance by more than 100% over a 12-month period². Advice, information and referral by community pharmacists have been demonstrated to significantly improve adherence to antihypertensive medications and improve blood-pressure control³. Similar results have been demonstrated in patients with asthma^{4,5}.

¹ Greenstein S, Siegal B. Compliance and noncompliance in patients with a functioning renal transplant: a multicenter study. *Transplantation*, 1998, 66:1718–1726.

² Chisholm MA et al. Impact of clinical pharmacy services on renal transplant patients' compliance with immunosuppressive medications. *Clinical Transplantation*, 2001, 15:330–336.

³ Blenkinsopp A et al. Extended adherence support by community pharmacists for patients with hypertension: A randomised controlled trial. *International Journal of Pharmacy Practice*, 2000, 8:165–175.

⁴ Cordina M, McElnay JC, Hughes CM. Assessment of a community pharmacy-based program for patients with asthma. *Pharmacotherapy*, 2001, 21:1196–1203.

⁵ Schulz M et al. Pharmaceutical care services for asthma patients: a controlled intervention study. *Journal of Clinical Pharmacology*, 2001, 41:668–676.

These are only examples of many indications where improved compliance and outcomes have been clearly demonstrated to result from pharmacists' interventions. Many studies on this subject have been published, especially during the last 10–15 years.

Pharmacists are an important resource for improving adherence to long-term therapy.

7. Psychologists

The role of psychologists in improving adherence to therapies

By Pierre L.-J. Ritchie. Secretary General. International Union of Psychological Sciences (IUPsyS)

Psychologists work as applied health researchers and practitioners in primary, secondary and tertiary care settings and as members of multidisciplinary teams of health service providers, as well as in independent practice. In these varied roles, the involvement of psychologists increases the effectiveness of programmes aimed at identifying and treating prevalent behaviourally-based health problems. Nonadherence is arguably the most widely distributed and prevalent of these problems.

The success of any treatment depends on both its efficacy and the manner in which a patient uses it. Adherence occurs in the process of adaptation to illness or to the threat of illness. While the past 50 years have witnessed considerable progress in developing powerful treatments for a wide variety of chronic and acute illnesses, patients' use of these treatments has been far from optimal. The global challenge now facing health systems is to become more effective in creating the conditions that enable people to derive maximum benefit from available treatments. Establishing the optimal conditions for adherence early in the treatment process sets the stage for long-term maintenance. Psychological science and practice concerning adherence focus on the systemic, biological, social, cognitive, behavioural and emotional contributing factors. Psychologists bring an understanding of both adaptive and maladaptive psychological, social and behavioural processes that are critical for understanding, preventing and treating nonadherence.

In every situation in which treatment involves an aspect of a patient's behaviour, adherence is a potential problem. This is the case for health-seeking behaviours, the self-administration of medication or making lifestyle changes. Adherence is a behavioural issue, and psychology is a behavioural discipline. It is therefore not surprising that psychologists have been very active in efforts to improve adherence since at least the 1950s. Furthermore, adherence to both medical and behavioural treatments has been a major subject of research and practice in health psychology and behavioural medicine since their emergence as specialty areas. Since the 1980s, many psychologists have embraced a population-health perspective, and have supported public health goals by putting psychological know-how to work at all levels of the health care system. Their work supports the development of effective health policy, surveillance of behavioural risk factors in the population, and the design, implementation and evaluation of interventions.

Psychologists have unique and specialized training. They are behavioural specialists, often trained as scientist-practitioners, who bring an evidence-based perspective to the problem of nonadherence. Through research and practice, psychologists have developed compelling, effective approaches to help patients to cope with the demands imposed by chronic illness that frequently contribute to nonadherence. Psychologists also possess expertise in interpersonal communication, and have contributed to knowledge concerning the importance of good communication between health providers and patients for promoting adherence. This has led to innovations in training in interpersonal skills for health service providers targeting this determinant. Recognition of the importance of psychological and behavioural skills in the training curricula of health disciplines has drawn further on the skills of psychologists as educators.

As a health discipline, psychology blends basic and applied scientific enquiry with clinical service delivery to increase knowledge about adherence behaviour and its determinants, and to improve people's health and well-being, and the quality and efficiency of health services. Psychology was founded in response to the need to understand, predict and influence such basic phenomena as human motivation, cognition and behaviour. Over time several sub-disciplines have emerged including, clinical, health, rehabilitation, community, experimental, organizational and social psychology. Each of these has made substantial contributions to the knowledge base on adherence.

As scientists, psychologists produce knowledge that helps to identify the causes of the nonadherence, develop and test theories that help to explain the mechanisms of causality and to design and evaluate interventions to increase adherence. In this regard, psychologists have contributed to adherence research and patient care in areas such as HIV/AIDS, diabetes, hypertension, obesity, ischaemic heart disease, stroke, chronic pain, asthma and chronic obstructive pulmonary disease, kidney disease, headache, addictions, seizure disorders, a range of mental illnesses and dental hygiene, as well as behavioural risk factors for illness such as poor diet, insufficient physical activity, smoking and risky sexual behaviours among others.

As health service providers and members of the health care team, psychologists bring unique skills in psychological assessment and behavioural measurement to help identify those patients at risk of non-adherence, and to identify the determinants of nonadherence where it has already become a problem. They bring sophisticated treatment skills to ameliorate these risk factors and determinants. These skills are applied to individuals, families, groups or communities in the service of illness prevention, acute and chronic care or rehabilitation. With regard to nonadherence, these skills are commonly used to address the cognitive, motivational, emotional and behavioural barriers to the self-management of illness, or the modification of health risk behaviours. In clinical service settings, psychologists function in varied roles; as providers of direct service, consultants to health care teams with respect to diagnosis and treatment planning, and patient advocacy.

In addition to the basic science, clinical and population health research described above, psychological practice in the area of adherence comprises:

- assessment of risk for nonadherence including the relative contributions of patient attributes, illness- and treatment-related factors, social context of illness, and health provider and system factors;
- assessment and treatment of mental health co-morbidities that confer additional risk for nonadherence;
- specific cognitive, motivational and behavioural interventions to enhance the ability of patients to manage their own illness or to reduce risk of illness;
- relapse prevention intervention to assist with the long-term maintenance of treatment;
- continuing education interventions for other health service providers that teach skills in communication, motivation enhancement, and behaviour modification; and
- systems interventions aimed at improving the availability, accessibility and acceptability of treatments.

Psychological service providers have an integral role in primary health care teams that aim to deliver optimal, cost-effective care. They contribute by monitoring the psychological and behavioural risks to patients' health, identifying and treating psychological and behavioural problems that threaten the effectiveness of treatment and they optimize treatment planning by helping to integrate behavioural science practices with biomedical interventions.

Annex III – Table of reported factors by condition and dimension

	Socioeconomic-related factors	Health care team/health system-related factors
Asthma	(-) Vulnerability of the adolescent to not taking medications; family conflict and a denial of severity of disease in adolescents; memory difficulties in older patients; polypharmacy in older patients; cultural and lay beliefs about illness and treatment; alternative medicine; fear of the health care system; poverty; inner-city living; lack of transport; family dysfunction	(-) Health care providers' lack of knowledge and training in treatment management and/or an inadequate understanding of the disease; short consultations; lack of training in changing behaviours of nonadherent patients
Cancer	(-) Long distance from treatment setting	(-) Lack of knowledge of health professionals about pain management; 'inadequate understanding of drug dependence by health professionals; health professionals' fears of investigation or sanction; poor delivery of care-education to the patient; poor delivery of care-education to family and caregivers; reluctance of health professionals to prescribe opioids for use at home (+) Good relationship between patient and physician
Depression	No information was found	(-) Poor health education of the patient (+) Multi-faceted intervention for primary care
Diabetes	(-) Cost of care; patients over 25 years (adherence to physical activity); older adolescents (insulin administration); older adolescents (SMBG); males (adherence to diet); females (adherence to physical activity); environmental high-risk situations (+) Patients aged less than 25 years (adherence to physical activity); younger adolescents (insulin administration); younger adolescents (SMBG); males (adherence to physical activity); females (adherence to diet); social support; family support	(-) Poor relationship between patient and physician
Epilepsy	(-) Long distance from treatment setting; under 60 years old; teenagers; poverty; illiteracy; unwillingness to pay the cost of medicines; high cost of medications; local beliefs or beliefs about the origin of illness (+) Elderly patients (over 60 years old); children from family reporting less parental education; non-English speaking in an English-speaking community; lower income; recent immigrants	(-) Inadequate or non-existent reimbursement by health insurance plans; irregular or poor drug supply; lack of supplies of free medicines; poorly developed health services; lack of education about AEDs (+) Good relationship between patient and physician

Condition-related factors	Therapy-related factors	Patient-related factors
(-) Inadequate understanding of the disease	(-) Complex treatment regimens; long duration of therapy; frequent doses; adverse effects of treatment	(-) Forgetfulness; misunderstanding of instructions about medications; poor parental understanding of children's asthma medications; patients lack of perception of his or her own vulnerability to illness; patients' lack of information about the prescribed daily dosage/misconception about the disease and treatments; persistent misunderstandings about side-effects; drug abuse (+) Perceiving that they are vulnerable to illness
(-) Nature of the patient's illness; poor understanding of the disease and its symptoms	(-) Complex treatment regimens; taking too many tablets; frequency of dose; having no treatment instructions; misunderstanding instructions about how to take the drugs; bad tasting medication; adverse effects of treatment; inadequate treatment doses; perceived ineffectiveness; unnecessary duplicate prescribing (+) Monotherapy with simple dosing schedules	(-) Forgetfulness; misconceptions about pain; difficulty in taking the preparation as prescribed; fear of injections; anxieties about possible adverse events; no self-perceived need for treatment; not feeling it is important to take medications; undue anxiety about medication dependence; fear of addiction; psychological stress
(-) Psychiatric co-morbidity (+) Clear instructions on management of disease; nature of the patient's illness; poor understanding of the disease and its symptoms	(-) High frequency of dose; co-prescribing of benzodiazepines; inadequate doses of medication (+) Low frequency of dose; clear instructions on management of treatment	(-) Personality traits
(-) Depression; duration of disease	(-) Complexity of treatment (+) Less frequent doses; monotherapy with simple dosing schedules, frequency of the self-care behaviour	(-) Depression; stress and emotional problems; alcohol abuse (+) Self-esteem/self-efficacy
(-) Forgetfulness; memory deficits; duration and previous treatment failures; high frequency of seizures	(-) Complex treatment regimens; misunderstanding instructions about how to take the drugs; adverse effects of treatment (+) Monotherapy with simple dosing schedules	(-) Disbelief of the diagnosis; refusal to take medication, delusional thinking; inconvenience of treatment; denial of diagnosis; lifestyle and health beliefs; parental worry about a child's health; behavioural restrictions placed on the child to protect his/her health; fear of addiction; doubting the diagnosis; uncertainty about the necessity for drugs; anxiety over the complexity of the drug regimen; feeling stigmatized by the epilepsy; not feeling that it is important to take medications (+) Parents and child satisfied with medical care; not feeling stigmatized by epilepsy; feeling that it is important to take medications; high levels of stressful life events

Annex III – Table of reported factors by condition and dimension (suite)

	Socioeconomic-related factors	Health care team/health system-related factors
HIV/AIDS	(-) Women (stress of childcare); low income; African American men; lack of social support (+) Support of family and friends; Caucasian men	(-) Lack of clear instructions from health professionals; poor implementation of educational interventions (+) Good relationship between patient and physician; support from nurses and pharmacists
Hypertension	(-) Low socioeconomic status; illiteracy; unemployment; limited drug supply; high cost of medication	(-) Lack of knowledge and training for health care providers on managing chronic diseases; inadequate relationship between health care provider and patient; lack of knowledge; inadequate time for consultations; lack of incentives and feedback on performance (+) Good relationship between patient and physician
Tobacco Smoking	(-) High cost of treatment (+) Higher levels of education, older age	(-) Unavailability for follow-up or lost to follow-up; failure to recall the receipt of a prescription (+) Access to free nicotine-replacement therapy; more frequent contact with physicians and pharmacists
Tuberculosis	(-) Lack of effective social support networks and unstable living conditions; cultural and lay beliefs about illness and treatment; ethnicity, gender and age; high cost of medication; high cost of transport; criminal justice involvement; involvement in drug dealing	(-) Poorly developed health services; inadequate relationship between health care provider and patient; health care providers who are untrained, overworked, inadequately supervised or unsupported in their tasks; inability to predict potentially non-adherent patients (+) Good relationship between patient and physician; availability of expertise; links with patient support systems; flexibility in the hours of operation
Common Elements	(-) Long distance from treatment setting; low socioeconomic status; illiteracy; high cost of medication (+) Family support	(-) Lack of knowledge and training of health professionals about treatment management and/or an inadequate understanding of the disease; poor relationship between patient and physician; short consultations; poor implementation of educational interventions (+) Good relationship between patient and health professionals

AEDs, antiepileptic drugs; CO, carbon monoxide; SMBG, self-monitoring of blood glucose; (+) factors having a positive effect on adherence; (-) factors having a negative effect on adherence.

Condition-related factors	Therapy-related factors	Patient-related factors
(-) Asymptomatic patients (+) Symptomatic patients; understanding the relationship between adherence and viral load	(-) Complex treatment regimens; close monitoring; severe lifestyle alterations; adverse effects of treatment; lack of clear instruction about how to take the medications (+) Less frequent dose; fewer pills per day; fewer dietary restrictions; fitting medication to individual's lifestyle; belief that medication is effective	(-) Forgetfulness; life stress; alcohol use; drug use; depression; hopelessness and negative feelings; beliefs that alcohol and drug use interfere with medications (+) Positive beliefs regarding the efficacy of antiretroviral medications
(+) Understanding and perceptions about hypertension	(-) Complex treatment regimens; duration of treatment; low drug tolerability, adverse effects of treatment (+) Monotherapy with simple dosing schedules; less frequent dose; fewer changes in antihypertensive medications; newer classes of drug: angiotensin II antagonists, angiotensin converting enzyme inhibitors, calcium channel blockers	(-) Inadequate knowledge and skill in managing the disease symptoms and treatment; no awareness of the costs and benefits of treatment, non-acceptance of monitoring (+) Perception of the health risk related to the disease; active participation in monitoring; participation in management of disease
(-) Daily cigarette consumption; expired CO; plasma nicotine and cotinine levels; Fagerstrom tolerance questionnaire (FTQ) scores; greater tobacco dependence; psychiatric co-morbidities; depression; failure to stop or reduce smoking during treatment	(-) Adverse events or withdrawal symptoms (+) Attendance at behavioural intervention sessions	(-) Weight gain, no self-perceived need for treatment; no perceived effect of treatment (+) Motivation; good relationship between patient and physician
(-) Asymptomatic patients; drug use; altered mental states caused by substance abuse; depression and psychological stress (+) Knowledge about tuberculosis	(-) Complex treatment regimen; adverse effects of treatment; toxicity	(-) Forgetfulness; drug abuse, depression; psychological stress (+) Belief in the efficacy of treatment; motivation
(-) Poor understanding of the disease and its "side-effects"; depressive illness; psychiatric co-morbidities; asymptomatic disease; long duration of the disease (+) Understanding and perception of the disease	(-) Complex treatment regimen; adverse effects of treatment; frequent doses; lack of clear instructions about how to take the medications (+) Monotherapy; less frequent doses; fewer pills per day; clear instructions on management of treatment	(-) Forgetfulness; misunderstanding instructions about to take the medications; inadequate knowledge and skill in managing the disease symptoms and treatment; anxieties about possible adverse effects; lack of self-perceived need for treatment; psychosocial stress; depression; low motivation (+) Belief in the efficacy of treatment; motivation; perception of the health risk related to the disease

Annex IV Table of reported interventions by condition and dimension

	Socioeconomic-related interventions	Health care team-/ health care system- related interventions
Asthma	List-organized instructions; clear instructions about treatment for older patients	Education on use of medicines; management of disease and treatment in conjunction with patients; adherence education; multidisciplinary care; training in monitoring adherence; more intensive intervention by increasing number and duration of contacts
Cancer	Optimizing the cooperation between services; assessment of social needs; family preparedness; mobilization of community-based organizations	Training of health professionals on adherence; pain education component in training programmes; support to caregivers; multidisciplinary care; follow-up consultation by community nurses; supervision in home pain management; identification of the treatment goals and development of strategies to meet them
Depression	No information was found	Multidisciplinary care; training of health professional on adherence; counselling provided by a primary care nurse; telephone consultation/counselling; improved assessment and monitoring of patients
Diabetes	Mobilization of community-based organizations; assessment of social needs; family preparedness	Multidisciplinary care; training for health professionals on adherence; identification of the treatment goals and development of strategies to meet them; continuing education; continuous monitoring and re-assessment of treatment; systems interventions: health insurance for nutrition therapy, telephone reminders to patients, chronic care models
Epilepsy	Assessment of social and career needs	A regular, uninterrupted supply of medicines in developing countries; good patient–physician relationship; instruction by nurses and physicians about methods of incorporating drug administration into patient's daily life; training health professionals on adherence; adherence education
HIV/AIDS	Family preparedness; mobilization of community-based organizations; intensive education on use of medicines for patients with low levels of literacy; assessment of social needs	Good patient–physician relationship; multidisciplinary care; training of health professionals on adherence; training for health professionals in adherence education; training in monitoring adherence; training caregivers; identification of the treatment goals and development of strategies to meet them; management of disease and treatment in conjunction with the patients; uninterrupted ready availability of information; regular consultations with nurses or physicians; Non-judgemental attitude and assistance; rational selection of medications

Condition-related interventions	Therapy-related interventions	Patient-related interventions
Patient education beginning at the time of diagnosis and integrated into every step of asthma care	Simplification of regimens; education on use of medicines; adaptations of prescribed medications; continuous monitoring and re-assessment of treatment	Self-management programmes that include both educational and behavioural components; memory aids and reminders; incentives and/or reinforcements; self-monitoring
Education of the patient on adherence	Simplification of regimens; education on use of medications; giving clear instructions; clarifying misunderstandings about the recommendation of opioids; patient-tailored prescriptions; continuous monitoring and re-assessment of treatment; assessment and management of side-effects; coordination of prescribing	Interventions to redress misconceptions about pain treatment and to encourage dialogue about pain control between patient and oncologist; exploration of fears (e.g. about addiction); assessment of psychological needs; education on use of medications; behavioural and motivational intervention; self-management of disease and treatment; self-management of side-effects.
Education of patients on use of medicines	Education on use of medicines; patient-tailored prescriptions; continuous monitoring and re-assessment of treatment	Counselling; relapse-prevention counselling; psychotherapy; family psychotherapy; frequent follow-up interviews; specific advice targeted at the needs and concerns of individual patients
Education on use of medicines	Patient self-management; simplification of regimens; education on use of medicines; weight reduction assistance; teaching prescribed physical activity	Behavioural and motivational interventions; assessment of psychological needs; telephone reminders to patients in order to reduce missed appointments
Education on use of medicines	Simplification of regimens; single antiepileptic therapy (monotherapy); education on use of medicines; patient-tailored prescriptions; clear instructions; use of educational materials; continuous monitoring and re-assessment of treatment	Self-management of disease and treatment; self-management of side-effects; behavioural and motivational intervention; education on adherence; providing the patients with control and choices; assessment of psychological needs; frequent follow-up interviews; memory aids and reminders
Education on use of medicines; supportive medical consultation; screening for co-morbidities; attention to mental illness, as well as abuse of alcohol and other drugs	Simplification of regimens; education of the patient on the use of medicines; assessment and management of side-effects; patient-tailored prescriptions; medications for symptoms; adherence education; continuous monitoring and re-assessment of treatment	Monitor drug and/or alcohol use; psychiatric consultation; behavioural and motivational intervention; counselling/ psychotherapy; telephone counselling; memory aids and reminders; self-management of disease and treatment

Annex IV Table of reported interventions by condition and dimension (suite)

	Socioeconomic-related factors	Health care team/health system-related factors
Hypertension	Family preparedness; patient health insurance; uninterrupted supply of medicines; sustainable financing, affordable prices and reliable supply systems	Training in education of patients on use of medicines; Good patient–physician relationship; continuous monitoring and re-assessment of treatment; monitoring adherence; non-judgemental attitude and assistance; uninterrupted ready availability of information; rational selection of medications; training in communication skills; delivery, financing and proper management of medicines; development of drugs with better safety profile by pharmaceutical industry; participation of pharmaceutical industry in patient education programmes and in developing instruments to measure adherence for patients
Tobacco Smoking	Social assistance	Pharmacist mobilization; free access to nicotine-replacement therapy; frequent follow-up interviews
Tuberculosis	Assessment of social needs; social support, housing, food tokens and legal measures; providing transport to treatment setting; peer assistance; mobilization of community-based organizations; optimizing the cooperation between services	Uninterrupted ready availability of information; flexibility in available treatment; training and management processes that aim to improve the way providers care for patients with tuberculosis; management of disease and treatment in conjunction with the patients; multidisciplinary care; intensive staff supervision; training in monitoring adherence; DOTS strategy
Common Elements	Assessment of social needs; social support; family support and preparedness; mobilization of community-based organizations; uninterrupted supply of medicines	Multidisciplinary care; training educating patients about adherence; good patient–provider relationship; management of disease and treatment in conjunction with the patients; more intensive intervention in terms of number and duration of contacts; adherence education; training in monitoring adherence; uninterrupted ready availability of information

AEDs, antiepileptic drugs; CO, carbon monoxide; SMBG, self-monitoring of blood glucose; (+) factors having a positive effect on adherence; (-) factors having a negative effect on adherence.

Condition-related factors	Therapy-related factors	Patient-related factors
Education on use of medicines	Simplification of regimens	Behavioural and motivational intervention; self-management of disease and treatment; self-management of side-effects; memory aids and reminders
Therapeutic patient education; supportive psychiatric consultation	Nicotine replacement therapy; antidepressant therapy; education on use of medications; adherence education; assistance with weight reduction; continuous monitoring and re-assessment of treatment; monitoring adherence	Adjunctive psychosocial treatment; behavioural intervention; assistance with weight reduction; good patient–physician relationship
Education on use of medicines; provision of information about tuberculosis and the need to attend for treatment	Education on use of medications; adherence education; tailor the treatment to the needs of patients at risk of nonadherence; agreements (written or verbal) to return for an appointment or course of treatment; continuous monitoring and re-assessment of treatment	Mutual goal-setting; memory aids and reminders; incentives and/or reinforcements; reminder letters, telephone reminders or home visits for patients who fail to attend clinic
Education on use of medicines	Simplification of regimens; adherence education; education on use of medicines; patient-tailored prescriptions; continuous monitoring and re-assessment of treatment; monitoring adherence	Mutual goal-setting; incentives and/or reinforcements; behavioural and motivational intervention; counselling/psychotherapy; assessment of psychological needs; self-management of the disease and treatment that includes both educational and behavioural components; memory aids and reminders