

Understanding a Patient's Approach to Medication Use: An Aid to Tailoring Medication Information

Jana Bajcar

ABSTRACT

On average, 50% of patients do not take their medications as prescribed and therefore may not receive maximum therapeutic benefit. This problem may be intentional or unintentional. Intentional nonadherence, stemming from the patient's decision to self-regulate his or her medications without input from or knowledge of the physician, occurs frequently in spite of clear information about medications and instructions for their use delivered by physicians and pharmacists. In particular, patients receiving long-term medications regularly make conscious decisions to adjust their drug regimens. It has been proposed that a more patient-centred approach would address both intentional and unintentional nonadherence by incorporating information about an individual patient's decision-making into the medicine education process, thereby allowing the pharmacist to tailor education to the needs and context of the individual patient. This article examines some of the psychological factors underlying medication self-regulation by patients. It also explores strategies that pharmacists and other health care providers can use to examine intentional medication nonadherence and to support the development of effective medication-taking practices by tailoring their medication conversations with patients.

Key words: medication adherence, medication-taking practice, self-regulation, medication education

ABSTRACT

En moyenne, 50 % des patients ne prennent pas leurs médicaments comme prescrits et, par conséquent, n'en tirent peut-être pas les bienfaits thérapeutiques maximums. Ce problème de non-observance thérapeutique peut être intentionnel ou non. La non-observance intentionnelle, attribuable à la décision du patient d'autogérer la prise de ses médicaments sans en informer son médecin ou lui demander son avis, est courante, malgré les renseignements clairs que donnent les médecins et les pharmaciens sur les médicaments et la façon de les prendre. Plus particulièrement, il arrive souvent que les patients qui prennent des médicaments à long terme décident en toute connaissance de cause de modifier leur traitement. On a émis l'hypothèse selon laquelle une approche davantage centrée sur le patient permettrait de s'attaquer au problème de non-observance intentionnelle ou non, si on y intégrait des renseignements sur la prise de décision par un patient particulier dans la démarche de l'enseignement sur les médicaments, permettant ainsi au pharmacien d'adapter l'information aux besoins et au contexte de chaque patient. Cet article se penche sur certains des facteurs psychologiques qui sous-tendent l'autogestion de la prise des médicaments par les patients. Il examine également des stratégies que les pharmaciens et d'autres professionnels de la santé peuvent utiliser pour comprendre la non-observance thérapeutique intentionnelle et les aider à favoriser de bonnes habitudes de prise des médicaments, en individualisant l'information sur les médicaments qu'ils transmettent aux patients.

Mots clés : observance thérapeutique, habitudes de prise des médicaments, autogestion, enseignement sur les médicaments

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INTRODUCTION

All pharmacists have had to face situations in which a patient has decided to not take a medication at all, to stop taking a medication prematurely, or to depart from the prescribed regimen. Often, the pharmacist may not be aware of such decisions, as in the case of patients who leave the doctor's office or are discharged from hospital with a prescription and choose not to have the prescription filled (known as primary nonadherence). Even patients who do fill their prescriptions may take an incorrect dose, adjust the timing of doses, forget doses, or completely discontinue the treatment without the recommendation of the prescriber (known as secondary nonadherence). Approximately 50% of patients reportedly do not take their medications as prescribed,^{1,2} and pharmacists and other health care providers must cope with the phenomenon whereby information or advice shared with patients does not result in consistent, effective, and safe medication-taking practices.³ It can be perplexing and at times frustrating if, despite repeated conversations with a patient, the health care professional cannot fully make sense of the rationale for discontinuing a medication; in addition, health care providers must try not to become paternalistic and must not give up trying to address the issue.

Health care providers are and should continue to be concerned about how patients use their medications because of the potential impact that this may have on the patients' health. For example, McKenny and Harrison⁴ noted that 1 in 10 patients on a general medicine ward had been admitted to hospital because of secondary problems caused by nonadherence to prescription medications. McDonnell and Jacobs⁵ observed that one-third of preventable hospital admissions for adverse drug reactions were associated with nonadherence on the patient's part. There is also a concern with the economic impact of how patients use their medications. Sullivan and others⁶ estimated that 5.3% of hospital admissions in the United States were due to medication nonadherence, and they calculated that the associated direct medical costs were approximately US\$8.5 billion per year, with additional indirect costs of US\$17 billion to US\$24 billion. According to an analysis of 15 studies on hospital admissions in Canada, with a total of 6144 subjects, estimated hospital-related costs due to prescription drug nonadherence were approximately Can\$1 billion.⁷ Physician-related expenditures due to nonadherence were estimated at Can\$346 million, and consultations with other health care professionals at Can\$304 million.

The total health care expenses were estimated at Can\$1.7 billion annually.⁷

The aim of this article is to illustrate how an understanding of the psychological factors underlying a person's cognitive process in making decisions about his or her health may assist the pharmacist to engage in effective conversations about pharmacotherapy if the patient has intentionally decided not to take a medication as prescribed.

INTENTIONAL NONADHERENCE

Intentional nonadherence occurs when a patient intentionally alters medication therapy by changing the dose or by stopping or starting a medication.⁸⁻¹⁹ Various terms have been used to describe this phenomenon, such as testing,¹⁴ tailoring, self-tailoring, strategic nonadherence,⁸ self-regulation,^{10,16,20} and active or reflective self-regulation.¹⁵ The reasons for deviating from the prescribed course of therapy are perfectly rational to the patient but may not be apparent or understandable to the pharmacist or physician.^{9,10,13,18} The literature suggests that self-tailoring of medication occurs with many chronic conditions and represents a strategic move by patients to address a perceived problem with their medication-taking.⁸⁻¹⁹ This situation differs from unintentional nonadherence, which occurs when patients fail to take their medications properly because they forget to do so or have misunderstood the instructions.

Studies have revealed that patients deliberately self-regulate a prescribed regimen to address a variety of concerns, including the need to assess whether the medicine is still required, the need to confirm whether an adequate benefit from the medication can be obtained with a lower dose, or the need to determine whether an undesirable side effect is being caused by the medication. However, in practice it is often difficult to fully understand the patient's rationale; therefore, gaining insight into some of the psychological factors involved may be useful in strategizing how to tailor medication information for individual patients.

Such insight can be gained by examining a psychological model called the Common Sense Model.²⁰ This model explains that the patient may carry out a variety of self-regulating actions and suggests that the individual may believe there is a rational reason to alter the therapeutic plan set out by health care providers.²⁰ The model proposes 3 separate but related stages in decisions about self-regulation: the representation of the health threat, the action plan or coping strategy, and an appraisal of the effectiveness of the plan or strategy. By



becoming familiar with these stages, pharmacists and other health care providers may be better able to select and organize the medication information that they provide to patients during particular conversations. In the following sections, each of these 3 stages is described and then applied specifically to the medication-taking practice of patients, with examples from the literature.

Stage 1: Cognitive Representation of the Health Threat

The self-regulation process starts when an event occurs that leads the patient to form an idea or representation that is perceived as a potential threat to health.²⁰ In the pharmaceutical context, a prescribed medication or a prescribed dose may be perceived as more harmful than the perceived benefit. For example, patients with angina and hypertension may fear that long-term medications could accumulate in the body and trigger dependence.^{15,17,21} Gascon and others¹⁷ described patients who were afraid to take antihypertensive medication for a long time because they might be “stuck with it” for the rest of their lives. Other researchers have described patients who worried that regular use of a medication would lead to tolerance and immunity to its benefits.^{21,22} Medications can also be perceived as health threats if the patient feels that a required medication has not been prescribed or the dose of a prescribed medication is too low. Patients may be concerned that the symptoms of the disease will not be adequately controlled by the type or amount of drug that has been prescribed.²³ In turn, the patient may feel that he or she is not receiving the full benefit that modern medications can offer. Perception that the presence or absence of a particular medication represents a health threat may be particularly acute among patients with chronic illnesses who are already taking one or more long-term medications.^{11,15,17,21,24}

The patient may be concerned not only about the medication but also about the illness and diagnosis. The patient may find that the physician’s diagnosis is not congruent with his or her personal understanding of the illness.¹⁹ A patient who fears a diagnosis or who has not accepted the diagnosis may question the need for a medication and worry about exposure to an unnecessary and potentially harmful drug.^{14,25,26} A study on the use of bronchodilators and steroid puffers by patients with asthma included examples of how a patient’s acceptance and understanding of the illness can influence the decision to self-tailor medication.²⁷ The study subjects were patients with asthma for whom a corticosteroid puffer (a preventor) and β -agonist (for

symptom control) had been prescribed over the previous 12 months. On the basis of the study results, the investigators identified 2 subgroups. One subgroup consisted of patients who used the bronchodilators as prescribed but chose not to use the steroid inhaler. Members of this group, termed “deniers”, did not believe that they had asthma; instead, they thought they had some problems with their breathing. Using a “preventor” medication for a diagnosis that they did not believe applied to them was perceived as unnecessary, and they relied on the symptom-controlling puffers to relieve their perceived problem of shortness of breath. The other group, termed “acceptors”, consisted of patients who believed that they had asthma and who were therefore willing to use both medications.

The patient’s perception of a medication-related health threat, as illustrated in the preceding examples, is partly a product of his or her own mental model of the illness and medications.^{13,20} A mental model is a cognitive idea, picture, assumption, or belief through which the patient filters information before using that information to make decisions about his or her health.²⁰ If the mental model is inaccurate or incomplete, the patient may reject necessary information or interpret the information incorrectly.

During a clinical encounter with a health care provider, a patient may make comments or refer to decisions that on the surface do not make sense to the health care provider. It is during such moments that it may be useful to examine the notion of mental models and the impact such models may have on the patient’s concerns and perceptions of a medication-related health threat. If an inaccurate or incomplete mental model is identified during a conversation with the patient, then the health care provider can use this as an opportunity to clarify facts or provide more complete information. This information can help to replace an existing mental model that may be interfering with full understanding. But if the health care provider does not make the effort to identify the inaccurate mental model, the situation will likely continue: the health care provider will feel that adequate information is being provided, but the patient will persist in self-tailoring the medication to match the existing mental model.

Examples of mental models can be identified in various studies on medication self-regulation. The following is a list of some of the mental models that patients commonly hold with regard to medications:

- Medications are poisonous.¹⁵
- You should not take any medications unless it is absolutely necessary, and then you should use as little as possible.¹⁵

- High blood pressure may or may not be a disease.
- Shortness of breath means that you have a “small” breathing problem; it does not mean you have asthma.²⁷
- You cannot take all of your drugs at once; rather, you need to spread them out through the day.²²
- Medications save lives.²¹
- Medications can build tolerance and are addicting.²⁶

If information or advice provided by the pharmacist concurs with the patient’s existing mental model, the patient may be more likely to accept that information or advice. In such cases the patient may be less likely to perceive a situation as a medication-related health threat and more likely to adhere to the medication regimen as prescribed. If advice conflicts with the patient’s existing mental model, then the patient may be more likely to perceive the situation as a medication-related health threat and to engage in a coping procedure such as self-regulation of medication.

On discovery that a patient is self-regulating a particular medication, the pharmacist needs to remember that such a situation does not necessarily reflect failings in the patient, the doctor, or the system.²⁶ At this point, the pharmacist might reflect on what he or she knows about the first stage of the Common Sense Model and attempt to initiate a conversation with the patient so as to reveal the patient’s mental models and better understand the perceived medication-related health threat. At that point, it becomes possible to directly address the patient’s mental model of the illness. This must be done carefully to ensure that the patient feels safe in disclosing information. The pharmacist’s goal is to gain an understanding of the cognitive and emotional path that the patient has followed in concluding that there may be a medication-related health threat.

From the author’s experience in family practice, specifically through encounters with many patients who were self-regulating their medications, it is clear that there is no single perfect question by which to effectively initiate such a conversation. Each patient is unique, and so is each practice situation. It is essential to look for cues to guide this aspect of practice, especially nonverbal cues such as physical gestures, tone of voice, and eye contact, while listening to the patient’s description of concerns. It is important, too, to acknowledge that patients often wrap their medication experiences into their stories; the pharmacist must therefore be an active listener and attend to cues hidden in the stories. Picking up on these cues, exploring the patient’s concerns, and ultimately uncovering existing mental models may create an opportunity to provide tailored medication information that will enhance the

patient’s understanding of the illness and the medications. In turn, this may allow the patient to reassess the presence or severity of a medication-related health threat.

Stage 2: Action Plan or Coping Strategy

Once a patient has identified a potential concern or health threat, he or she moves to the next stage of developing a coping procedure, a plan to address the problem.²⁰ With respect to medications, the patient may try to negotiate with the prescriber to reduce or stop the medication as a way to monitor its efficacy. Depending on the relationship between the patient and the prescriber, this negotiation may or may not result in a coping strategy that is desirable to the patient. Other patients may test or experiment on their own to see how the illness responds to changes in medications.¹⁴

The literature describes 4 action plans that patients typically follow in the presence of a perceived concern or health threat, all of which pertain to medication use.

- The patient continues to accept the prescribed therapeutic plan even if there is a concern. Such a patient usually trusts the physician and is highly motivated to follow the physician’s instructions.¹⁴
- The patient rejects the therapeutic plan completely. Dowell and Hudson¹⁴ have characterized such patients as “non-believers”.
- The patient may suspend the therapeutic plan or may postpone starting the therapeutic plan.²⁷
- The patient may explicitly self-tailor the prescribed therapeutic plan (i.e., tailoring, testing).^{10,11,14-17}

The last of these action plans, self-tailoring of medications, is relatively common. Anywhere from 24%^{15,16} to 70%^{10,11} of patients self-regulate their medications at one time or another. The patient may adjust medication-taking over the course of a single illness.¹⁰ A patient receiving long-term medication may make decisions on a drug-by-drug or dose-by-dose basis. The latter strategy has been observed in HIV-positive patients.²⁸

During a clinical encounter, a key step is to determine if the patient is self-regulating a medication or has rejected a medication. This may be more easily discovered if the pharmacist has already established a relationship with the patient or the patient is confident and experienced in navigating the health care system, but the situation is usually not so simple, as many patients will not be well known to the pharmacist, in which case the pharmacist will have to probe for cues. One example of a cue would be determining whether the patient’s report of how he or she uses the medication throughout the day matches the instructions on the prescription vial. The patient may initially



describe following the medication regimen as prescribed, but answers to further questions (such as “How is the medication working?” and “Have you had any problems with your medications?”) may indicate that the patient has experimented with different regimens. For this purpose, it is useful to focus on the specifics of self-regulation, asking when, what, and how. Glean detail by prodding (e.g., “Can you tell me more about that?”) to gain a clearer understanding of how the patient takes the medications and how the patient thinks and feels about the medications.

During conversations with a patient who self-regulates medications, it is important to remember that the patient deserves and requires respect even if a particular alteration to the prescribed regimen appears irrational, bizarre, or dangerous. The patient believes his or her actions to be rational and aimed at reducing an actual or potential medication-related health threat. In the author’s experience in family practice, some patients have proved very insightful and have devised action plans that were not only effective but also, in the long-run, correct courses of action.

Stage 3: Appraisal

After implementation of the action plan to address a specific health threat, the patient assesses the plan’s effectiveness.²⁰ This appraisal uses patient-selected criteria because these are what the patient believes are relevant to the perceived health threat. However, these are usually “lay” criteria, which may be alien to health care providers. For example, Viswanathan and Lambert²¹ described patients who felt that they could tell when their blood pressure medication was working because their headaches resolved. In the study of asthmatic patients who were given steroid puffers and bronchodilators, those who did not use their steroid puffers regularly and who experienced immediate improvement in breathing after using the bronchodilator felt that they had made a rational decision to use primarily the bronchodilators and not the steroid puffers.²⁷

During the appraisal stage, the patient’s perception that sufficient progress has been made in relieving the health threat both reinforces the original representation of the health threat and also validates the choice of action plan.²⁰ If the patient perceives that sufficient progress has not been achieved, he or she may modify the original representation of the health threat (stage 1) and/or modify the action plan (stage 2). Thus, the cycle continues until the patient is satisfied that the perceived health threat has been resolved.

The third stage of the Common Sense Model suggests that pharmacists need to deliver strategically

selected medication information that is based on an initial exploration of the patient’s medication experience and the patient’s criteria for appraising his or her own plan of action. By taking this approach, the pharmacist may identify specific gaps in the patient’s knowledge about the disease or medication. Consequently, the patient may appraise the effectiveness of the action plan in a more informed way and in turn modify the original representation of the medication-related threat and/or the decision to use self-regulation of the medication as the action plan to solve the perceived problem.

CONCLUSIONS

Decisions that patients make at the 3 stages of medication self-regulation, as described in the Common Sense Model, can be complex and are influenced by emotions, cognitive ability, sociocultural factors, psychological traits, and personality.²⁰ Understanding the 3 stages of the Common Sense Model may allow the pharmacist to more effectively deliver information or education to a patient such that it will influence the patient’s thinking about his or her illness and medications. In turn, this may influence the patient’s decision to take the medication as prescribed.

It is widely accepted that the education that pharmacists provide to patients must be individually tailored. With so many factors influencing patients’ decisions to self-regulate medications, how should the pharmacist decide on the type of medication information, communication, or education to provide to an individual patient?

Medication education can no longer focus solely on the immediate enforcement of compliance with a prescribed regimen. This approach will not address the processes used by the patient to self-regulate medication, as described above. The primary reason for intentional nonadherence with a medication regimen is that people construct their own meanings about illnesses and medications which empower them to advocate for their own health and to have their concerns addressed. Health care providers’ reassessment of their own mental models of patients’ actions related to medications will be key. Such a reassessment could lead to consideration and recognition of the patient’s perspective, which will in turn create a new framework that will guide the health care provider to better tailor medication information to meet individual patient needs.

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Jana Bajcar, BScPhm, MScPhm, EdD, FCSHP, is Associate Professor, Leslie Dan Faculty of Pharmacy, University of Toronto, Toronto, Ontario.

Address correspondence to:

Jana Bajcar
 Leslie Dan Faculty of Pharmacy
 University of Toronto
 19 Russell Street
 Toronto ON
 M5S 2S2

e-mail: jana.bajcar@utoronto.ca

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