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Adherence: only the patient can tell us

Research suggests about half of patients with chronic conditions do not take their medicines as prescribed. This results in poorer outcomes, wasted resources and increased costs, so gaining greater understanding of how patients view their conditions may provide important and timely insights, suggests Alan Wade in this second article in his series.

In recent years, great advances have been made in developing treatments to tackle illnesses that were beyond the reach of medicine only a few decades ago. Large amounts of time, effort and money continue to be invested in attempts to uncover novel therapies based on drugs that are both effective and safe. Yet, despite this, it is estimated that among patients with chronic illnesses, approximately half do not take medications as prescribed. This low level of adherence results in poorer outcomes, wasted medicines, higher mortality rates and costs of approximately $100 billion per year.[1-3]

Sometimes, of course, non-adherence is unintentional. Patients may forget to take their medication, fail to understand the instructions or simply be unable to afford the treatment.

"Illness and medication beliefs are important determinants of adherence across a range of diseases"

Intentional non-adherence, however, happens when patients makes a conscious decision not to follow the treatment recommendations, often because of their attitude towards the illness and/or their treatment. Patients appear to make decisions about medicines based on an understanding of their condition and may balance their need for medication and the likely benefits it may bring against any concerns they have about the risks involved in taking it.[3-5] Indeed, it has become clear that illness and medication beliefs are important determinants of adherence across a range of diseases.[4, 6, 7]

Psychological frameworks, such as the Health Belief Model (HBM), have been used to try to explain and predict health behaviours by focusing on patient attitudes and beliefs.[8] The HBM suggests that adherence depends on factors such as a perception of vulnerability to the illness, a view of the likelihood of serious consequences arising from it, an evaluation of how effective a treatment is likely to be in dealing with the illness and the costs and difficulties involved in following any particular healthcare advice.[9]

In an HBM-based questionnaire study to investigate reasons for refusal of human papillomavirus (HPV) vaccination among female university students in Greece, participants who had high scores for 'perceived barriers' and 'no perceived benefits' were more likely to report being unvaccinated – demonstrating the usefulness of the HBM in understanding vaccination uptake.[8]

Trying to understand exactly how patients view their conditions might provide important insights into why they may choose not to adhere to prescribed medication. The Common Sense Model (CSM) of self-regulation proposes that patients form mental models of their illness based on characteristics such as symptoms, causes, expected progression, consequences and the level of control that might be exerted over the disease, with or without treatment.

In addition to a mental model, the CSM suggests that patients also form an emotional model of their illness, which accounts for sentiments such as anxiety that may be elicited by disease-related experiences. These inputs influence patients' responses to their illnesses, including medication adherence. Studies using the CSM to investigate medication adherence in asthma patients showed that misconceptions about the illness and the necessity of therapy were associated with lower odds of adherence.[6]

Other perceptions affecting adherence might be linked with particular types of illness. For example, it has been shown that the treatment of asymptomatic diseases may be associated with non-adherence. When symptoms are absent or intermittent (eg. in asthma, hypertension or inflammatory bowel disease), daily medication may seem unnecessary.[2, 4] Long-term illnesses may also have an effect on perceptions influencing adherence. For example, misconceptions regarding the natural progression of chronic conditions have been shown to be associated with low adherence in patients with asthma, diabetes and congestive heart failure.[6]

Certainly, patient attitudes towards medication are of crucial importance. In a study by Svensson *et al*, for example, adverse effects were the most commonly listed concern among patients who did not adhere to their antihypertensive medication.[10] Similarly, in a cohort of urban, minority adults with chronic obstructive pulmonary disease (COPD), concerns about medications were found to be important predictors of non-adherence.[6] Even when medication is well tolerated, patients may worry about its cost, the possibility of becoming dependent or the long-term effects of their treatment.[4]

It is also important to consider that different patient groups may have particular attitudes that could affect adherence. In a study done by Aikens *et al* to explore characteristics associated with negative beliefs surrounding the use of antidepressants, it was found that the most sceptical patients were those who were younger and new to antidepressants, those who viewed their symptoms as mild and temporary and those who were unclear about the factors affecting their depression.[7] In the study performed by Donadiki and co-workers on female Greek university students, it was found that smokers were more likely to refuse the HPV vaccine – perhaps indicating that less healthy lifestyle behaviours reflect reduced concern for preventative practices.[8]

Sensitivity to patient beliefs and concerns is also important and adherence is likely to be enhanced when patients are involved, whenever possible, in decisions about their treatment.[1, 2] Indeed, Svensson and co-workers found a direct link between adherence to antihypertensive medication and trust in the physician.[5, 10] Social support and the perceived views of family and friends may also play an important role in promoting adherence.[11]

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It is clear, then, that non-adherence is a challenging problem and adherence continues to be low. It is generally accepted that patient education will prove the answer to the problem. However, appropriate education can only be provided if patients' attitudes and beliefs about their illness and the risk and benefit of treatment are understood. Collecting this information has been challenging, with patients uncomfortable about expressing negative views to health care professionals.

Adopting a patient-centric approach may help patients feel empowered to respond to an invitation to share their experiences and report directly via web-based questionnaires. Many patients come from populations which do not necessarily have easy online access and so in order to provide a representative cross-section of most populations it is necessary to provide an alternative multilingual telephone service.[12]

Data accumulated in this way could form a basis for the development of educational programmes aimed at tackling the problem of non-adherence. So, for each disease and for each treatment, understanding the patient's perspective will be vital - and only the patient can tell us what he or she thinks.

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His second company, Patients Direct, has the specific purpose of collecting patient reported naturalistic, real-world data. It is currently being employed in areas as diverse as childhood rheumatoid disease, influenza vaccination and depression.

In addition to his clinical interests, Wade regularly gives presentations at international meetings, publishes in the medical press and sits on advisory boards.

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