
Reframing Adherence: Collaborative Enactment of Healthcare

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Abstract

A major impact on health outcomes is what has traditionally been termed the patient's compliance with medical advice, including medication regimes and lifestyle changes. More recently the industry has come to prefer the term medical *adherence*, intending to reflect that patients and providers share collective responsibility for outcomes. In practice, this remains a distant goal, and focus continues on individuals' ability to follow medical advice. We believe social computing can help providers and patients engage collaboratively with each other throughout the lifecycle of a care plan and outline our approach.

Author Keywords

Social computing, medical adherence, care plan.

ACM Classification Keywords

H.5.3. Information interfaces and presentation; Group and Organization Interfaces; Collaborative Computing

General Terms

Human Factors

Introduction

Medical adherence is an important topic in healthcare because it has significant effects on treatment outcomes. Two high-level summary statements emerge

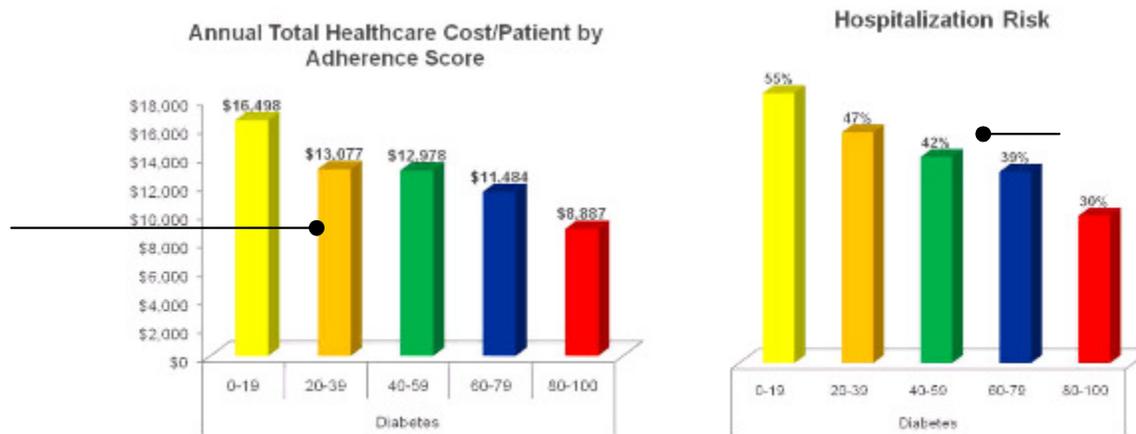
from the voluminous literature on medical adherence. First, medical adherence – defined as “... the patient’s participation and engagement in maintaining a regimen he or she believes will be beneficial ... for the self-management of disease” [1] – or more specifically, the *lack* of medical adherence is expensive to individual patients and to society as a whole [1,2,3]. Overall, 10% of hospitalizations and 25% of nursing home admissions are attributed to the lack of adherence with prescribed medication treatments [1]. An example of the relationship between adherence and healthcare costs is shown in Figure 1. Not only is this costly in terms of money, time and quality of life for individuals, it also contributes to increases in the cost of medical care and decreases productivity for society as a whole. For an individual the cost of non-adherence may be temporary, as when resumption of a medication regimen reinstates effective blood levels, but non-compliance can also render a treatment permanently ineffective, as is the case with HAARTS (highly active antiretroviral therapies) [2]. At a societal level, incomplete adherence to a course of antibiotics for a disease such as tuberculosis may result in the development of antibiotic resistant strains that are known to increase the entire range of aforementioned costs [3].

The second summary statement that emerges from the medical adherence literature is that adherence is a multi-faceted problem. The degree of adherence varies on factors at the intrapersonal, interpersonal,

organizational, community and policy levels [4] as well as characteristics of the regimens themselves [5]. For example, adherence to treatments entirely constituted by prescribed medication is significantly higher than adherence to treatments that require lifestyle changes, for example, changes in diet [5]. Similarly, levels of adherence vary by such factors as the amount of social support the patient enjoys, the effectiveness of communication between patient and healthcare provider, and the presence of a diagnosis of psychiatric illness or substance abuse in the patient [2, 5, 6]. This description suggests that social computing may provide valuable leverage in addressing a broader range of influences on adherence.

Reframing Adherence

Healthcare providers, of course, have been concerned with patient compliance for as long as there have been physician-created care plans. In recent years, the industry has shifted its terminology from *patient compliance* to *medical adherence*, signifying a desire to emphasize that providers and patients share a “collective responsibility” for health outcomes, and that patients must be active participants in their own care. Engaging patients more actively in their care and encouraging them to take greater responsibility for their health outcomes is not only a good idea, but one that has become increasingly necessary in the current climate of the healthcare in the U.S., if not worldwide.



Source: Michael C. Sokol, MD, MS, Kimberly A. McGuigan, PhD, Robert R. Verbrugge, PhD, and Robert S. Epstein, MD, MS, Impact of Medication Adherence on Hospitalization Risk and Healthcare Cost, *Medical Care* • Volume 43, Number 6, June 2005.

Figure 1. The relationship between diabetes patient adherence and cost factors (total healthcare cost and hospitalization risk). Downloaded from <http://pharmsolutions.org/MedRx.aspx>, January 13, 2012.

We note that despite the laudable intent behind this terminology shift that the practice of administering care plans to patients and the culture of interaction between providers and patients has not substantially shifted. We argue that the notion of adherence is still overly focused on the performance of the patient against medical recommendations – that is, it has not significantly shifted the discourse or practice away from compliance, and has not managed to take the notion of collective responsibility and collaboration seriously.

The premise of our project, consistent with [4], is that medical adherence needs to be reframed as a long-running activity in which providers and patients collaborate to co-create, enact, evaluate, and monitor the efficacy of a care plan. This requires shifting the usual discourse based largely on the asymmetry of knowledge and power between providers and patients and the concomitant dominant conceptualizations that govern ideas about how to improve adherence (e.g., better patient education, better validation of patient-reported compliance, coaching/encouraging patients to “do better” at complying, etc). It is not that these behaviors or ideas are wrong or undesirable, but that

at their heart they do not invoke a collaborative framework or mentality of collective responsibility. The perspective offered here explicitly recognizes that providers are expert at some parts of the health plan (e.g., what the goals should be, the medication regime to be tried, etc), and patients are expert at other relevant parts (e.g., details of their context, practical obstacles and facilitators to adherence, the implications of integrating multiple providers' recommendations, and of course how they feel and behave on a daily basis).

The goal of this project is to enhance medical adherence by taking seriously its reframing as a collaborative enactment between providers and patients. This involves not only recognizing the multiple layers of factors that impact adherence [1], but supporting the particular and situated context of each patient and their social and caretaker networks (lay and professional). This approach puts the focus on providers and patients taking collective responsibility for creating, acting on, monitoring & evaluating, and adjusting the care plan over time through specific designs that treat patients as critical players in their health. Crucial elements of our approach include: 1) creating effective (technical and non-technical) (social) mechanisms that increase the desire and ability of patients to actively take responsibility for their care plan, including capturing and using daily data; 2) increasing the appreciation of providers for patients' areas of expertise and contributions to a successful care plan in a way that is

meaningful and visible to patients and that shifts the dialogue from a "test about compliance" to an active "partnership for health," as well as increasing providers' knowledge of patients' actual behavior; and 3) to define a balanced set of metrics to help providers and patients to evaluate the efficacy of the care plan on an ongoing basis.

Our project is at its beginning; we are planning to build and test a prototype for a particular patient subpopulation | chronic disease (e.g., hypertension). We anticipate that the design of the prototype will draw on notions of self-assessment, social dynamics (peer pressure, imitation, reputation), social gamification, life logging, and collaboration/communication with care coordinators and providers. A key research question is whether a well-designed social application can inspire patients to capture and make use of daily data about their lives, including activity, well-being, etc. – whether or not they are inclined to share it with others in their social network or with their care providers.

With respect to the theme of the workshop of bridging clinical and non-clinical settings, adherence is by definition a phenomenon that spans these settings. We hope we can contribute some thinking about how social computing might play a role in creating an active collaboration between patients and care providers, and hope that the workshop will also teach us how clinical and non-clinical settings are being bridged in other ways and with respect to a variety of health-related issues.

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