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Non-Adherence: A Symptom of the Current Health Care Model

Margaret Duggan
Sociology Honors Thesis
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Patient non-adherence is an issue of concern across the medical field. Most commonly, rates of adherence represent the percentage of the prescribed dose of medication that is actually taken by the patient over a specified amount of time. Adherence, however, extends beyond pharmaceuticals. The World Health Organization (WHO) adherence project defines adherence as, “The extent to which a person’s behaviour - taking medication, following a diet, and/or executing lifestyle changes- corresponds with agreed recommendations from a health care provider” (WHO 2003:3). It is difficult to obtain a precise measurement of adherence, but studies place the average rate of non-adherence between 30 and 60 percent (Meichenbaum and Turk 1987:21). The lowest rates of adherence are recorded among those with chronic¹ disorders (Meichenbaum and Turk 1987). Research studies have found that the average rate of adherence to medications among patients suffering from chronic diseases² such as HIV or AIDS falls to only 50% (WHO 2003:7). More than 70% of patients fail to enact permanent lifestyle changes such as diet and exercise (DiMatteo 1993:298). Noting these difficulties, researchers have sought “innovative interventions” to help patients adhere. While some of the proposed interventions use new technology, such as electronic medication monitors or beepers that remind patients to take their doses, many approaches have to do with strengthening a weak relationship between doctor and patient, and simply taking the time to ask a patient about their adherence, including surmounting obstacles in the health care structure that decrease their ability to adhere.

¹ WHO defines chronic disease as, “Diseases which have one or more of the following characteristics: they are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation or care” (WHO 2003:4).

² The WHO adherence project has defined chronic disease as, “Diseases which have one or more of the following characteristics: they are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation or care” (WHO 2003:4).

Sociologists have long been interested in health and the health care system, but only slowly has the literature begun to acknowledge system-level factors, in addition to the individual-level factors that still tend to be the focus of investigation. Sociologist Marshall Becker explains that we have a tendency in the United States to emphasize the capacity and importance of individual agency. This theme, when applied to health, results in “locat[ing] the responsibility for the cause and the cure of health problems in the individual” (Becker 1993:3). Note two major assumptions that underlie this approach: personal health-related behaviors are discrete and independently modifiable; and anyone can decide to alter his or her behavior and then do so (Becker 1993:3). However, this paradigm of thinking ignores the fact that individuals frequently “encounter barriers that block their capacity to maximize health” (Link and Phelan 2005:78). When addressing issues of adherence, it is essential that **all** potential barriers be considered: those under the patient’s control; interactions between the patient and the health care provider; interactions between the patient and the health care system, and the relationship between patient and the larger societal structure (Osterberg and Blaschke 2005). Changes must be multi-factorial if they are to prove effective in helping a wide range of patients (Osterberg and Blaschke 2005; Meichenbaum & Turk 1987). Amid an increasing arsenal of medicines, low adherence continues to undermine their potential benefits. Progress will remain at an impasse until the issues around non-adherence are addressed with respect for its dynamic and complex nature, and a greater focus on the gaps within current discourse. That adherence continues to be an issue after several decades of study, and an effective resolution still eludes the medical practice, only confirms that there is no quick fix, no “magical formula,” or “universally effective solution”. Any plan to enhance adherence

must be customized to address the particular needs of individual patients. The inclusion of the influence of structural factors will help to remove *blame* from the individual and refocus attention on the interplay between the individual and the health care system as an institution. Any chance of finding effective solutions will involve broadening our discussion. “By locating the source and the treatment of problems in an individual, other levels of intervention are effectively closed” (Zola 1975:182). Most notably, the health care system itself, with all of its complexities within our social, political, and economic world, has been absolved of responsibility.

Part of the reason for this narrow focus is the way the discussion of adherence is framed. As sociologist Erving Goffman has emphasized, the framing of any discussion is extremely important. He warns of falling into the “analytic flaws and failures that arise from our unthinking acceptance of the constraints of conventional thinking” (Becker 2003:660). As will be explained later in this paper, compliance is a loaded term and by using it we run the risk of overlooking important aspects of the issue. It narrows discussion and focuses it on preconceived thinking, analyzed within the conventional framework. The words and framework used to approach a subject come embedded with socially constructed assumptions and ideas. Applying his frame analysis, Goffman sees frames as being unconsciously adopted during our discursive processes and subsequently manifesting themselves in the cognitive structures that guide our perceptions and representations of reality. Frames thus structure which parts of reality are noticed (Konig) and they become powerful tools with real societal impact, affecting our actions and reactions to social problems. While Goffman conceptualizes frames as an innate property of social interaction, framing can also be used deliberately, to “select some aspects of a

perceived reality and make them more salient in a commentary text, in such a way as to promote a particular problem definition, causal interpretation, moral evaluation, and/or treatment recommendation” (Konig). To date, the discourse around patient non-adherence has been framed to place blame on the individual patient while reducing the responsibility of providers and policy makers. This conceptualization of the problem has then affected the way in which interventions are created and implemented.

For decades, researchers and clinicians have sought reliable methods to assure patient adherence. However, their efforts have been met with only limited success. Since the mid 1970s, when interventions started being proposed, researchers and clinicians have mostly framed noncompliance as both a definable and potentially “fixable” problem, a scientific problem that researchers can study and correct by implementing an intervention program (Lerner 1997:1427). The glaring limitation of this approach is that it neglects the fact that adherence is a dynamic phenomenon that operates within the larger structure of the health care system and society as a whole. Individual-focused intervention will not be a long term fix; structural issues must also be addressed.

The structure of the health care system has changed, but current approaches have been particularly unable to balance the complex relationship between health care and the economy. As health care becomes subjected to the values of the marketplace, as is the current trend, institutions must alter their standards to survive within said constraints. Market driven care poses a serious dilemma for providers: “On the one hand doctors are expected to provide a wide range of services, recommend the best treatments, and improve patients’ quality of life. On the other, to keep expenses to a minimum they must limit the use of services, increase efficiency, shorten the time spent with each patient, and

use specialists sparingly” (Kassirer 1995). In many cases, doctors are being forced to choose between their patients’ best interests and their own (the doctors) jobs and livelihood. Productivity, not quality, becomes the new objective. Attempts to maximize profits are creating perverse incentives and unacceptable outcomes. There is reason to be concerned that continued attempts to bring “market efficiency” to a sector that is inherently extra-market will further negatively impact the provision of care (Kuttner 1996). At 16% of the gross domestic product, the United States spends more than any other country on health care, and spending continues to rise at the fastest rate in history (NCHC 2004). However, high spending alone does not necessarily equate to good care. High levels of non-adherence are just one warning sign that provision of care has not kept up with technological and structural change.

This paper aims to provide a systematic review of the discourse surrounding patient adherence in an effort to illustrate the extent of the problem, how it is framed, and how intervention is currently approached. The paper begins with a general review of adherence, to ground the reader in the current discourse. The next section of the paper will focus specifically on adherence through the lens of HIV/AIDS. Since HIV/AIDS treatment and adherence to antiretroviral drugs is pertinent to adherence issues due to the complexity and lifelong duration of treatment. Furthermore, adherence with HIV/AIDS medications is particularly important due to the high potential for harder to treat, drug resistant strains when drugs are not taken exactly as prescribed. A national survey of 1080 HIV patients discovered that 78% of those with >500 copies HIV RNA/mL had drug resistant virus, and one fifth of treatment naïve patients had resistant virus (Finkelstein 2002). Clearly, drug resistance is a spreading problem, and only makes

treatment of HIV/AIDS more difficult. The paper then will move to discuss and analyze non-adherence and targeted interventions in relation to the current marketization of health care. Though less pursued due to the current way of framing discourse, an analysis of the literature on adherence and adherence interventions illustrates that non-adherence is, in part, a manifestation of the troubling direction that the health care system is moving.

Non-adherence has been an issue since the early days of medicine, so by no means can it be argued that the current model of care is wholly to blame. Some patients will forget to take their medication, not exercise, or not follow a diet, no matter how close a relationship they have with their provider, or how accessible care is made by their insurance company. However, a look at the interventions suggested to improve adherence, specifically those that involve strengthening the doctor-patient relationship, reveals several areas in which the health care system is sorely lacking and must improve upon in order to first establish a solid foundation from which to provide care. In short, by focusing on the individual and de-emphasizing structural constraints, the current model is not set up to provide high quality care to all patients.

Although these interventions are commendable they must occur in tandem with a larger reconceptualization of medicine and medical care. Furthermore, implementing many of the proposed interventions will not even be feasible to implement in the current clinical climate due to an emphasis on cost and time. At the root of non-adherence is the need for a fundamental change in the way health care is provided. It should be no surprise that getting to know a patient, developing a cooperative, trusting, and respectful relationship, and fitting the regimen to the patient's lifestyle, will enhance adherence. Moreover, it is detrimental to talk of the services provided in these interventions as

innovative above and beyond standard care, as is too often done in today's model, and to focus on the added time and cost. By framing something as extra it suggests that it is optional, not expected in standard care. Furthermore, the individual-level focus of these interventions reinforces a model of patient blame. Addressing adherence outside of the broader context of the health care system only sets us up for failure. Rather than narrowly approaching the issue of adherence with band-aid fixes, it would be wise to target broader changes in the structuring of the health care system and in the provision of care.

Adherence

In an area where efficacious therapies exist or are being developed at a rapid rate, it is truly discouraging that one half of patients for whom appropriate therapy is prescribed fail to receive full benefit through inadequate adherence to treatment.

(Haynes 1976:26)

As new discoveries expand our ability to control disease processes, the list of health-enhancing circumstances will only grow... people who command more resources will, on average, hold an advantage in gaining access to and benefiting from this new knowledge.

(Link and Phelan 2005:74)

The majority of compliance research has been carried out by the health care providers and by the pharmaceutical industry. The focus has been on the extent and the possible determinants of non-compliance as a failure on the part of the patient, rather than on the shared responsibilities of doctor and patient.

(Vermeire et. al. 2001:9)

The medical field has made great progress over the past 50 years in terms of advances to help improve the clinical outcome of many diseases: the development of antibiotics to treat infectious disease in the 1950s, medications to treat hypertension in the 1960s and 1970s and highly active antiretroviral therapy (HAART) to treat HIV in the 1990s. HAART, a combination of antiretroviral agents, was a celebrated advancement in

the treatment of HIV/AIDS. It has proven highly effective in reducing viral loads and improving clinical outcomes, but near perfect adherence ($\geq 95\%$) is required to achieve these positive results (WHO 2003). Advanced scientific ability has overshadowed the need for the nuts and bolts of quality medical care. Scientific advances are only effective if used appropriately. Low adherence has been shown to produce unsuccessful treatment outcomes, and non-adherence has also been linked to the spawning of mutated, drug-resistant strains which are more difficult to treat and can be transmitted to others. Patients have been known to be non-adherent since the days of Hippocrates but the growth in the number of effective medications, especially those that treat chronic diseases, where non-adherence is particularly problematic, called attention to the issue of non-adherence between the late 1950s and 1970s. Unfortunately, continued research has yielded few improvements or new insights since the 1980s (Vermeire et. al. 2001). This failure is due in part, to the narrow framing of the adherence problem, and neglect of the interplay between the individual and structural levels.

“The Language of Medication-Taking”³

The terms “compliance” and “adherence” are often used interchangeably. Both terms are used in literature and discourse when discussing the extent to which a patient follows a treatment regimen as prescribed by their health care providers (Osterberg and Blaschke 2005). Osterberg and Blaschke (2005), in their article *Adherence to Medication*, argue that while both terms are “imperfect and uninformative descriptions of medication-taking behavior... and applying these terms to patients who do not consume every pill at the desired time can stigmatize these patients” (1), “adherence” is preferable to

³ The title of an article by Steiner and Earnest (2000).

“compliance,” because the latter suggests that “the patient is passively following the doctor’s orders and that the treatment plan is not based on a therapeutic alliance or contract established between the patient and the physician” (1). Vermeire et. al. (2001) concur in *Patient adherence to treatment: three decades of research. A comprehensive review*, that compliance is a word that carries negative connotations: “Non-compliance is failure or refusal to comply and can imply disobedience” (2). However, they found in their review that the majority of papers used the term compliance rather than the two alternates they discuss, adherence and concordance, which only proves the dominance of the compliance framework.

The terms adherence and concordance are proposed as alternatives that aim to lessen the sole power of the doctor in the doctor-patient relationship and to put more emphasis on harmony between the two, emphasizing the role of the patient as a decision maker. Meichenbaum and Turk (1987) agree that “*noncompliance* incorporates an evaluative concept that may imply a negative or prejudicial attitude toward the patient and often presumes that failure to comply is the patient’s fault” (20). They choose to use the term “adherence” in their text believing that it implies a “more active, voluntary collaborative involvement of the patient in a mutually acceptable course of behavior to produce a desired preventative or therapeutic result” (Meichenbaum and Turk 1987:20). The World Health Organization (2003), in support of a systems approach, concur that “adherence,” as opposed to “compliance,” “is a better way of capturing the dynamic and complex changes required of many players over long periods” (v).

Drawing on the work of Goffman, Howard Becker (2003) uses the example of marijuana to illustrate how the words we choose structure our collective attitudes and

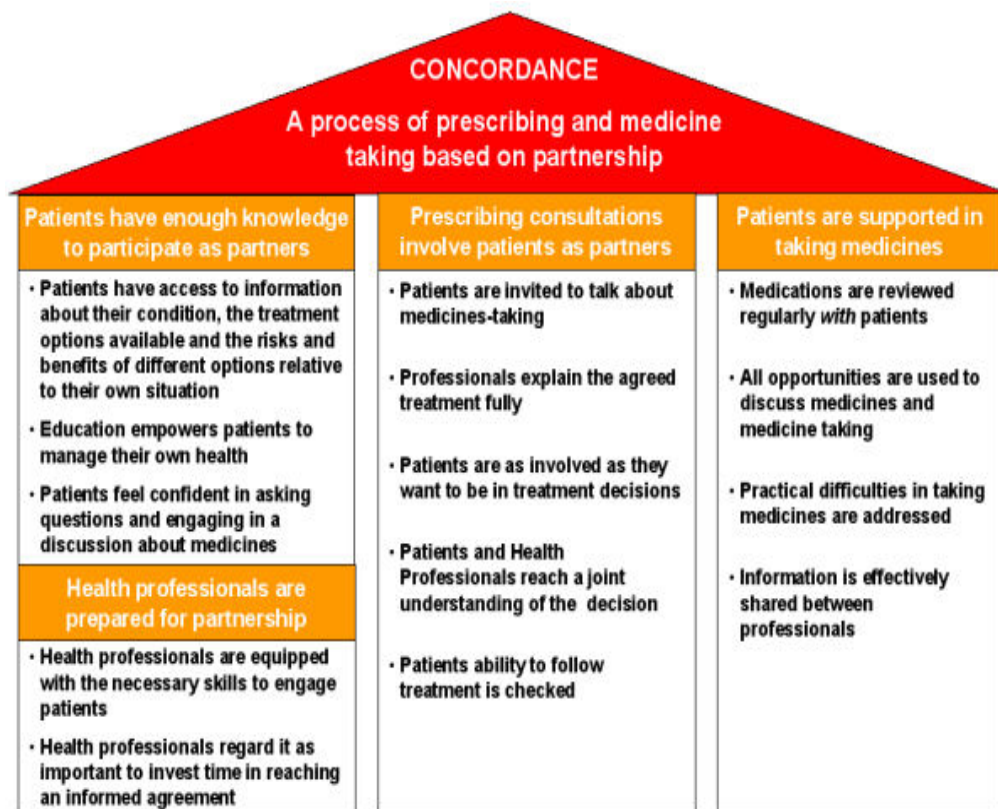
understandings. People who use marijuana use different terms from those used by physicians, lawyers and police. Users speak of “getting high,” not “addiction”. Users call it “grass,” while physicians call it “cannabis;” users buy from their “connection,” not a “pusher”. The language choice greatly influences how people evaluate the use of marijuana. That is, a user’s language suggests it is voluntary, pleasurable and innocent, but the police officer or lawyer’s language frames it as involuntary, illegal and harmful. A similar discourse analysis of the term noncompliance reveals how doctors and researchers have developed this term to describe patient behavior. It expresses the doctor’s understanding of patient behavior, but not the patient’s experience. Without patient input, doctors and researchers will largely work off of stereotypes and generalizations, which will then be taken as fact and made into treatment recommendations. Simply put, language is important because it frames our knowledge and thus, importantly, our actions. Max Weber, German sociologist and political economist, defined power as “The chance of a man or a number of men to realize their own will in a communal action even against the resistance of others who are participating in the action” (Weber 1946:39). As Becker points out, it is most often those who are in a position of power who choose the language and thus frame the discussion and ultimately the policy around an issue. In this case, those in the positions of power are doctors and health care executives, with a vested interest in shifting blame and responsibility away from themselves, onto the patient. In adopting the existing language around drugs we promote “the idea that addicts are people who have lost control of themselves and therefore cannot help doing things which are inherently bad” (Becker 2003:662). Likewise, by using the term “noncompliant,” we reinforce the conception of a submissive

patient, who is to follow treatment directives, and if he or she fails to do so, it is he or she, as an individual, who is to blame.

The search continues for more neutral terminology. Following a report from the members of a working party of the Royal Pharmaceutical Society of Great Britain on medicine taking, the Royal Pharmaceutical Society has made a paradigm shift from compliance to concordance (Vermeire et. al. 2001). The term “concordance” indicates a valuing of the patient’s perspective and thus places an emphasis on the consultation process. This alternate framework acknowledges the patient’s personal knowledge of his or her body’s experience of illness and treatment. While a patient’s expertise may be different from the Health Care Provider’s (HCP⁴) scientific expertise, the patient’s views are of equal relevance and value in formulating a treatment plan (Weiss and Britten 2003). The “concordance package” includes exploring patient medication concerns and working cooperatively with the patient to develop a treatment program (Weiss and Britten 2003). The goal is a “therapeutic alliance,” rather than one-sided power. Framing the discussion under the concordance model, rather than using the patient-blaming language of compliance, will also encourage a broader, multi-faceted approach to care. The Working Party argues, “[concordance’s] strength lies in a new assumption of respect for the patient’s agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust and concealment” (Bissell 2003:498). The diagram below outlines the necessary factors to establish concordance. Particularly important to note is the emphasis on taking the time to have an open dialogue with a patient (“Health

⁴ The term health care provider is often used instead of doctor to include the wide range of professionals who deal with treatment non-adherence. Some examples are physicians, public health workers, social workers, psychologists and nurses.

professionals regard it as important to invest time in reaching an informed agreement”) and being supportive throughout the process (“Medications are reviewed regularly with patients” and “Practical difficulties in taking medicines are addressed”; Medicines Partnership 2005). Unfortunately, these are among the basic features of quality care that are deteriorating in the current science and market driven model of health care.



(Medicines Partnership 2005)

Part of the difficulty in moving to concordance as a model is resistance from doctors who are uncomfortable or unwilling to sacrifice a portion of their power. Professionals who have “expertise” in the field find it difficult to acknowledge or legitimize patient views (Pollock 2005). While this partly stems from pride, the role of doctor has become associated with power. Through medical training and credentialing,

the role of doctor has been framed as a professional position with exclusive power that allows the doctor to establish what is best in all cases because of their expert status. The degree to which a doctor should take the patients decisions into account may also raise concerns about medical responsibility. What happens if even after being fully informed of the consequences of not following a certain treatment program, the patient still refuses and then suffers adverse effects? In the current litigious society doctors fear being sued for malpractice⁵. Beyond legal issues, it may be difficult emotionally and ethically for doctors to watch patients refuse to take advantage of all that modern medicine has to offer. Ultimately, however, it is the patient who will decide whether or not to follow a treatment program, and thus, the goal should be to somehow reconcile what the doctor sees as the best plan according to pharmacology, scientific evidence and the doctor's professional opinion, with what the patient desires and can feasibly do (Marinker and Shaw 2003).

Acknowledging the potential stigmatizing nature of terms like “non-compliance” is an important first step. The Royal Pharmaceutical Society should be applauded for its efforts in advancing a new model for patient care. Nevertheless, simply changing our vocabulary from “compliance” to “adherence” or “concordance” falls short of re-framing the issue and, instead, the new terms simply become de facto synonyms for “compliance,” rather than enabling the paradigm shift that is needed. Christine Bond (2003) laments in her article *Concordance- is it a synonym for compliance or a paradigm shift?*, how many of her colleagues “happily substitute the word “concordance” for

⁵ This fear is largely unfounded. In fact, a study by Levinson et al found that physicians with no malpractice claims compared to physicians with a history of malpractice, “had better communication skills, using more facilitative talk such as soliciting the patient’s opinion and encouraging them to talk” (Weiss and Britten 2003).

“compliance”, believing this to be politically correct while not appreciating the difference” (1). If we are actually committed to making positive improvements in the care of patients and the structuring of the doctor-patient relationships, change needs to move past semantics. In addition to the linguistic change, what is needed is an effort to reframe the knowledge of those involved- doctors, patients, and the health care system in aggregate, so that change occurs not only in discussion, but also in practice. In their review of the subject, Vermeire et. al. (2001) identified “one of the most striking reasons for the lack of progress in compliance research is the absence of a crucial factor: the patient’s perspective” (4). Patients’ voices need to be at the center of the discussion. As Paul Bissell (2003) points out, “...it seems unlikely that respect, trust or openness can be reduced to a set of procedures or guidelines; rather, it is more to do with a philosophy or an attitude towards patients and relationships more generally” (500). HCPs must actually understand and believe in the paradigm shift, and commit to enact necessary changes.

Furthermore, simply giving a patient more power and choice in the doctor-patient relationship, what proponents claim to be one of the major benefits of the shift away from the compliance model, neither fully addresses the concerns surrounding this discourse nor sets us on the right path toward getting to the bottom of this complex issue. As will be discussed in later sections, adherence to a treatment regime cannot be simplified to patient choice. In addition to moving toward a doctor-patient relationship where the patient is included in treatment decisions, has a voice, and is listened to, research on adherence must also cast a wider net, taking into account other factors such as built in flaws in current treatment programs and structural barriers that are out of the patient’s

control. That is, rather than focusing solely on choice, we must look at the very things that take away the patients' ability to choose.

Finally, all of the aforementioned terms- concordance, adherence and compliance- are imprecise, which leaves room for confusion and misinterpretation. There are many different ways in which a patient can be non-adherent to a treatment program, each of which may be for different reasons and require a different response. The current terminology lumps them all together with little concern for cause, and this of course creates limitations and inefficiencies in achieving our goal of effective treatment.

Structure vs. Agency

The structure-agency and active-passive split, two of the major sociological dichotomies, are informative when analyzing the issue of adherence. As Chris Jenks (1998) explains, the active-passive dichotomy centers around how people are motivated to act in the social world: "This can take the form of an active perspective, where it is supposed that people exercise free will and choice, or a passive perspective, where it is supposed that human action is organized by social pressures and constraints that are not of the individual's choosing" (261). Similarly, David Walsh (1998) outlines the two extremes in the structure-agency split: "...structuralist sociology treats society as an autonomous entity composed of structures and institutions that impose themselves upon and control the actions of the members of society by organizing themselves in terms of their own logic, which is dictated by the economic and cultural factors that have produced it and which are extra-individual" (11). Whereas the structuralist view does not account for personal agency, the other extreme argues, "Human beings can and do make themselves into what they are; they are able to take charge of their own lives and to shape

the social world in terms which meet their own needs” (Walsh 1998:13). That is, proponents of human agency see the world as full of alternatives, opportunities and choices for the active individual, without taking into account the impact of external factors that may act on the individual.

These dichotomies come into play when discussing patient adherence because the way in which a doctor views a patient is shaped by the framework they use to make sense of individual behavior. Aaron Cicourel contends, “...any attempts at theory or any views on method and measurement in sociology presupposes a certain view of the actor”, an initial conception that will then influence later theorizing (Cicourel in Jenks 1998:262). That is, a doctor who is a strong believer in human agency may be more likely to blame a patient for their non-adherence without taking into account mitigating structural circumstances. To date, the discourse surrounding adherence has emphasized an active agent, and in doing so, has reduced responsibility for HCPs and limited pressure for system level change.

As is the case with many stubborn dichotomies, neither extreme is the answer.

Jenks (1998) explains:

Human beings are not simply cogs in a machine or puppets on a string because they can and do make sense of their social environment, exercise choices in relation to it and modify it in a whole variety of ways, which makes them agents in the social world and creatures of social structure... On the other hand, they do it in the form of structures and institutions which are supra-personal entities with an organizational basis in conditions other than those simply a product of human need and interest; which cannot be transformed just at will by human beings; and which do have a regulatory and directive effect on human behaviour in society since they are the basis of its sociality. (15)

In other words, having free will certainly has its advantages. We would not want to subscribe to a theory of unidirectional causality and determinism that reduces us as human beings to “cogs in a machine,” but at the same time, we must account for the barriers that individuals face due to their placement within a predetermined system of hierarchies and limitations. While the active perspective may seem freeing and empowering, it holds so only for those who are properly placed to use that power potential. In terms of patient adherence, it is important to emphasize the view of the patient as an active agent. The patient should be an active member of the treatment team, and has the right to refuse medications, once fully informed of the risks. However, the reasons for a patient “deciding” not to receive medical treatment should not be because of a choice between food and medicine. That is where the structural perspective comes in to account for external factors that influence an individuals actions and decision making.

Karl Marx makes an important distinction between actor and agent. “At no point does Marx suggest that the human actor is an agent of his or her action but only that social conditions of production can emerge in which actors can become agents” (Walsh 1998:18). Similarly, patients have the responsibility to make changes in their own lives, but it is foolish to think that they can take on the entire structure (i.e. health care providers, insurance companies, hospitals, pharmaceutical companies, etc.) by themselves. Agency can reenter the picture only when a system emerges that meets and expresses the patients’ needs. That is, we can only talk about adherence in terms of patient choice when we are speaking in relation to a system that provides the patient with every opportunity to make an informed decision amongst several options. As Michel Foucault, a French philosopher, states, “...individuals do have the power to define their

identities, master their own bodies and desires and forgo practices of freedom for themselves but in a dialectical relationship to a constraining social field that seeks to impose limits on the individual” (Foucault in Walsh 1998:32). These external, constraining forces must be acknowledged and controlled for in the current model so that individuals can realize their power potential. Given that individuals do not act in a bubble, self-direction is always limited and individual lives are greatly affected by societal structures. The goal is to make allies of the individual, HCPs and the health care system. Interventions are not meant to take away power or freedom from the patient, but rather, to empower him or her to make informed decisions and then act upon those choices.

Mrs. D

In order to better illustrate the themes of this paper, it will be helpful to examine the following case study. For his doctoral thesis, Paul Bissell (2003) investigated how patients and professionals think of decisions to comply or not comply with a certain treatment program. Part of his research included patient interviews. One of his respondents, Mrs. D, exposes some of the pervasive problems with the current conceptualization and management of patient care.

A native of Pakistan, Mrs. D, who was in her early thirties at the time of the interview, had been living in North-West England for most of her life. She was married with four children and caring for her elderly mother. When interviewed, Mrs. D was six years into treatment for diabetes. She also had a very high body mass index and suffered from arthritis, hypertension and migraine headaches.

Her treatment program consisted of medication, diet and exercise. She was knowledgeable about when and how to take her medication and test her blood sugar and knew she was supposed to follow a specific diet and exercise regime. Knowledge clearly was not the problem, but Mrs. D was still having a difficult time sticking to her treatment plan.

Mrs. D explained that it was difficult to follow her diet because she felt she had to cook two completely different meals at each sitting, one for her family and one for herself. Not only was this time consuming, but also, Mrs. D wanted to fit in with her kids: “They want some Western-like pudding- I don’t know, ice cream. And I want to fit in with them” (Bissell 2003:498). It was also more expensive to buy the food that she was supposed to be eating. Furthermore, her father had recently died, exacerbating a history of depression and emotional overeating. Mrs. D also had difficulty following the exercise prescription. The doctor recommended walking, which was not only difficult with her arthritis, but also, she had been mugged once while walking locally, and was afraid to exercise alone because she had fainted during previous episodes of hypoglycemia.

When asked if she discussed these difficulties with her doctor, Mrs. D said she had not. She replied, “All they say is you should lose weight and you are overweight, and they don’t know its hard... And they shout at me and say, lose weight or you will die. I know I am a bit overweight but it’s so hard. I want to eat with my family... if they knew how hard it was. They might not say it to me. You going to die. You going to die. Can they not see it will make me upset?” (Bissell 2003:499). Clearly Mrs. D and her doctor had not taken the time to discuss potential barriers that could impact Mrs. D’s ability to follow through with her treatment plan, one of the first steps in delivering quality care.

This omission is not completely the doctor's responsibility. Any relationship is bilateral. Mrs. D would have to be honest with her doctor and discuss any difficulties with her treatment program. The doctor, then, has to listen with an attentive and empathetic ear and creatively work with Mrs. D to address those problems. Furthermore, just as patients are limited by external forces, so too are doctors. Doctors are forced to work within a model of medicine that forces them to make concessions in the quality of care that they provide with an eye toward efficiency and cost-containment. HCPs must be given the skills, resources and incentives to establish a "treatment alliance".

Mrs. D's doctors used the method of reinforcing simple messages to lose weight along with intimidation on what would happen if she did not comply. This strategy, however, was obviously not effective. Mrs. D felt as though the doctors were blaming her, which made her feel ashamed, angry and frustrated, but had no positive effect on helping her follow the treatment program. She internalized the doctor's words, referring to herself as "lazy" and "a failure," but was not motivated to comply, the doctor's intention. Mrs. D did not feel there was the option of having an open dialogue with her doctor: "They just go, right, your blood level's this, your this is this. And then you are out... They never say, **why** are you not sticking to your diet" (Bissell 2003:499), my emphasis). Rather than a holistic focus on the individual, the current medical model, as elaborated upon in the next section, has a scientific focus on biological and chemical markers. Mrs. D's doctor was treating her diabetes and her obesity, not Mrs. D. For example, Mrs. D's doctor has no way of knowing that she is afraid of walking because of being previously mugged, unless she has an open dialogue with Mrs. D. Once the issue is put out on the table the two could work together to reach a solution; walk around a

shopping mall instead of outside. However, when there is lack of communication, and no individualization of treatment, the patient does not get all the help they need.

Mrs. D understood the consequences of not following her doctor's prescription but her decisions were not narrowly based on these medical considerations. There were several mitigating factors that played a role in Mrs. D's "choices". Mrs. D did not always have the luxury of putting herself and her health first. Recall the previous discussion of the interplay between structure and agency. Agency assumes the individual is able to operate independent of the constraints of structure. In Mrs. D's case, her "choices (agency) were mediated or constrained by the social context of her life" (Bissell 2003:499). In this situation repeatedly telling a patient what to do, or trying to motivate them using scare tactics, is futile. Knowledge and motivation are not always the cause of non-adherence, even though they are most often pointed to as the causes for non-adherence because of the framework we use to explore the subject: a framework that sees all actions as related to individual choice and does not account for the limiting aspects of external structural forces (Bissell 2003).

Limits of the Biomedical Model

Good medicine may sometimes begin just at the point where the possibility of biological reprieve has ended. (Gunderman 2000)

The type of relationship seen between Mrs. D and her doctor stems, in part, from the current emphasis on the biomedical model of care. The early days of medicine, "bedside medicine," centered on a person-oriented framework whereby the physician sought to develop a rapport with the patient and meet his or her needs (Annandale 1998:5). However, in the nineteenth century "hospital medicine" eclipsed this person oriented framework with an object-oriented model that no longer focused on the

individual as a whole, but rather studied specific organic phenomena. This model was reinforced by the development of “laboratory medicine”. “The patient, as sentient being, moved out of the frame altogether to become a material thing to be analysed, and disease became ‘a physio-chemical process to be explained according to the blind inexorable laws of natural science’” (Annandale 1998:6). Modern biomedicine was born. As was seen with Mrs. D, this shift in the framing of discourse and knowledge around medicine has had serious implications for the provision of health care. While the two need not be mutually exclusive, treating disease with advanced scientific knowledge and technology has largely displaced the person-oriented framework of earlier days.

There are three characteristics central to the biomedical model. First, it follows a reductivist approach. That is, the body and mind are viewed as separate entities and disease is an objective natural phenomenon, independent from the experience of the patient. Second, biomedicine operates under the “doctrine of specific aetiology”. Whereas disease was once viewed as a disharmony between the sick person and the environment, the biomedical model associates it with a virulent micro-organism (Annandale 1998:7). The doctrine of specific aetiology fails to consider interactions with the broader social environment, factors such as stress or nutritional deficiency, as part of a multi-factorial explanation of an individual’s susceptibility to disease and response to treatment. Again we can see the inability of the agency-framed discourse on adherence to account for structural-level forces that limit the individual. Finally, the biomedical model claims scientific neutrality: “medicine can be rational, objective and value-free, treating each individual according to their need and irrespective of any sense of moral worth” (Annandale 1998:7). The biomedical model operates in opposition to frameworks, such

as the biopsychosocial model, that acknowledge the psychological and social factors that influence a patient's perceptions, actions and healing (Wade and Halligan 2004). Each patient is an individual with a distinct history and situation, a fact that medical care cannot ignore.

It is important to note that framing the medical conversation through the lens of the biomedical approach was not originally accepted without a wave of criticisms from its outset. In *The Condition of the Working Class in England*, German political philosopher, Friedrich Engels, challenged the narrow gaze of the biomedical model. He argued that the aetiology and distribution of disease was directly associated with capitalist relations of production and concluded that medical intervention alone would not eradicate disease. This contradiction between the pursuit of health and the pursuit of profit remain at the center of health care discussions today.

Bruce Link and Jo Phelan have continued on a similar line of criticism differentiating between proximal and distal causes of disease. They are concerned that “modern epidemiology and cultural values conspire to focus attention on proximate, individually-based risk factors and away from social conditions as causes of disease” (Link and Phelan 1995:81). Marshall Becker (1993) is disturbed by the importance that Western culture places on the ability and importance of the individual controlling his or her own fate and how that translates into locating responsibility for the cause and cure of illness solely with the individual. It is assumed that “personal health-related behaviors are discrete and independently modifiable; anyone can decide to alter his/her behavior and then go on to do so successfully; and everyone has a personal responsibility to ‘live well’ through self-discipline and behavior modification” (Becker 1993:3). By locating the

majority of blame and responsibility with the individual, other possible interventions are overlooked as the health care system and society, as a whole, are absolved of responsibility. Of course, individuals do not function in isolation. Thus, interventions will not be fully effective “without concomitant attempts to alter the broader economic, political, and structural components of society that act to encourage, produce, and support poor health” (Becker 1993:4).

Phelan and Link stress the importance of “contextualization” for the design of more effective interventions. While they are speaking of the causes of diseases, their discussion is also relevant to a patient’s ability to adhere to treatment once they are sick. Let us think back to the case study of Mrs. D. She was educated as to the importance of exercise. However, her doctor failed to contextualize her situation and therefore did not address the fact that it was painful for her to walk because of her arthritis or that she was afraid to walk after being mugged in her neighborhood. Contextualization would involve asking what it is about a person’s life circumstance that shapes their ability to follow a treatment plan. Without contextualization, the intervention is wrongly focused on individual behaviors that are resistant to change not because of willful disobedience but because of unacknowledged social conditions (Link and Phelan 1995:89). As Guderman (2000) so eloquently states, “We need to get to know patients well enough to understand their life outlook, including biographical and cultural perspectives that are barely hinted at in the medical record, that are impossible to quantify or analyze through laboratory tests and imaging studies, and that no health insurer will ever pay for”.

A person’s access to resources, defined broadly as money, knowledge, power, prestige, social networks and support, has a large impact on that individual’s ability to

avoid risk and maximize health (Link and Phelan 1995:87). Individually focused interventions that do not consider the special needs of groups who may encounter barriers in implementing those interventions necessarily result in people benefiting unequally depending on the resources at their disposal. Link and Phelan (2005) offer the example of asthma where there are certain known risk factors that can be modified to lessen symptoms and prevent the condition from worsening. For example, patients are told to keep homes well ventilated, spotlessly clean and free of cockroach infestation. However, those who are most likely to live in poor conditions are also least likely to have the resources to make the recommended changes. A more effective approach would promote city sponsored roach control for entire buildings or infested areas. In assessing a proposed intervention, always consider if it is something that anyone could adopt, or only those with prerequisite means (Link and Phelan 2005). It is similarly impractical to tell doctors to spend more time with patients, educating and monitoring adherence, until structural-level changes occur to reemphasize the importance of that aspect of care.

The biomedical model is also limited by its narrow focus on scientific answers. “The health professional has a set of beliefs about the appropriateness of particular medicines, and about how they should be used based on a biomedical model. These beliefs are shaped by the content of professional training, and on the evidence from a large body of scientific research” (Medicines Partnership 2005). This focus tends to discount alternative⁶ treatment options, even though there is increasing awareness that health care professionals have been wrong in their diagnoses and treatment suggestions. Becker (1993) criticizes the health profession for “prematurely” pressing the public to

⁶ The mere fact that these therapies termed “alternative” or “complementary” illustrates a value judgment that gives them less respect than contemporary scientific conclusions due to this framing of language. Some examples are acupuncture, massage therapy or osteopathy.

undertake certain behaviors. By prematurely he refers to the fact that recommendations are advanced as fact even when there still remains considerable disagreement over their validity. It should then not be a surprise that the public has become confused and skeptical about the health advice they receive (Becker 1993:1). People are faced with overstated and conflicting claims which have only been exacerbated with the advertising power that pharmaceuticals have in the mass media. Pickering's estimate "that in about 90% of medical conditions there is no specific remedy or the effectiveness of the treatment is unknown" (Meichenbaum and Turk 1987:40) should be a sobering reminder to HCPs that their arsenal of science and technology is not infallible. Since Pickering made this estimate in 1979, there certainly have been important advances in the field of medicine. The caution he provides is not to discount important improvements, only to contextualize them.

Modern physicians are trained in the use of medicines and have come to see them as *the* method of treatment. A patient's refusal to take a certain medication, however, does not necessarily mean that they are refusing all treatment. Again, the issue is one of how treatment is being framed. A biomedical frame, that sees the doctor's job as medication prescriber, may view non-adherence as a patient's unilateral refusal of medical care. A more holistic framework, however, would see the HCP as serving other roles, and thus the doctor's responsibilities would not end when a patient refused the prescription. The refusal would simply signal that the HCP must try a different method of treatment. Unfortunately, although today's physicians are well trained in prescribing drugs, "they are often quite unskilled in the more subtle 'medicine' of support for which there exists no physical armamentarium" (Jonsen 1979:116). This may also stem from the

fact that the biomedical model conceptualizes health as the absence of disease and does not advance a positive definition of health (Turshen 1977:46). The WHO, on the other hand, defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (IHC 1946). Under the WHO definition, the individual must be treated as a whole person, in the context of their social world, not simply a disease. Part of health is being empowered to live a full life, a concept a narrow scientific model has difficulty accounting for.

Finally, the biomedical model does not account for cultural differences. Ethnic and cultural factors may influence a group’s attitudes, values and beliefs about health and illness⁷. For example Mexican Americans view health as the absence of pain. It should be noted then that treatment of asymptomatic conditions may be problematic among this population because they will not see themselves as sick and needing treatment (Carter, Taylor and Levenson 2005:72)⁸.

In *The Spirit Catches You and You Fall Down*, Anne Fadiman (1997) exposes the importance of cultural considerations in medical care. Lia Lee, a three-month old, epileptic, Hmong child gets caught in the middle of fatal a war between traditional healing and beliefs, and modern medicine. Her parents, refugees from Laos, took her to the hospital where they live in Merced, California. When Lia was brought to the hospital, the doctors diagnosed her with epilepsy, a common neurological disorder. Her parents, however, had already diagnosed her with “qaug dab peg” (the spirit catches you and you fall down), her symptoms being a result of soul loss. Both parties, the doctors and her family, wanted what was best for Lia, but due to a lack of effective communication and

⁷ This by no means suggests that we should assume ethnic sub-groups to be culturally homogeneous and disregard the individual. However certain common beliefs and traditions may be relevant to compliance.

⁸ See discussion of Health Belief Model in section on Predictors of Non-adherence p. 37.

understanding, what was best for Lia was lost. Lia's doctors were extremely well intentioned. Her chart was 400,000 words long, and "every one of those words reflected its author's intelligence, training and good intentions, but not a single one dealt with the Lees' perception of their daughter's illness" (Fadiman 1997:259). The doctors operated under one of the major pitfalls of the biomedical model. To them, Lia was her seizures and not a whole person to be treated in the context of her family and culture. On a basic level, the hospital did not even have interpreters to allow for effective communication between the family and the doctors⁹ ¹⁰. Lia's death was a tragedy that could have been prevented had the doctors treating Lia been able to step outside of the narrow biomedical framework that they were so used to operating under. Had the doctors sought to understand Lia and her family as more than a disease that needed to be treated, they would have been able to provide higher quality, more effective care.

There certainly were aspects of the biomedical model that could have helped Lia, but without taking into account the cultural context, the doctors' hours in medical school dissecting cadavers and memorizing disease symptoms and categorizations were of little use, and could have been aided by a course in cross-cultural medicine (Fadiman 1997:61). Lia's parents loved her dearly and were devoted to caring for her including animal sacrifices and traditional herbal remedies. The doctors, however, labeled this behavior as non-compliance because it did not conform to their medical recommendations. Neil Ernst, one of Lia's doctors, noted in retrospect that although it is

⁹ Lack of interpreters is a serious problem across US hospitals. Often ad hoc interpreters (on hand staff or family members) are used, even though studies have documented problems with this approach. Forty percent of hospitals do not even collect data on patients' primary language to help them assess the needs of their patients (Taylor and Lurie 2004).

¹⁰ Paying for translation services can in fact be financially profitable once indirect costs, such as an increased use of preventive services potentially reducing the cost of elaborate interventions when patients wait until their condition gets very bad, are considered (Taylor and Lurie 2004).

difficult to do so, when dealing with other cultures, doctors have to be willing to give up complete control (Fadiman 1997:257). Lia's case study gives us insight into the importance of holistic care. The best doctors, medications and machines, were unable to save Lia because the fundamental steps of understanding the individual they were dealing with and tailoring care to that specific situation were not taken.

The Blame Game

In initial adherence research and continuing at a disproportionate rate today, the patient is the focus for much of the blame when it comes to looking for the source of the “problem of non-compliance”. Slowly, the role of the health care provider has been looked at in greater detail and today we are slowly moving towards a systems approach¹¹ (WHO 2003). While blaming the patient is much simpler than seeking explanations for their actions in a wider structural and psychosocial context, blaming the individual does not fully address the problem and, moreover, can have a profound negative impact on a patient's dignity, identity and self-respect (Bissell 2003). While the doctor does have a responsibility to warn patients when their actions are jeopardizing their health, it should be done in a non-confrontational way. Blaming patients when they become sick or when their condition does not improve is failing to offer patients care and advice when they need it the most. While sometimes it may seem as though patients have brought their condition upon themselves by way of their actions, remember that individuals do not always have full control over their actions. Many behaviors are the result of social and economic forces over which the individual has little control. Some argue that patients who do not heed medical advice do not deserve our full attention, resources, ministrations

¹¹ This broader focus looks at the way health systems are structured, financed and operated, how health professionals are trained and rewarded, and a more thorough investigation of the barriers patients and their families may encounter (WHO 2003).

and sympathy (Gunderman 2000). However, while we must sympathize with the frustration that HCPs feel and the wastefulness of non-adherence, it is not fair to disregard patients who for one reason or another do not have the ability to adhere to certain recommendations. Instead, HCPs should be provided with more training and support to help these patients. More to the point, blaming only moves us further from the ultimate goal of finding a treatment that will return the patient to good health.

Herbert Blumer's (1969) theory of symbolic interactionism states that people "act toward things on the basis of the meanings that the things have for them" (5). Blumer's theory explains how a provider's subjective understanding of their patient's noncompliance structures further interaction with that patient. Similarly, Norman Fineman (1991) argues that "noncompliance, like other categories of deviance, is socially constructed and subjectively defined and interpreted... noncompliance is a provider-constructed category of unacceptable client behaviours...in accordance with their expectations of appropriate, proper and reasonable client behaviour. In addition, they interpreted the meanings of their clients' noncompliance in accordance with their subjective assessments of the intent underlying their clients' noncompliant acts" (355). He found that doctors separated noncompliance into two categories: unwilling and unable, based on the doctor's perception of their conscious and deliberate choice. Based on this assessment, clinicians assigned differing degrees of blame to their clients and assumed differing degrees of responsibility for helping them. Those classified as unwilling were blamed for their noncompliance, and staff members felt only limited responsibility to them. In contrast, if a patient was labeled as unable rather than unwilling, the provider was more likely to reassess the client's needs before confronting

the patient with medical threats or terminating services. Mrs. D's doctor telling her she would die is an example of a medical threat. The problem is, doctors most likely make their assessments based on stereotypes and generalizations that can be incorrect, rather than first getting to know the patient, and judging based on evidence. Furthermore, even patients who are at first unwilling or seemingly uncooperative should not be deserted.

Constant blame and focus on the patient's weaknesses not surprisingly often causes more harm than good. In Mrs. D's case, instead of repeatedly admonishing her for not losing weight, her doctor could have said something along the lines of, "I know losing weight can be difficult. I have a hard time resisting sweets too. But I feel it is worth it to maintain a normal weight and good health. So, what steps do *you* think we need to take in order to better ensure that you will be able to lose the weight in order that you can become healthier?" This method validates the patient's difficulties and makes the doctor seem more human, interested and approachable, while still reiterating the importance of the doctor's initial, scientific based, recommendations. Reframing the treatment approach in a way to account for both inputs is more likely to produce a workable plan. Patients are less likely to talk to their HCPs in an open and honest way, asking for help when they need it, if the doctor gives the impression that they should be able to deal on their own and are weak if they cannot (Gunderman 2000). The physician's job is not to determine fault, but rather to promote health. So far as reprimanding certain patient behaviors is successful at reaching these ends without undermining the doctor-patient relationship, inhibiting care seeking, or eroding hope, it can be one valid approach. It should not, however, serve as an outlet for HCPs to vent their frustrations (Gunderman 2000).

Simply switching from blaming the patient to blaming the doctor is not the answer. Today's HCPs are educated in the biomedical model. HCPs are interacting with patients and providing care as they were trained to do within the biomedical framework. Society has come to accept the biomedical model because that is the framework offered, but it is possible that the model itself is flawed.

Types of Non-adherence

Non-adherence can present itself in many forms at many different stages during the treatment process. Actions associated with adherence include:

1. Entering into and continuing a treatment program
 2. Keeping referral and follow-up appointments
 3. Correct consumption of prescribed medication
 4. Following appropriate life-style changes (e.g., in the areas of diet, exercise, stress management)
 5. Correct performance of home-based therapeutic regimens
 6. Avoidance of health risk behaviors (e.g., smoking, alcohol, drug abuse)
- (Meichenbaum and Turk 1987:20-21)

Someone who is classified as non-adherent could fall into any of the following permutations: never adhered to any aspect of the recommended regimen, adhered to some but not all of the plan, initially adhered but over time defaulted, or performed the prescribed tasks but in an inappropriate manner (Meichenbaum and Turk 1987:25).

Studies done using electronic medication-monitoring devices, which record the frequency and time the medication bottle is opened, show that among patients taking medication for a chronic illness, one sixth have close to perfect adherence; one sixth take nearly all doses but with timing irregularities; one sixth have timing inconsistencies and miss an

occasional day's dose; one sixth miss occasional doses and take a "drug holiday"¹² three to four times a year; one sixth frequently miss doses and have a "drug holiday" at least once a month; and one sixth give the impression that they are adherent while taking few or no doses (Osterberg and Blaschke 2005:2). The current discourse does not account for these complexities.

Failing to fill a prescription represents a different problem from taking the prescription improperly. Even taking a prescription improperly can break down into many scenarios. For example, the patient might intentionally stop the prescription prematurely because they no longer have symptoms and thus think the medication is no longer needed. Or, the patient may have misunderstood the doctor's instructions and unintentionally defaulting. Those are only two of numerous possibilities for why a patient may not take a prescription as directed. Each individual will have a collection of internal and external factors that influence their adherence behavior. This can only be understood on a case by case basis, by taking the time to talk with and understand where the patient is coming from. A one-dimensional intervention will not account for these individual intricacies. Successful intervention programs will tackle individual issues of adherence, not adherence as an abstraction.

Along the same lines, adherence is not a black and white issue. While adherence is often discussed as a dichotomous matter, it is a dynamic continuum that can range from 0 to more than 100 percent (Osterberg and Blaschke 2005:2). Especially when dealing with chronic disease, patients' adherence rates may change over time. Adherence among

¹² A drug holiday is the omission of medication on three or more sequential days (Osterberg and Blaschke 2005:3). Another trend found in studies using electronic medication-monitoring devices was white coat adherence: improving medication-taking behavior in the 5 days before an appt as compared with the 30 days after (Osterberg and Blaschke 2005:4).

patients with chronic conditions drops most dramatically after the first six months of treatment (Osterberg and Blaschke 2005:1). Need the goal always be 100% adherence, or just enough to realize the positive effects of the treatment? For example, in the treatment of hypertensives, although taking less than 50% of the medication proved ineffective, adherence rates of 80% resulted in normalization of blood pressure (Meichenbaum and Turk 1987:31). However, treatment of HIV with HARRT has been shown to require >95% compliance. In light of this, Gordis suggests conceptualizing adherence as, “the point below which the desired preventive or desired therapeutic result is unlikely to be achieved” (Meichenbaum and Turk 1987:31). While 100% adherence may not be necessary in all cases, doctors do not always know the exact percentage of medication that is required to have success, and telling patients that it is alright to be non-adherent some of the time may put us atop of a slippery slope to sanctioning non-adherence. Also, this definition seems to focus mainly on prescriptions. Treatment programs also include life-style changes such as diet and exercise which are even more difficult to enact and quantify. While we should aspire for perfect adherence, doctors and patients must realize that no one is perfect. The doctor should educate the patient on the importance of taking their medication as directed but at the same time let the patient know that the majority of patients do struggle with adherence so the patient knows they are not alone. It is most important for the doctor and patient to have open and honest communication so the patient feels comfortable discussing problems and concerns with the doctor, rather than feeling ashamed like a failure or deviant.

Predictors of Non-adherence

The human psyche is not simple. People often do things for reasons we do not understand or cannot explain. Among the 200 variables that have been studied since 1975, none, neither socio-economic nor pathology-related factors, have been shown to be consistent predictors of adherence (Vermeire et. al. 2001:2). This does not mean that there are not important correlations that should be further researched and addressed. Being familiar with certain major indicators of poor adherence can help HCPs identify those patients who might have more potential to struggle with adherence. Nonetheless adherence is an issue across the patient population and something that HCPs should be mindful of with all of their patients. Osterberg and Blaschke (2005) highlight several factors that have been cited in studies as major predictors of poor adherence to medication. Whether or not there are steadfast predictors of adherence, it is undeniable that non-adherence is a significant medical issue that needs to be addressed. The lack of predictors only confirms the complexity of the issue and the need for individualized treatment. The danger lies in framing the discussion exclusively in any one variable. Doing so will limit the range of intervention strategies and thus hinder success in the long run.

The variables can generally be divided into five areas: patient characteristics, characteristics of the treatment regimen, elements of the disease, HCP – patient relationship, and the clinical setting (Meichenbaum and Turk 1987:41). WHO differentiates them as condition-related, therapy-related, patient-related, health system/health care team related and social/economic factors (WHO 2003:27). Each of these five areas overlaps and interacts and the ability of patients to adhere to treatment is usually compromised by more than one area. The specific insertion of the

social/economic category in the WHO dimensions is important because all too often, factors that are out of the patient's control are attributed directly to the patient. That is, an emphasis is put on agency, when it should be balanced with a structuralist view. It is no doubt interesting that in a survey of physicians, 76% attributed non-adherence to patient characteristics even though these factors have been proven no less predictive (Meichenbaum and Turk 1987:42). Similarly, Stone (2001) found that a large proportion of physicians report little sympathy with their patients' difficulties in adhering, and view non-adherent behavior as the result of an attitude problem on the patient's part (Meichenbaum and Turk 1987:42). Doctors feel less responsible for patient care beyond writing a prescription. This attitude can lead to pessimism and indifference on the part of HCPs in trying to improve adherence. Even the most well meaning and motivated patient may default at times due to structural forces out of their control (i.e. the effects of poverty) or honest mistake (i.e. misunderstanding directions or forgetting). When an HCP enters the doctor-patient relationship with preconceived, pessimistic notions about patient adherence, there is less of a chance that he or she will take the time to get to the bottom of a patient's difficulties.

Patient Related Factors

Patient related factors can be summarized as the “resources, knowledge, attitudes, beliefs, perceptions and expectations of the patient” (WHO 2003:30). Some factors that affect adherence include anxiety about medication taking or potential side-effects, disbelief in efficacy of treatment, disbelief in the diagnosis, misunderstanding of instructions, hopelessness, feeling stigmatized or forgetfulness¹³. For example, there is

¹³While forgetfulness is one of the most common self-reported reason for missing a dose, keep in mind the actual reason is often more complex. That is, “forgetfulness is a product of both cognitive and motivational

increasing concern about doctors over prescribing medications, harmful side-effects (Vioxx), potentials for dependency (Xanax) and more general concerns about chemicals in food and the environment (WHO 2003:30). These beliefs stem from personal experience, the experiences and suggestions of family and friends and the media. Anxiety, misunderstandings and personal beliefs are exactly the things that should be discussed in an open dialogue with a provider. The Health Belief Model suggests that patient beliefs and perceptions will be influential when it comes to adherence. The importance of patients' beliefs and perceptions has only recently started to be acknowledged. Doctors are still more likely to dismiss patient views for their "expert" opinion.

Patients hold their own sets of beliefs and theories about health and illness and these determine how the patient makes sense of the advice given to them and whether or not to take it (Vermeire et. al. 2001:6). Basically, the Health Belief Model says that patients must believe that they are susceptible to the disease, that they have it and that the consequences of the disease will negatively affect their wellbeing. Furthermore, they must believe that following the HCP's prescription will eliminate or reduce their condition and the costs or barriers associated with following the recommendations are outweighed by the benefits (Meichenbaum and Turk 1987:52, Vermeire et. al. 2001:6). So, when a patient is in denial about being sick or there are no obvious symptoms to be treated the patient may not feel the need to follow the doctor's recommendations. For example, it is not uncommon for a patient on antibiotics to stop taking their medication after three or four days when the symptoms subside, even though the medication is

issues; thus, it cannot be assumed that reminders alone (focusing only on the cognitive aspect) will solve the "forgetfulness" problem" (Stone 2001:3). Finding one factor related to adherence does not mean that other factors can be disregarded.

prescribed for ten or more days. When no symptoms are present the patient believes they are cured, not realizing that the remaining few stronger bacteria can multiply resulting in a relapse (Meichenbaum and Turk 1987:50). Whether or not the patients' beliefs are scientifically valid, they must be acknowledged by the HCP and incorporated into the treatment plan. Simply ignoring a patient's beliefs and concerns does not make them go away.

Gunderman (2000) points out that "individuals living in poverty may be more firmly grounded in the present, giving less thought to the morrow than health professionals, who by dint of character and long experience take delayed gratification for granted". An impoverished patient may have to choose between competing priorities such as food and medication. In the mind of a hungry person, choosing food today, rather than an anti-hypertension medication that will decrease his risk of heart disease in the future, is the rational choice. In a survey of US physicians, 73% reported that patients' ability to afford necessary treatment was a serious problem, and on the whole, U.S. physicians were less satisfied than their Canadian and West German counterparts with the system's ability to care for the poor (Blendon et. al. 1993). Cost¹⁴ is a real issue, and although we speak of a patient choosing not to take their medication, choice in this situation is fictional. While HCPs may see non-adherence as irrational behavior based on some type of patient deficiency, be it laziness, forgetfulness, or lack of motivation and will power, in many cases the patient's behavior is the result of a thought out cost-benefit analysis. What is needed then is a system in which care is affordable so that patients are not forced

¹⁴ Cost refers not only to the payment for medication and clinic visits, but also, such things as lost wages, transportation and child care (Haynes 1979).

to make these difficult choices. HCPs are responsible for identifying such barriers and helping their patients to access and navigate the appropriate aid networks.

Patients want treatment approaches that are “manageable, tolerable and, in their view, effective” (Vermeire et. al. 2001:9). Questioning the concept of compliance, Jenny Donovan and David Blake (1992) found that, “Patients complied with medical advice when it made sense to them and seemed effective. It made sense if it accorded with their own lay beliefs, and was possible to carry out within the constraints of their everyday lives” (511). While scientific evidence and compliance may be the priority in the eyes of the HCP, “for the patient, especially one with a chronic health problem, concerns such as controlling symptoms, preventing medical crises, maintaining financial comfort or enjoying quality lifestyle may take precedence” (Vermeire et. al 2001:9). Although it may at first seem counterintuitive, health is not the singular goal. Health is but one element of a free and dignified human life. The drive to obtain health cannot be addressed in isolation of a range of other human goals (Jonsen 1979). This may be difficult to understand for those of us who are not forced to make these difficult choices. Part of quality care is knowing the patient so that a treatment program is created to fit his or her lifestyle.

Patients’ views of what is in their best interest may not always coincide with their doctor’s. This is the case in any relationship, and the reason for open dialogue. For many patients, part of the illness process is experimenting with their treatment to try and regain a sense of self-control and find the minimum amount of disturbance (Vermeire et. al. 2001:6; Steiner and Earnest 2000:3). Experimenting with treatment may be a patient’s means of assessing if their condition is improving and an attempt at returning to a

“normal” life (Meichenbaum and Turk 1987:50). If part of the adherence struggle is the patient vying for some control over their body, illness, and life, a start would be giving the patient more power by creating a collaborative relationship between doctor and patient. Discounting the patient’s thought process as irrational is taking the easy way out. As Vermeire (2001) suggests, “health professionals need to shift the emphasis away from attempting to encourage patients into taking the medication they prescribe, towards learning how they can contribute to the decisions that patients currently make about their medications” (6). HCPs must reclaim their role as teacher, counselor and supporter, rather than simply prescriber.

Treatment Related Factors

While so much emphasis is placed on individual factors, even though they are not reliable predictors of adherence, one dimension that has had a stronger correlation in studies is treatment related variables. The more complex the therapeutic regimen is, the lower the adherence rates. Regimen complexity refers to the number of doses required per day, the number of pills and different medications taken, the presence of food-dosing restrictions, fluid intake requirements or other disruptive lifestyle changes (Stone 2001). Simple dosing, that is one pill per day, especially when combined with frequent follow-up visits, has a positive correlation with adherence¹⁵(Osterberg and Blaschke 2005). One pill a day regimens have the highest adherence rates (81%). When the dosage is increased to three times a day, adherence rates drop to 77%. An increase to four pills a day results in a sharp decline in adherence to 39%. Researchers explained this by the natural division of a day. That is, if a person is told to take the pill once a day, they can take it when they

¹⁵ However, even with in those cases, 10-40% of patients continue to struggle which reiterates the complexity of the issue.

get up, or before they go to bed, similarly with a two a day regimen. For a three a day regimen, pills can be taken after each meal. With a four a day regimen however, there exists no such natural division (Gottlieb 2000). Studies have shown that a patient's ability to recall basic information about even a single prescription following a clinical visit is low. With one drug, the error rate is 15%. This rate increases to 25% when two or three drugs are prescribed, and 35% with five drugs (Meichenbaum and Turk 1987:56).

Take the example of an outpatient clinic for homeless individuals. It is not uncommon for patients to leave with five or more prescriptions for different medications. While keeping track of that many medications would be difficult for anyone, homeless individuals will face even more challenges due to their unstable day-to-day life and limited social support. Furthermore, due to the high volume of patients seen, doctors are not able to spend extended periods of time checking in with patients, reviewing instructions and probing for new barriers, all fundamental aspects of quality care. The importance of continuity of care is illustrated by studies that have found higher rates of compliance in private practice with a regular physician as compared to clinic settings or unknown practitioners (Hulka 1979:77). Although the instructions may seem obvious to the HCP, failure to adhere is associated with incomplete or vague directions. For example, if a patient is told to take a pill every six hours, do they need to wake up in the middle of the night to take their medicine? If they miss a pill should they take twice the dose when they remember? Or, if they are supposed to take frequent baths, does that mean 4 times a week or twice a day? When dealing with complex regimens and information overload patients may react in several ways: omission, error, delaying or avoiding, filtering to fit input with their existing beliefs or approximation (Meichenbaum

and Turk 1987:59). Side effects and the intrusiveness of the treatment will also have an impact on compliance. Referring back to the patient belief model, the patient may deem that the costs of adhering are too great for the benefits acquired. Meichenbaum and Turk (1987) stress throughout their book that even the ideal therapeutic regimen will have no positive effects if the patient does not implement it because they find the demands excessive given their current life situation and resources. Often, even when speaking of regimen-related factors, the discussion is shifted back to the patient's forgetfulness or misunderstanding. Instead, more emphasis should be placed on the time the HCP spends explaining the regimen or thinking of creative ways to simplify complex regimens or at least alter them to fit better with a particular patient's lifestyle.

Illness Related Factors

Illness related factors overlap with the treatment variables. For example, studies consistently show that adherence decreases with time. Therefore, adhering to treatment for a chronic disease or implementing permanent lifestyle changes or prolonged preventative behaviors prove to be the most challenging. Adherence rates also tend to be higher when symptoms of the illness are easily recognizable. This relates back to the patient's beliefs that they are indeed sick and need treatment. Interestingly, the *objective* seriousness of the patient's disease has less correlation with adherence than the patient's *subjective* perception of the seriousness (Meichenbaum and Turk 1987:62). The presence of co-morbidities such as depression, substance abuse can also impact adherence behavior (WHO 2003:30).

HCP-Patient Relationship Factors

Even though only 25% of surveyed physicians acknowledged their role in patient adherence (Meichenbaum and Turk 1987:63), doctor responsiveness and satisfaction are found to be positively associated with compliance. “Compliance seems to be related to the quality, duration and frequency of interaction between the patient and doctor. The doctor’s attitude towards the patient and his ability to elicit and respect the patient’s concerns, to provide appropriate information and demonstrate empathy are of the utmost importance” (Vermeire et. al. 2001:6). Components of an effective relationship include good communication, rapport and discussion, exploration of alternative therapeutic means, negotiation, continuity, and steady follow-up (WHO 2003:3). Although some patients might be content simply letting the doctor take control, many patients become frustrated if their preferences and ideas are not elicited and accounted for (WHO 2003:20). Unfortunately, time pressures often make this seem infeasible. Shorter office visits do not allow for a full discussion of alternatives, proper instruction, and identification of concerns or potential problems. Other health care team and system-related factors that have a negative effect include, issues with insurance plans and reimbursement, barriers in obtaining medications, lack of non-science knowledge and training, overworked HCPs, lack of incentives or feedback, and limited community networks and support systems (WHO 2003:29). It would seem obvious, and studies have confirmed, that a caring and approachable attitude, combined with a personalized treatment approach would correlate with higher adherence rates. That is, if HCPs adopt an open, honest, respectful, supportive style and provide the patient with clear explanations, adherence will increase (Meichenbaum and Turk 1987:63). The HCP-patient relationship is such an important starting point because knowing the patient well

enough to uncover adherence issues in the first place and successfully intervening will hinge on a foundational working relationship.

The type of training that doctors currently receive does not support a collaborative approach. *Heart Failure*, Michael Greger's (2000) book, suggests that creating this type of dynamic may be more difficult than imagined. He writes based on his experiences at Cornell Medical School. He highlights how students are taught to depersonalize and desensitize themselves from care. Medical education erodes the student's recognition and sensitivity to patients as people and creates doctors that "sweep in, grab the chart, and ignore the patient". Students learn to exact compliance by purposefully diminishing the patient's sense of autonomy. The sole objective of personal contact is seen as the extraction of medical information. "To accomplish this primary objective while restricting other demands of their heavy case loads, the interns and residents collectively developed several strategies: (1) avoiding patients and their families; (2) narrowing the focus of interaction to strictly 'medical' concerns; and (3) treating patients as non-persons - even in their presence" (Greger 2000). Limited communication allows the doctor to stay detached and prevents the constant interruption of questions. Students who may have entered with an interest on social justice and medical reform, they leave more or less conformed to the established system (Greger 2000).

Clinical Setting Factors

Organizational factors and the clinical setting can play a large role in the format of patient care and the development of the doctor-patient relationship, thus impacting adherence. Not surprisingly, greater continuity of care, that is seeing the same HCP each visit, is associated with higher adherence levels. Especially, with the increase in HMOs

and walk-in clinics, it is important to remember that patients receiving treatment in private primary care facilities are more likely to keep follow-up appointments and adhere to treatment recommendations than patients seen in walk-in clinics or emergency rooms (Meichenbaum and Turk 1987:65). It is also more common for clinics serving lower income patients to have block scheduling, rather than individually scheduled appointments¹⁶, which are associated with greater adherence. Under our current health care system, some patients do not have the option of seeking care anywhere other than clinics and ERs, so strategies must be built into these settings to counteract the challenges inherent in them. To the extent that an entire treatment team (primary HCP, specialists, pharmacists, secretaries- all those in contact with the patient) can be formed and effectively communicate with one another and the patient, creating a support system, especially for those patients lacking a support system in their lives, adherence and patient health should increase.

When seeking care for themselves or their families, doctors look for “the type of physician who leaves no stone unturned and will burn the midnight oil if need be to ensure the highest-quality care possible” (Gibbs and Bower 2006). At the same time, they acknowledge that, the current trends of marketization have strained the doctor-patient relationship and do not encourage that type of care.

If the discourse around predictors of non-adherence was not so focused on attributing blame to the patient, system-level factors that are impeding quality care and frustrating doctors and patients could be addressed. Regrettably, the discussion continues to emphasize patient agency when it come to adherence. Therefore, the necessary

¹⁶ Block scheduling means that patients are told to come during a certain time but they do not have specifically scheduled appointments.

structural changes are not addressed and the problems are only worsened as the system moves more towards the biomedical, market model.

The Doctor-Patient Relationship

Until recently, the patient-practitioner model could be understood through Talcott Parson's role theory, with the patient filling the "sick role" and the doctor the "professional role". Under this model, which fits well with the biomedical model, the doctors are supposed to apply their specialized knowledge in the interest of the patient to make all the decisions. Those occupying the sick role are supposed to be motivated to return to a healthy state which would entail trusting the HCP's opinion and passively follow their recommendations (Meichenbaum and Turk 1987:72). Parson's model assumes an unquestioning and uncritical patient and fails to respect the patient's autonomy or account for patient beliefs, knowledge, expectations and abilities. It neglects to account for cultural beliefs, social and economic constraints, psychological state, and a variety of other crucial factors. Furthermore, it assumes that all patients are or should be motivated to follow health recommendations, despite the fact that behavioral science research has discounted this assumption, showing different levels of readiness among patients to follow health recommendations (WHO 2003:34).

Doctors therefore need to learn to balance their expertise and power with empathy, compassion and patient participation. They must be trained to understand that the patient is the sole source of individual knowledge which should not be minimized in relation to the doctor's medical knowledge. Each party brings different perspectives and resources to the encounter. Neither party is automatically in charge (Haug and Lavin 1981:213). Although the medical jargon that doctors use is inaccessible and confusing to the average person, doctors often give patients too little credit and assume that their

patients will not understand an explanation and thus do not bother to attempt the explanation. If HCPs start out with the assumption that their patients are incompetent and irresponsible, a collaborative relationship with shared responsibility will be difficult to get off the ground (DiMatteo 1993), and an uneven power relationship develops that ultimately will infringe upon the mutually held goal of improving the patient's health. Communication and relationship-building has to be bilateral. The goal is not to place blame on either party. Robin DiMatteo (1993), author of *Interpersonal Expectations: Theory, Research and Applications*, reminds us that for each HCP who does not provide adherence enhancing information, there is a patient who did not ask for it and for every patient who leaves confused, there is an HCP who did not confirm understanding. That said, emerging from the conventional doctor-dominated model, the doctor may have to take the first steps to show the patient that collaboration is in fact encouraged. It is interesting and important to note that the word doctor comes from the Latin docere which means to teach. A doctor's role goes beyond that of scientific diagnostician to educator, supporter and troubleshooter. However, if we are to require this of doctors, we must create an atmosphere in which this type of relationship is possible. This includes alterations in the operation of the health care system, for example, allowing the doctor enough time with each patient¹⁷, and providing HCPs with adequate teaching of communication and adherence enhancement skills and support.

Putting in the time and effort early on to spearhead issues around adherence will ultimately save time, frustration and money in later stages. Medical care is not simply a

¹⁷ The average medical visit in the US is 18 minutes with an internist and 15 minutes with a specialist. However it is estimated that 19 minutes is essential for full patient participation. However just as important as the length of the appointment was the patient's subjective feeling of satisfaction with the length of time spent (DiMatteo 1993).

straightforward application of science and technology. The patient-HCP encounter is an interpersonal process which serves as the point at which the HCP can determine the patient's willingness and ability to follow treatment recommendations (DiMatteo 1993:301). Listening to patients is not only a sign of respect but a gateway to effective treatment. When physician-patient encounters were tape recorded, the findings illustrate that although doctors self-reported that they spent more time listening than talking, they in fact spent most all of the time talking. Moreover, only a small percentage of that time is used for critically educating the patient (DiMatteo 1993:303-4). Good care is attentive, responsive, responsible and competent (Dougherty 1996:54). As scientific knowledge and technology improve, the standard of care must not be forgotten. The importance of individualized, holistic care must not be lost to the pressures of cost-containment and efficiency. The cornerstone of care, the doctor-patient relationship, cannot be replaced with drugs or machines. Simply spending ten more minutes taking a patient's history can reveal important clues relevant to that patient's treatment that would not have been discovered otherwise.

Consequences of Non-adherence

Poor adherence spawns serious consequences. Less than optimal management and control of illness because of non-adherence is the primary reason for poor clinical outcomes (WHO 2003:11). Furthermore, poor adherence can lead to frustration on the part of both the doctor and patient, worsening of the condition, death, increased health care costs from increased visits, unnecessary diagnostic tests, emergency care, additional medications or hospitalization (Osterberg and Blaschke 2005:2; Meichenbaum and Turk 1987:25). Also, with some diseases such as HIV/AIDS, poor adherence can lead to the development of drug resistant strains which pose dangerous public health problems and

require the output of more money to develop new medications for the resistant strains (WHO 2003:21). Non-adherence can also skew the investigations of medical researchers who are trying to evaluate the effectiveness of interventions on certain populations.

Referred to as the nation's "other drug problem," the cost of non-adherence is estimated at \$100 billion per annum in direct costs alone (Osterberg and Blaschke 2005:2, Elliott et. al. 2003:508, Frost and Sullivan 3). Non-adherence is estimated to be the cause of 125,000 deaths, 10% of hospitalizations and 23% of nursing home admissions annually (Frost and Sullivan 3). Among the poor and elderly, non-adherence is often linked to inadequate prescription drug insurance. If a patient delays starting a medication, his or her condition may worsen and be more expensive to treat than if proper care had been provided early. Development and access to medications is necessary but insufficient if we hope to realize the full potential of advances in biomedical technology for treating diseases. Haynes states, "Increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments" (Haynes in WHO 2003:xiii). In many cases, investments made in interventions aimed at improving adherence will be fully repaid once the savings in health care utilization are calculated. While this may require an output of money at the start, the potential of improving health outcomes justifies the expense¹⁸ (WHO 2003:22). Again, it is an issue of how health care goals are framed. Looking at the big picture, effective treatment will require a shift in focus from a system centered on episodic care of acute illness, to a proactive system that emphasizes

¹⁸ It is important to realize that by talking in terms of cost-benefit analyses, we are not treating individuals as though they are entitled to health as a human right.

health throughout a lifetime¹⁹ (WHO 2003:23). Recall the WHO definition of health as not simply the absence of disease, but a state of complete physical, mental and social well-being. Framing care under the WHO's definition will establish higher expectations for provision of care.

Intervening

Interventions are often complex, labor intensive and may not even be predictably effective (Elliott et. al. 2003). Nevertheless, even moderate improvements have the potential to save lives and costs. Multi-faceted interventions with a combined focus on educational, behavioral and affective interventions: educating patients about their illness and treatment, teaching them strategies to cope with symptoms and medication taking, and addressing moods and emotions, have proved more effective than single-focus interventions (Carter et. al. 2005:10). Simply providing people with an information pamphlet, or giving them instructions is not very effective. Beyond just providing people with new information, successful strategies will also focus on enabling people to act on the information they already have, managing their own care, and coping with the challenges of daily life (Carter et. al. 2005:76). Much of this used to be part of basic care. Health care is grounded in caring. HCPs have always had a special obligation to help patients, putting the needs of the patient first (Dougherty 1996:52). As the health care system enters the market model, HCPs' obligations are being torn between their patients and a drive for profit.

The literature on adherence-improving interventions remains weak. Due to small sample sizes, many studies to date lack the statistical power to identify clinically

¹⁹ This move is especially important noting the epidemiological shift in the disease burden over the past fifty years from acute to chronic diseases (WHO 2003).

important effects. A review of interventions to improve compliance found “only a few rigorous trials... [which] provide little evidence that medication adherence can be improved consistently, within the resources usually available in clinical settings, and that this will lead predictably to improvements in treatment outcomes” (Carter et al. 10). Shortcomings in these areas have kept solutions elusive even after more than three decades of research. Furthermore, a shift in methodology from a quantitative to qualitative focus may also shed some new light on the issue of treatment adherence.

The World Health Organization (2003) is quite clear in its belief that the focus of interventions needs to continue to broaden, taking sole focus off of patient-related factors and targeting relevant factors in the health care environment. They recognize that there is no simplistic solution but see that the potential rewards of addressing non-adherence for both patients and societies are worth it. WHO (2003) advocates a stronger commitment to a multidisciplinary approach that coordinates action of researchers, health professionals, health planners, policy-makers, patients, families, and community organizations.

Delmos Jones (1976) suggests the role a social scientist might play. Jones responds to his experience teaching medical students about the social and cultural dimensions of health at a neighborhood health program in New York City. The point of the neighborhood clinics was to bring health facilities into the neighborhood, providing comprehensive care in a more intimate setting. All but one of the clinics were used to full capacity. When considering the problem of low utilization at one clinic, staff and directors immediately made assumptions and generalizations about the subgroup they were dealing with, attributing the causes of low utilization to the individuals. They did not consider the possibility that the problem was with something about the clinic itself

rather than the target population. For example, upon further investigation, researchers learned that some people had tried to visit the clinic, which was located inside a hospital, but there were no signs to direct potential patients.

It is naïve to think that a single approach will work for all patients. A combination of improvements, in the areas of patient education, improved dosing schedules, increased convenience of care (i.e. longer clinic hours), and improved communication, are needed. That is, interventions that target all aspects of adherence at all levels: individual and system.

HIV and Challenges to Adherence

A look at adherence to HIV/AIDS treatment should help us to apply and understand some of the general concepts that have been addressed thus far. HIV infection is an informative example of a chronic disease associated with adherence difficulties. As with other chronic diseases, regimen complexity, side effects, required lifestyle alterations, patient-provider relationship, are all potential barriers to adherence to HIV treatment (Chesney 2003). The average adherence rate to highly active antiretroviral therapy (HAART) is better (74.7% by MEMS²⁰) than that of other chronic diseases (50%), but still falls short of the greater than 95% adherence that is required to achieve therapeutic success, defined as, a non-detectable viral load, in 80% of treated patients (Stone 2001). Greater than 95% adherence means a patient who is on a twice daily regimen cannot miss more than three doses a month (Machtinger et. al. 2005). Even missing a single dose in 28 days has been shown to predict treatment failure (WHO 2003; Chesney 2003:171). Even among those patients with at least 95% adherence, 22% still

²⁰ The 74.7% is sited from a study by Paterson, D.L. et al (Annals of Internal Medicine 2000, 133:21-30). Other studies have also found adherence rates ranging from 70%-80% (Stone 2001).

experience treatment failure²¹ (Chesney 2003:171). Antiretroviral therapy (ART) adherence is the second strongest predictor, behind CD4 count, of progression to AIDS. Adherence explains 40%-60% of variation in viral load. A multivariable analysis, controlling for drug resistance, duration of therapy and CD4 count, found that each 10% decrease in adherence meant a doubling of the viral load (Machtiger et. al. 2005). Although several factors influence the success of ART, for example, genetics, prior drug resistance, or presence of opportunistic infections, but adherence is a large, and potentially alterable factor. For a combination of these reasons, HAART fails in nearly half of patients for whom it is prescribed (Ickovics and Meade 2002:98). Only individualized and flexible approaches that “fit” the treatment regimen to the patient’s life and daily schedule, will foster the levels of adherence necessary to keep people healthy.

While ART can keep people relatively healthy for many years, it is not a cure, and thus treatment continues every day for the rest of someone’s life. Seeing that adherence declines over time, it is not surprising that treatment of HIV poses a special challenge in terms of adherence. Furthermore, HIV disproportionately affects the urban poor, women and ethnic minorities, populations that are already more likely to be dealing with barriers such as mental illness, substance abuse, social isolation, homelessness or marginal housing, incarceration, difficulty accessing care and distrust in the health care system, all factors that have been shown empirically to have a negative impact on adherence (Stenzel 2001). The consequences of non-adherence are felt on the individual, the public health and on aggregate economic levels. Individuals with lower adherence rates have a higher

²¹ Treatment failure is defined as a detectable viral load (> 50 copies/cc), usually accompanied by falling CD4 T-cell count (APHA 2004).

chance of developing viral resistance, treatment failure and disease progression. In terms of public health considerations, drug resistant strains are spread to newly infected individuals making the disease harder to treat. Finally, looking at health economics, low adherence necessitates the use of more expensive, second-line and salvage regimes, higher rates of hospitalization, and the cost of treating opportunistic infections when the disease progresses (Poppa et. al.2003).

Some survey studies show that people with marginal housing situations or who have a history of substance abuse are less likely to be prescribed HAART (Stenzel et al. 2001; Chesney 1997). Another study found racial disparities in physician prescribing habits. Guidelines for drug therapy are based on the stage of disease, but among 838 patients with no racial difference in stage of HIV at presentation, there were racial disparities in the receipt of prescriptions. Sixty-three percent of eligible whites, but only 48% of eligible blacks received antiretroviral therapy (Moore et. al. 1994). This suggests that health care providers have designated certain populations as “untreatable”. They prescribe based on their judgment of whether the patient fits a “non-adherent profile,” even though research has repeatedly found there is no such thing. This framework is false and unacceptable. No patient is untreatable. In some cases HAART should not be started until the patient’s life has been stabilized, for example, by providing treatment for addiction or mental illness, or basic needs like food and shelter (Stenzel et. al. 2001), but, simply withholding treatment from certain subpopulations of individuals is not a valid option. This serious misconception must be addressed by shifting emphasis away from the individual, acknowledging the flaws in the system and the barriers that individuals face, and then providing the best care possible in an effort to help the patient attain his or

her treatment goals. Especially in the case of HIV/AIDS, which requires lifelong treatment, a strong working relationship between doctor and patient within the larger health care structure is essential for successful outcomes.

HIV/AIDS Treatment

Although the number of newly diagnosed cases of HIV infection remains stable, and the prevalence of HIV continues to rise, in 1996, coinciding with the introduction of HAART, for the first time since the start of the HIV epidemic in the United States, the AIDS death rate began to decline (APHA 2004:7). Much advancement has been made since the release Retrovir (AZT), the first antiretroviral drug approved for the treatment of HIV, in March of 1987. Retrovir alone needed to be taken six times a day.

Furthermore, for ART to be effective over a long period of time, individuals are required to take more than one antiretroviral at a time. HAART describes regimens using a combination of three or more drugs, which has become the standard of care. The traditional “AIDS cocktail” consists of two reverse transcriptase inhibitors and a protease inhibitor. The use of this combination therapy can mean swallowing as many as 20 pills each day (aidsmeds.com 2005; avert.org 2005). Additionally, the typical patient is also taking a variety of other medications to prevent or treat opportunistic infections, stimulate appetite or libido, manage pain, combat depression or fatigue, supplement diet, and control side-effects of the original medications (Chesney 1997). Multidrug regimens of this sort are characterized as the most difficult prescription needed for open-ended treatment (Chesney 2003). Other challenging factors in anti-HIV regimens include the high cost, food and drug interactions and unpleasant side effects (Osterberg and Blaschke

2005). The following section is meant to give the reader a better understanding of the virus and why it remains so difficult to treat even with major scientific advances.

The Disease Process and Groups of Antiretroviral Drugs

HIV replicates and spreads through the body by “hi-jacking” cells²² and using them to make new viruses. After binding to a cell, viruses hide their own DNA in the DNA of the cell so that when the cell manufactures new proteins, it will accidentally produce new viruses as well. With HIV, the genetic information is carried in RNA rather than DNA so a process called “reverse transcription” must occur, in which a viral enzyme, reverse transcriptase, makes a DNA copy of the viral RNA. Once the viral DNA is integrated with the cell’s DNA in the nucleus, it directs the cell to make new HIV (aidsmeds.com 2005).

Different groups of antiretroviral drugs attack HIV at different stages in this process. Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs), the first type of drug to treat HIV in 1987, block the proper replication of viral RNA into DNA, so replication of HIV cannot continue. Most combination therapies include at least two NRTIs. Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs), which began to be approved in 1997, also interfere with reverse transcription by impeding reverse transcriptase, the enzyme that carries out the process (avert.org).

Protease Inhibitors (PIs), first approved in 1995, inhibit protease, the enzyme that cuts up the long chains of viral proteins, created by the human cell, making smaller pieces that would be used to construct the cores of new viruses. A fourth class of antiretrovirals, Entry or Fusion Inhibitors, an example being T-20, which has been used

²² HIV specifically targets the T-4 lymphocytes, white blood cells that are responsible for warning the body of infections. These cells have many CD-4 receptor proteins, a protein that allows the virus to bind to the cell (aidsmeds.com 2005).

in the US and Europe since 2003, to prevent HIV from entering the cell. T-20 must be injected, and is only prescribed after other treatments have been tried (avert.org 2005).

Simplification

Regimens that used to require taking pills 6 times each day, totaling as many as 20 pills, have been reduced to twice-daily and even once a day dosing, and three-drug therapy that requires only two pills a day. Simplifying HIV treatment means altering two factors, the number of times per day (doses) the medication is taken, and the number of pills at each dose. The tables below show some of the simplified options. Furthermore, regimens have become more flexible in terms of dietary requirements. It is more likely now that treatment regimes will be less obtrusive to individuals’ daily lives. Finding the proper regime will require active collaboration between the patient and health care provider so their combined knowledge: the HCP’s scientific and the patient’s personal knowledge can be pooled producing a plan that is effective and agreeable to both the patient and provider.

Drugs that now require fewer pills (officially approved by the U.S. Food and Drug Administration)		
Drug	Before	Now
<u>Epivir</u> ® (lamivudine, 3TC)	2 pills a day	1 pill a day
<u>Kaletra</u> ® (lopinavir/ritonavir)	6 pills a day	4 pills a day*
<u>Retrovir</u> ® (zidovudine, AZT)	6 pills a day	2 pills a day
<u>Videx & Videx</u> ® EC (didanosine, ddI)	4 pills a day	1 pill a day
<u>Rescriptor</u> ® (delavirdine)	12 pills a day	6 pills a day
<u>Sustiva</u> ® (efavirenz)	3 pills a day	1 pill a day
<u>Viracept</u> ® (nelfinavir)	10 pills a day	4 pills a day

*New Kaletra tablets (approved October 2005), compared to older Kaletra capsules.

Medications Containing More Than One Drug

Drugs used individually	# pills a day	Combination Name	# pills a day
<u>Retrovir®</u> (AZT) & <u>Epivir®</u> (3TC)	4	<u>Combivir®</u>	2
<u>Retrovir®</u> (AZT), <u>Epivir®</u> (3TC), & <u>Ziagen®</u> (abacavir)	6	<u>Trizivir®</u>	2
<u>Ziagen®</u> (abacavir) & <u>Epivir®</u> (3TC)	3	<u>Epzicom™</u>	1
<u>Viread®</u> (tenofovir DF) & <u>Emtriva®</u> (emtricitabine)	2	<u>Truvada®</u>	1
<u>Lopinavir</u> & <u>Norvir®</u> (ritonavir)*	N/A*	<u>Kaletra®</u>	4

*Lopinavir has never been available for use, alone, without the addition of Norvir. As a result, it is not known how many pills of lopinavir and ritonavir would have been necessary if they were to be used together as individual drugs. (aidsmeds.com 2005)

Factors to consider when tailoring an ARV regimen include, pill characteristics, side effects, availability of symptom relieving medications, toxicity concerns, timing and frequency of doses, food restrictions, baseline viral load and CD4 cell count, treatment history, health status, resistance, existence of co-morbidities, domestic issues, employment status, and drug interactions. Thus, pill burden, while important is just one factor that must be weighed when creating a treatment plan. The HCP and patient must discuss and prioritize the factors to find the optimal regime of those available. This will differ depending on the patient.

Side Effects

For those individuals who are asymptomatic, HARRT may negatively impact their quality of life due to temporary and long-lasting side effects. From the patient's perspective, a short-term cost-benefit analysis might conclude that they are better off not taking the medication. A study of 860 treatment-naïve patients found 25% of patients discontinue treatment within the first year due to toxicity. Patients' subjective experience of side effects in the first four months is a stronger predictor of long-term adherence than sociobehavioral and other medical variables (Chesney 2003). Side effects may include

anemia, fatigue, digestive problems such as nausea, gas or diarrhea, lipodystrophy²³, neuropathy²⁴, bone loss and mitochondrial toxicity²⁵. While some of these symptoms can be treated, for example patients experiencing neuropathy can alter their regime to AZT, abacavir, non-nucleoside reverse transcriptase inhibitors (NNRTIs), or protease inhibitors that do not seem to cause neuropathy, other conditions, such as lipodystrophy and mitochondrial toxicity may be permanent (Aidsinfonet.org 2006). In either case, patients, especially those starting an ARV regimen for the first time, need to be prepared for the potential side effects. If patients are aware of the fact that some unpleasant side-effects can be directly treated or at least ameliorated with various coping mechanisms, patients will be less likely to take matters into their own hands by discontinuing or altering their treatments. One patient said, "...Sometimes when I really feel unwell, for example when I feel a bit dizzy, I will try to take, say, two out of the three pills that I have to take. Making such compromises is better than not taking anything at all..." (Molassiotis et. al., 2003:130). This patient's symptoms clearly are not being adequately addressed and their misconception that taking two out of the three pills is better than nothing shows that they have not been properly educated about the regimen.

Resistance

In the United States, as many as 50% of patients on ART are resistant to at least one antiretroviral drug. Drug resistance can then be transmitted to others resulting in newly infected individuals already being resistant to one or several treatment options.

²³ Lipodystrophy is characterized by the loss of fat from the arms, legs and face, and fat gain in the stomach and behind the neck. It can also cause metabolic changes that result in an increase in blood fats and sugars. Patients may develop insulin resistance and have increased risk of heart attack and stroke. This condition affects around 50% of patients (aidsinfonet.org 2006).

²⁴ Neuropathy affects about 30% of HIV patients. It causes sensations, sometimes extremely painful, starting in the feet and hands.

²⁵ The enzyme "pol gamma," which helps mitochondria multiply, is very similar to HIV's reverse transcriptase enzyme that is targeted by NRTIs and NNRTIs.

The combination of HIV's rapid infection rate, and the high mutation rate in each infection cycle, results in a complex and diverse mixture of viral species, some of which may have decreased susceptibility to certain medications (Clavel and Hance 2004). While HARRT tries to address the natural development of resistance by combining multiple drugs, poor adherence is a major cause of the development of resistant strains. The relationship between resistance and adherence is bell-shaped. At either extreme, high levels of adherence, resulting in maximum suppression of viral replication, or low levels of adherence, when viral replication still takes place, but there is not a high enough concentration of the drug to allow for resistance to develop, there will be minimal resistance development²⁶. In between these two extremes however, there is a high risk of developing resistance since viral replication continues to occur in the presence of the drug (Sethi 2004).

Other Factors Influencing Adherence to Antiretroviral Treatment

As if the complexity of the regimen was not enough itself, adherence is further complicated by other factors including patient-related, provider and system-based, and illness specific elements. Analogous to studies of adherence in general, demographic factors, such as, age, gender, ethnicity, and socio-economic status have not proven to be consistent correlates to adherence behavior. Rather than being predictive of adherence behavior, demographic data is useful in identifying certain populations that would benefit from interventions addressing specific barriers that they disproportionately face (APHA 2004:20). Non-adherence may be erratic, unwitting, or intentional. That is, patients may

²⁶ Findings of this bell shaped distribution further complicate the issue of adherence interventions. These findings suggest the potential for an intervention to improve adherence may actually increase chances of viral resistance if the intervention is successful at improving adherence, but only for example from 45% to 75%.

understand what to do, but forget or be too busy to follow through, other patients may misunderstand instructions and therefore accidentally omit a dose, or patients may deliberately alter their regime. Among patients participating in a clinical trial, reasons for missing doses were reported as follows: forgetting (43%)²⁷, sleeping through a dose (36%), being away from home (32%), changing routine (27%), being too busy to take the dose (22%), feeling sick (11%), and being depressed (9%; Kalichman 1998:130). Due to the multitude of different factors for a patient's non-adherence, non-adherence should be addressed with all patients. In each case, the reason for non-adherence must be uncovered before effective care can be provided.

Patient-related factors that do seem to have an impact on treatment adherence include, knowledge and understanding of the treatment plan, personal health beliefs, presence of a support system and co-morbidities such as substance abuse or depression (APHA 2004:21). Depression, injection drug use, and heavy alcohol use have all shown strong correlations to poor adherence (Stone 2001, APHA 2004). In fact, depression and stress are among the strongest predictors of non-adherence, with negative feelings and hopelessness lowering motivation for self-care. It is not surprising that many patients suffering from chronic illnesses also deal with depression. Once discovered, depression can be treated with medication²⁸. A supportive network of family and friends has also been shown to positively impact depression and adherence in general. Even though it has been shown that "family members' support and knowledge of the patient's disease and treatment are critical to successful adherence" (Stone 2001:6), it is not uncommon for

²⁷ Forgetfulness is not as simple a reason as it may first appear. Stone (2001) explains, "forgetfulness is a product of both cognitive and motivational issues; thus, it cannot be assumed that reminders alone (focusing only on the cognitive aspect) will solve the "forgetfulness" problem" (3).

²⁸ Some antiretrovirals, especially protease inhibitors, are contraindicated for use with psychiatric medications (Kalichman 1998).

HIV infected individuals to conceal their diagnosis from even their own family members for fear of the stigma they might face. The desire to conceal treatment also poses logistical problems to adherence. One patient said, “It is inconvenient to take pills when I go out. I feel embarrassed to take the medication in front of others so I take the pills earlier at home...” (Molassiotis et. al. 2003:131). The fear of being stigmatized, a common disease specific concern, plays a factor in accessing care. For example, one reason that barriers to care are more common among the black community in comparison to the mostly-white, middle-class gay community, is that the gay community has established organized support systems to exert political influence. This however requires individuals to be vocal about the HIV status (Moore et al. 1994:7). Physicians, nurses and counselors that the patient encounters while accessing treatment may be the only people with whom the patient can be honest and seek assistance, which puts that much more emphasis on the establishment of a trusting, collaborative relationship between patient and provider.

HIV is disproportionately prevalent in groups underserved by the health care system in the first place (APHA 2004:28). These individuals often have stressful and unstable lives and weak support systems, all factors that increase the challenge to adhere to long-term complex treatment plans (Stone 2001). Consider homeless people living with HIV. Even simply storing their medications, some of which may require refrigeration, becomes a challenge (Kalichman 1998:131). This certainly does not mean that homeless people as a group cannot adhere to treatment or should not be prescribed antiretrovirals. Rather, it means collaboratively identifying potential challenges to adherence and then creating a realistic treatment program and support system for the

patient. Anything that disrupts a person's routine can make adherence difficult. The purpose of the HCP is to help people develop strategies for dealing with changes in routine, and to offer long-term support as aspects of the patient's life or disease may change necessitating the development of new strategies (Crawford 2003).

As with research on adherence to other chronic diseases, an unbalanced amount of research has been on individual factors, even though these alone have not been able to predict adherence (VanServellen 2002:271)²⁹. More in depth research of some of the system- level factors may help to fill the explanation gap left between individual factors and non-adherence. For example, simply accessing the proper care is a challenge for the high percentage of Americans who are uninsured. Some aspects of access to care include, paying for medication³⁰, accessing primary medical and dental care, arranging childcare, and obtaining transportation to and from appointments. Structural changes, such as co-locating services facilities so that patients have same day access, will enhance adherence. Also, efforts to utilize the patient's waiting time (snacks, counseling or education settings) will limit patient frustration especially at clinics where all patients arrive at the same time (Birkhead et. al. 2001). A clinical setting that provides competent, confidential and convenient care can be expected to have better patient adherence. Patients who receive adherence services at their care site were more likely to be adherent (Ickovics and Mead 2002:99). Because we approach adherence enhancement from a biomedical perspective, identifying a clinical problem and then specifically treating that issue when

²⁹ In a study of 182 patients from 5 different community-based clinics Van Servellen et al. (2002) found that six factors- younger age, female, birth outside the US, lower hopefulness, lower access to care, and poorer treatment by clinic staff- accounted for 19.3% of the variance in adherence.

³⁰The combination of drugs in the antiretroviral regime can cost upwards of \$10,000-\$15,000 a year, not including labs and doctors visits (Kalichman 1998:112). Remembering that HIV treatment is a lifetime commitment, antiretrovirals are a huge expense.

adherence improves after a certain intervention is implemented, the success is associated with the specific intervention. Improved adherence, however, could be related to the perception that these services show sincere effort of the staff to support their clients, and the clients' perception of that interest, rather than only related to the adherence measures themselves. For, it has been shown that the strength of the doctor-patient relationship is an influential factor. Patient-provider relationships that exhibit good communication, compassion, convenience, and continuity of care, are linked with improved rates of adherence (WHO 2003). It is important to assess patient satisfaction. This can be done by eliciting patient evaluations on a regular basis. Evaluations can be done by interview, survey or group forum, and will help to identify specific areas where changes are most needed. A quality improvement initiative is a way to get providers "on board" with care expectations. Montefiore Medical Center has set a goal of providing all individuals receiving HAART with adherence counseling or intervention at each visit. Monthly, a team of physicians and nurse practitioners review patient charts to confirm that providers are in fact fulfilling this goal (Birkhead et.al. 2001). A program such as this is an excellent way to set the bar high when it comes to standards of care, and then make sure those priorities are not lost to other objectives such as maximizing profit.

Initiating Treatment

The time to first assess adherence is *before* the initiation of treatment, not once problems start to arise. Framing adherence enhancers as "interventions," suggests that they are only implemented, if need be, once the patient runs into problems. However, given the high likelihood of the development of resistance if drugs are not taken properly, patients do not have unlimited chances to get it right. Thus, in the case of HAART, it may

prove more prudent to delay treatment until the patient is ready to commit and barriers that would negatively impact adherence have been identified and managed (Stone 2001). Clinical guidelines recommend the initiation of ART when CD4 cell count drops from the normal levels of 500-1500 cells/mm³ to levels below 200. CD4 levels this low make the patient vulnerable to the opportunistic infections and tumors that are the AIDS-defining diagnoses (OARAC 2006). Once again, though, more than biological markers must be taken into account when treating an individual.

The Transtheoretical Model of Learning describes nicely the process of readiness. A patient moves along the continuum through the stages of pre-contemplation, contemplation, preparation, readiness, action, maintenance and relapse. Starting or changing ARVs is an action, but this approach highlights the prerequisite and subsequent steps which also require attention. Thinking in this type of framework encourages providers to see treatment as a process, in which they have an ongoing role: to help patients move stage to stage rather than simply focus on the act of adherence (APHA 2004:21). Taking a moment to step back from the biomedical focus and get to know the patient on an individual level, “learning as much as possible about the patient’s health history, beliefs, and attitudes about HIV, treatment, and sources of social support in addition to addressing the concrete problems of inadequate housing, lack of medical insurance, domestic violence, alcohol and drug use, mental illness, or other pressing issues may be the first priorities in preparing a person for the rigors of HAART” (Birkhead 2001:9). The basics of care cannot be underestimated.

A patient’s readiness can be gauged using a placebo “dummy run” in which the patient practices taking medication in the form of jellybeans or sugar pills so they find

out in advance problems they may encounter. In a study involving 20 men, participants were allowed to commence ART only once they had achieved over 90% adherence in their dummy run. Of the fifteen men who started treatment, nine needed only one pre-treatment week, but others required up to four weeks of practice. At a one month follow-up, 13 of the 15 men held 90% adherence levels (Aidsmap.com 2005).

While adherence is often treated as an end in itself, it is actually one of many factors to reach the larger end of good health in the WHO sense of the word. For the health care provider, the goals may seem obvious: viral suppression, prevention of viral resistance and health maintenance. It is important however, not to be presumptive of the client's goals which may or may not coincide with those of the provider. It is essential to make adherence meaningful to the individual patient by linking it to personal goals, thus creating the incentive to adhere (APHA 2004:4). These goals are uncovered during the process of open dialogue with the patient.

Like any condition, non-adherence must be properly diagnosed before it can be treated. That is, “define the conditions and circumstances leading to the adherence problem, prioritize these in some rational manner, and identify potential strategies to improve adherence and select objectives for trials” (APHA 2004:30). Before the initiation of treatment, the health care provider should have evidence of the patient's status in each of the following areas: environmental factors (What is the patient's living situation? Do they have a refrigerator to store medication? Do they have a phone if you need to contact them?), mental and emotional health (Are they depressed or have a history of depression?), substance use (Is the patient currently addicted to drugs or alcohol, or have a history of substance abuse?), knowledge of HIV and HIV treatment (Does the patient

understand what treatment entails and why adherence is important?), attitudes and beliefs (Is the patient open about their HIV status? Does the patient believe in the efficacy of ARVs?), social support (Is there anyone to assist the patient take their medication?), and past experiences (Does the patient have a history of missed appointments? Has the patient had troubles taking medication before?; hivforum.org). The answers to these questions do not preclude anyone from treatment, but rather give the doctor and patient a better idea of what stage of readiness the patient is in, and where to move to next.

Discussion

A review of studies measuring antiretroviral interventions may at first glance lead to more frustration than constructive data³¹; “ironically, the value of these studies may lie precisely in their failure to come up with consistent determinants of adherence or non-adherence. The surprise expressed by researchers when encountering findings contradictory to their expectations amply demonstrates the ease with which assumptions can be made about adherent or non-adherent individuals” (aidsmap.com 2005). The best that HCPs can do is to be competent in a range of intervention strategies, not to rush into treatment before getting to know and understand the patient they are dealing with, and then collaborate to find the right strategy for each patient. “True cooperation and collaboration require that each person respects the integrity and dignity of the other, even if circumstances of life and choices differ” (Birkhead 2001:2). Assumptions and stereotypes are misleading and dangerous. With such a complex and protracted regimen, at some point or another nearly all individuals will need help with adherence.

³¹ Most studies are small and underpowered. Of those reviewed by Simoni et. al. (2003), the average sample size was 66, with only 5 larger than 100. It is thus difficult to make reliable conclusions.

To date, the medical model's explanation of adherence has been too narrow, and because of that, so to has our response. Most of the research has had a quantitative focus. However, qualitative research, inspired by methods used in anthropology and sociology, has a lot to offer. Paul Koegel (1992) explains how an anthropological perspective, with its "commitment to an ethnographic approach, its focal concern with culture and adaptation, and its emphasis on holism," (2) can offer important information for health care providers. Quantitative research alone gives us only an incomplete snapshot of what is in fact an intricate canvas.

Koegel challenges the accepted terms, "service-resistant" and "non-compliant," which have become part of the medical vocabulary in referring to patients. Instead, Koegel introduces two concepts that are less likely to be addressed: "service-resistant service providers" and "service-resistant service settings". Again, the choice of words proves extremely important for how the issue is framed and thus discussed and dealt with. His point is that too often the focus is on individuals' actions, in isolation from the macro-level factors that influence those actions. The broader context he proposes includes, "not only the individual but the service provider, the service setting, the services themselves, and the conditions under which they are delivered" (Koegel 1992:8). Before dismissing a patient as resistant, think of all the patients who do want treatment, but "in seeking them, have failed to get what they want and thus do not return, or have found services are set up in such a way that accessing them is too difficult, too costly, or too frustrating" (Koegel 1992:8). Rich qualitative research includes not just interviewing, but also, participant observation. When added to self-report, observation can provide an alternative, sometimes corrective, view.

Regardless of the intervention ultimately chosen, the American Public Health Association (2004) suggests four general steps to approaching adherence. First, thoroughly assess those factors that may influence or function as barriers to adherence. Some factors to consider include, type of regimen, history of adherence, general health status, life goals, stage of readiness, co-morbidities, social stability, employment status, health/cultural beliefs, mental status and social support. Second, an ongoing effort must be made to establish and maintain a therapeutic relationship of trust, respect and co-operation. Third, monitor adherence. By both maintaining an open dialogue with the patient, and monitoring HIV viral load, adherence and treatment success can be tracked³². Fourth, various interventions can be implemented and changed as needed to resolve barriers to adherence. Focusing on fully understanding the reasons behind non-adherence, not just addressing one aspect, with short-term fixes, will prove most useful in the long run. So, to the extent possible several issues should be addressed at one time instead of waiting until secondary issues undermine the new plan.

The steps proposed by the American Public Health Association are hardly earth-shattering. In many cases, a successful intervention is simply providing services that once were part of a standard medical relationship but are eroding in an era of biomedical primacy and cost containment. One pilot study (Molassiotis et. al. 2003), involving six HIV-infected³³ non-adherent men, tested the efficacy of a behavioral intervention on adherence to ARVs. The three month intervention included education about ARVs and their side effects, positive reinforcement and encouragement, weekly individual counseling, follow-up calls, and lifestyle assessment and the identification of adherence

³² Treatment failure is not necessarily due to non-adherence. The HCP should thus not automatically assume that adherence is the issue and disregard other possibilities.

³³ This study was carried out in the outpatient clinic of a large teaching hospital in Hong Kong.

barriers. Assessment at six months suggested a 17% increase in adherence. Interviews with the patients at the end of the study revealed the following comments:

...She [the project nurse] also asked about issues in our lives, didn't just talk to us only about medication. She also cared about our condition after we take the medication. She gave us a bit more care... I liked the fact that the programme was concerned about my general wellbeing, the effects of the disease on my life, and not only my pill-taking habits...

...I felt there was someone to monitor me... well, not really monitor... but I felt that, although it was ultimately up to me to take the medication or not, I was to some extent responsible to someone. I had to fill in questionnaires at regular intervals and it made me realize that...Gee, I've been good this past month, I haven't skipped a single time!.. I was clearer about my situation... I also felt that the programme gave me support and encouragement in how to deal with life, how to look at the disease and my values...

...She [the project nurse] gave us answers and helped us analyze problems in detail, and let us know the benefits of taking the medication... When we didn't understand something about the pills, she would explain it to us... Actually she helped me clarify many things...It [regular contact] led me to reflect on whether I really wanted to take the medication... and I came to the conclusion that I needed to take them...

(Molassiotis et.al. 2003:131)

Not only did patients take their medications better, but also, patients had an overall improvement in quality of life and their ability to manage their life and treatment. This relates to the bigger picture, "The goal of therapy is to help patients maintain or improve their health, not to arbitrarily enforce their adherence to schedules of medication usage" (Steiner and Earnest 2000). The first respondent points out how the project nurse was concerned about his general wellbeing, not just his disease and medication taking behavior. Moreover, the second patient acknowledges his individual responsibility to take his medication, but appreciated the support of the project nurse to keep him on track and act as a guide. The third quote also illustrates that it is ultimately the patient who reaches the conclusion that they need to take their medication, but the doctor is there to teach, clarify and support along the way.

A Flawed Model

The notion that medical practitioners can enact unique practices according to their assessments of patient adherence highlights the potential impact of individual-level interactional and cognitive phenomena within healthcare systems. The ability of a healthcare system to provide the sorts of customized care...is not simply a matter of employing individual providers with the requisite skills to enact various strategies; it is also limited by the ecological environments in which those providers work and the organizational characteristics that may constrain and enable individuals' medical 'artistry'. (Lutfey 2005)

This paper has emphasized the fact that it is wrong to blame patients for factors outside of their control. Likewise, it is wrong and unproductive to simply shift blame and responsibility to the provider. The type of care required to improve adherence is not easily practiced in today's medical model. Even if it is proven to improve patient adherence, increasing services and spending more time with patients does not mesh well with biomedical skills and principles of efficiency and profit. A survey of 12,385 physicians, published in the New England Journal of Medicine, found that 1 in 4 thought the scope of care expected from primary care physicians was greater than it should be (St. Peter et. al. 1999). The current set up of the health care system makes it difficult for health care providers, even those with the best intentions, to follow through on the basic steps, such as really taking the time to get to know their patients and to identify and understand areas where they need support. Many physicians, especially those treating marginalized individuals, most likely to be infected with HIV and in need of the most support, are already overwhelmed. Increasingly, physicians are forced to change the way they may want to practice medicine to remain cost-efficient.

Managed care, defined as, "a system of providing health care (as by an HMO) that is designed to control costs through managed programs in which the physician accepts constraints on the amount charged for medical care and the patient is limited in the choice of a physician" (Dictionary.com 2006), has become a familiar term as health care has become increasingly subject to survival in the market. Increasingly providers are forced

to make trade-offs between cost and quality. There is an underlying motivation to spend less on care, and in many cases, providers are given incentives to minimize the expense of care. Capitation, for example, a system of reimbursement that pays a flat fee per covered patient per month, regardless of whether or not an enrollee uses services, encourages providers to spend as little as possible per person and treat those least likely to actually need care. Providers will be reluctant to implement adherence enhancers, which are currently framed as above and beyond standard care. Although improving adherence may result in long-term efficiency and profit, it will require an initial investment (Dougherty 1996:59). The conflict here is clear. The HCP is stuck between the financial incentive to under-treat and the moral incentive to provide quality care. Unfortunately, today's model increasingly emphasizes the financial side.

Furthermore, the squeeze placed on hospitals and providers by managed care will limit support for research, education and the provision of community services (Kassirer 1995). In a society where individualism and competition are celebrated, market principles have begun to permeate all aspects of life, but not everything fits so nicely into the marketplace. A national survey of students, residents, faculty, and deans at US medical schools revealed largely negative feelings towards the effects of managed care.

Especially when asked specifically about access to care, minimizing ethical conflicts and the quality of the doctor patient relationship, the overwhelming majority responded that the system of managed care made these more difficult (Simon 1999). More than ever before professionals are burning out, largely due to dissatisfaction with the medical field. Many doctors report that they would not choose to enter the profession if did it again, nor

would they recommend it to child or relative. This degree of dissatisfaction and alienation can seriously affect a doctor's ability to provide quality care (Dougherty 1996:13).

“Cost containment, American-style, causes the shoe to pinch in the wrong places, while the forces of medical entrepreneurship are constantly looking to beat the system by looking for new profit opportunities” (Kuttner 1996:156). Reform was needed in the health care system, but not all change is inherently good. Change needs to be in the right direction, guided by moral tenets not profit margins; a normative view frames health as a human right, not a privilege. We must remind ourselves of the values at the root of health care: caring, human dignity, and protection of the least well-off (Dougherty 1996). As with anything health care reform is not a black and white issue: “No doubt, the rapid and in some ways revolutionary market changes sweeping through the system will bring some improvements; but it is equally clear that they will also exacerbate some of the system's failures and exaggerate some of its imbalances. Moreover, “market changes tend as a rule to be unconscious of moral values –sometimes supportive, sometimes inimical, generally unaware” (Dougherty 1996:viii). Quality care must be rooted first in moral values, not market values.

Even the best interventions will not be practicable until systematic barriers, such as the fragmented HIV care system and poor coordination of clinical and support services, if they exist at all, are addressed. Demand is higher than available capacity, and providers are inadequately trained to deal with treatment beyond the initial prescription. The importance of HCP education is illustrated by the fact that levels of adherence have been positively related to the provider's experience in caring for HIV patients (Mantell et. al.). Partly, this is because those doctors will be more knowledgeable of the range of

medications available and thus there are more possibilities that one will fit their patient's daily routine. HIV trained doctors will also be armed with more experience in strategies to troubleshoot adherence barriers. Finally, it has been shown that a patient's perception of their doctor as competent is linked with better adherence (Ickovics and Mead 2002). Programs like Health Care Provider Adherence Training Curriculum- train clinicians, offer clinical consultation and technical assistance helps keep providers up to date so they can be as helpful as possible to their clients. This is a good example of widening the response to include more than patient targeted interventions.

To try to mitigate a shift to market values, The Center for Health Services Research and Policy at the George Washington University School of Public Health and Health Services has pushed for Medicaid Managed Care Contract Specifications. Around half of HIV-positive people are receiving health benefits from Medicaid, which in 54% of states is done through managed care. With contract specifications, when states contract with managed care organizations to provide services, the contract describes the services the managed care organization is expected to provide (hivforum.org). This allows for the perfect opportunity to ensure that high quality care, that includes counseling, education and consistent follow-up, is a priority. Finally, this is an intervention that addresses policy and structural change.

Creating a Culture of Quality

The Institute of Medicine defines quality care as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (Bodenheimer 1999). By this definition, supporting adherence is integral to providing quality care, because good adherence is linked to better health outcomes. Often, patients and doctors have a

different understanding and assessment of quality. In accordance with the biomedical model, physicians view quality as “the application of evidence-based medical knowledge” (Bodenheimer 1999). Patients, however, may put more emphasis on not just the care, but the way in which care is provided (i.e. communication, waiting time, support).

Accreditation has been a method used to pressure, either by loss of clientele or embarrassment, health care institutions into satisfying a minimal standard of care. However, most people have limited choice of where to receive care, so being able to compare report cards will not necessarily allow them to access better care. As Mark Chassin (1998), co-chair of the National Roundtable on Health Care Quality, laments “Our present efforts resemble a team of engineers trying to break the sound barrier by tinkering with a Model T Ford. We need a new vehicle or, perhaps, many new vehicles”. Serious structural readjustment is necessary if we are serious about improving quality of care, and as a result, improving adherence. A “perfect” system will always be illusive, but we can certainly do better than the current model. For the changes needed, a piecemeal approach will not work. Providers will not be able to make the changes needed to improve quality within the current climate of care.

Expectations for quality care when it comes to adherence need to be made explicit. Adherence needs to be identified as a priority, not an afterthought. We cannot hold providers accountable unless their responsibilities are clearly delineated.

Providers must then be trained to provide the type of care expected. “Their rigorous clinical training has not equipped them to make maximal use of a variety of methods to assess and improve their own practices. Principles of quality measurement and

improvement could be included in the education and training of future practitioners to better prepare them for this ongoing responsibility” (Chassin 1998).

Incentives should be based on high quality rather than low cost. In the long run, improved quality will reduce costs due to misuse and wasted services. There will however be an initial investment. Adherence interventions, similar to childhood vaccinations, are immensely cost-effective socially but may not be profitable to the provider.

There are three standard issues addressed when evaluating a health care system: quality, cost and access (Dougherty 1996). What makes change so difficult is that these three factors often conflict. For example, it would seem in most cases that an improvement in quality would also increase cost, or that seeing more patients to increase access would necessarily lower quality. At first glance, it is difficult to see how there can be a high quality, low-cost, universal system of care. Again, while we may not reach a perfect balance of the three, we can improve on the current balance or lack there of.

What is most important to understand is that health and quality health care are universal human rights. Once we begin to frame our conversations with this understanding, market values in this situation will take their proper place behind moral responsibilities. Non-adherence is just one symptom of current misplaced priorities. A solution to the long-troubling problem of non-adherence may not be in further technological advancements or randomized controlled trials, but rather, in a return to the basic building blocks of high quality care.

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