Chapter 7
Adherence Technologies and Treatment Engagement

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Why Adherence Matters

Non-adherence to treatment regimens of all sorts presents an ongoing threat to effective medical care. The challenge of non-adherence has long been recognized, yet despite hundreds of empirical studies on the topic, non-adherence rates remain high. Estimates of adherence failures vary substantially across disease type, severity, and complexity of regimen (DiMatteo, Haskard, & Williams, 2007) but one large-scale meta-analysis that included all English-language empirical studies from 1948 to 1998 ($N = 569$) suggested that approximately one in four patients is non-adherent (DiMatteo, 2004a, 2004b, 2004c); and, the costs associated with non-adherence are striking—as much as $290 billion annually in the United States (New England Healthcare Institute, 2009). Data clearly indicate that effective adherence is crucial for managing chronic illnesses, achieving viral suppression, reducing symptoms, minimizing relapses, and attaining a healthy immune system (Mahgerefteh, Pierre, & Wirshing, 2006; Westerfelt, 2004) and thus, effectively addressing the non-adherence problem is vital.

Poor adherence is linked to diminished health outcomes across a variety of domains; when medical regimens are not followed symptoms may not be improved and conditions typically worsen, leading to therapeutic failure, decreased satisfaction, and increased medical costs. For individuals with diabetes, non-adherence can result in higher blood glucose levels, all-cause hospitalizations, and mortality (Chisholm et al., 2007; Ho et al., 2006). For patients with viral conditions, failure to adhere may increase the risk of the virus becoming immune to the treatment (Westerfelt, 2004). Patients with other chronic diseases are also at greater risk, such

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as in the case of asthma, where sufferers have an increase in frequency and severity of asthma exacerbations and a greater risk of hospitalization if they fail to adhere to treatment regimens (Gandhi et al., 2013). Improper adherence to chronic pain medication can exacerbate perceived pain and this may, in turn, contribute to medication abuse and addiction (Graziottin, Gardner-Nix, Stumpf, & Berliner, 2011) and failure to adhere to medications for managing cardiovascular disease (which remains the leading cause of death, globally) can also lead to a range of harmful, or even fatal, results (Albert, 2008). In all, it is clear that although the specific outcomes associated with non-adherence vary by disease type and severity, they are uniformly detrimental, costly, and discouraging.

Predictors of Adherence

Predicting adherence is nearly as difficult as achieving it, but among the factors found to influence it are: complexity of the recommendations, psychosocial issues, knowledge about the illness or treatment, and patient-provider relationships and communication.

Adherence is consistently linked to the complexity of the treatment regimen itself. Research has shown that when treatment regimens include more doses per day, multiple drug-related restrictions (such as strict dosing schedules or requirements that foods be avoided within certain time frames), and/or pervasive lifestyle changes individuals are less likely to successfully adhere to them (Ingersoll & Cohen, 2008). Patients with chronic diseases, who often undergo complex treatments that may interfere with their normal daily routines, struggle a great deal with treatment adherence (Hauber, Mohamed, Johnson, & Falvey, 2009; Mellins, Ezer, Cheng-Shiun, Havens, & Chesney, 2003; Westerfelt, 2004).

Another set of factors that plays a vital role with regard to adherence is the psychosocial. For example, the odds of non-adherence for patients with depression is significantly higher than for those who are not depressed (DiMatteo, Lepper, & Croghan, 2000; Grenard et al., 2011) and other mental health issues, including anxiety disorders, may also interfere with patients' motivation and ability to carry out treatment recommendations (Haskard-Zolnierek & Williams, 2014). A large body of evidence not only demonstrates that psychosocial factors such as stress and depression are leading predictors of non-adherence, but also that these associations are similar across a multitude of different illnesses and diseases (Mackin & Areán, 2007; Mann, Ponieman, Leventhal, & Halm, 2009; Thames et al., 2012). Social support networks are also recognized as exerting important influence on adherence and chronic illness self-management, as demonstrated in several quantitative reviews (DiMatteo, 2004b; Gallant, 2003; Levy, 1983), with stronger social networks linking to better outcomes.

In addition to treatment-related and psychosocial factors, lack of knowledge (about one's disease, its treatment, and potential side effects) is a strong predictor of whether a patient is likely to adhere to treatment (Ingersoll & Cohen, 2008; Mei-Yu,

Su-Ching, Yorker, Chi-Chen, & Ya-Lin, 2008; Ulfvarson, Bardage, Wredling, von Bahr, & Adami, 2007). If patients have a better understanding of what they are being asked to do, why they are being asked to do it, and what outcomes are likely if they do (or do not) carry out the action, they are better able to comply with their treatment recommendations—they are better informed and more motivated (Martin, Haskard-Zolnierek, & DiMatteo, 2010). This knowledge and its associated motivation are best achieved when clinicians engage with patients and create meaningful care-partnerships with them.

Data clearly indicate that engaged patients—those who share in decision-making and enjoy effective communication with their health care providers—are more adherent, have better health outcomes, and are more satisfied with their medical care (DiMatteo, 2004c; Golin, DiMatteo, & Gelberg, 1996; Guadagnoli & Ward, 1998; Hall, Roter, & Katz, 1988; Stewart, 1995). A key question, then, centers on how to engage patients in the process of their own care, so that optimal outcomes can be achieved.

Technology, Patient Engagement, and Adherence

Technology is regularly used in medicine to prolong life and improve its quality (Thompson & Walker, 2011) with tools ranging from genomic mapping and data storage/retrieval to sophisticated real-time scanning and robotic surgical techniques. Patients can access information more easily than ever before, and possibilities for healing and health seem endless as new medications, devices, and interventions are developed. But despite all the high-tech aids at the disposal of clinicians and their patients, non-adherence remains a serious problem. It is as C. Everett Koop, U.S. Surgeon General from 1982 to 1989 so aptly stated, “Drugs don’t work in patients who don’t take them.” Indeed, we may have the best medical care available, but if patients do not engage with that care and adhere to recommendations, that top-quality care cannot be effective. So, if patients are not following the recommendations of their clinicians, where are they getting their health advice?

It is estimated that about one quarter of those using social-network sites have followed medical advice given by other users based on their anecdotal experiences (Fox, 2012). There were approximately 1.35 billion active monthly users on Facebook as of July of 2014 and 284 million active Twitter accounts in October of 2014; these are just two of many hundreds of social-network sites. Add to these the many (sometimes cleverly disguised) health-related advertising sites, the governmental and nonprofit sites providing information, and scores of empirical research reports and articles and it is easy to see how one might be overwhelmed, confused, misled, or worse.

Patients have many reasons for seeking health-relevant information online, ranging from self-diagnosis to checking on the competency of their healthcare providers (Hay, Strathmann, Lieber, Wick, & Giesser, 2008). But although many patients say that the information they find online changes their overall approach to their health

(Tu & Cohen, 2008) most still desire professional, expert advice about their symptoms, conditions, and possible treatments (Czaja, Manfredi, & Price, 2003). Because there is little quality control associated with online health information, and inaccurate information is associated with negative health outcomes, it is vital that patients bring what they have found to their medical encounters for discussion with their providers. Correcting misconceptions and helping patients to be better consumers of health information is vitally important (Bird, Conrad, Fremont, & Timmermans, 2010). When clinicians are responsive to their patients' needs for information improved adherence, better symptom resolution, and greater satisfaction result (Bultman & Svarstad, 2000). But without a healthy, trusting relationship it is unlikely that patients will feel comfortable sharing alternate views or information garnered from online sources; this highlights the importance of establishing and maintaining strong partnering relationships with patients. Health beliefs, worries, and other potential barriers to adherence cannot be addressed if they are not identified.

From Marx to Turkle, technology has long been regarded with some suspicion and a sense that it may be alienating us from our communities and even ourselves (Turkle, 2012; Wendling, 2009). Thus, it is not surprising that people sometimes have a hard time thinking about technology as a means of strengthening and improving the partnerships between clinicians and their patients. Data suggest, however, that patients often have a difficult time reporting their adherence accurately, and also indicate that most patients want to please their physicians and to adhere to their recommended treatments—they do not want to be "bad patients" (Roter & Hall, 2006). Therefore, when technologies enable patients to better adhere, to better understand, or to take more responsibility for their own outcomes, technologies will surely contribute to stronger partnerships with their care providers and, ultimately, to better outcomes. Thus, we turn now to an examination of the ways in which technology can be used to improve adherence with a particular emphasis on the ways in which it might foster patient engagement.

Automated Messages and Text/SMS. One of the most widespread and useful technological tools used by both patients and health professionals is the short message service (SMS). The SMS technology can be used to remind patients of appointments and dosage schedules, to support their self-monitoring efforts, and to facilitate patients' sharing of information and treatment concerns with their providers. These prompts may help patients to feel more control over their care-management and can encourage them to engage in the day-to-day process of optimizing their own health.

A large proportion of the population possesses cell-phones making SMS and text messaging convenient mediums for communication and reminders. de Niet et al. (2012) describe SMS via mobile phone as easy to use, inexpensive, quick, and customizable to the patient and SMS has been shown to improve treatment adherence and reduce treatment dropout (de Niet et al., 2012; Hardy et al., 2011; Haug, Meyer, Dymalski, Lippke, & John, 2012).

Because SMS allows providers to interact with patients at times that are most practical and because they are not limited to a specific location, patients can often get their questions answered, their concerns alleviated, and their appointments

scheduled more promptly and efficiently. Additionally, it has been suggested that for some patients this form of communication is less anxiety-provoking and may feel more comfortable than face-to-face discussions or phone conversations.

Short message services may be particularly helpful in certain contexts, such as in rural areas with limited resources. For example, one study in rural Kenya found that patients who received text message treatment reminders were significantly more adherent and less likely to experience treatment interruptions than patients who had no text message reminders (Pop-Eleches et al. 2011); likewise, a study focusing on rural communities in the United States found that compliance rates of treatment in borderline personality disorder patients were much higher using text messages to monitor mood changes than compliance rates for the usual paper-pencil mood charts (Foreman, Hall, Bone, Cheng, & Kaplin, 2011). Similarly, a study in rural Bangladesh found that participants who received mobile phone calls and reminders for screenings were more likely to have their malaria detected and to receive appropriate treatment earlier than those who were not contacted via mobile phone (Prue et al., 2013). In neither of these studies were the living conditions of participants conducive to taking care of one's health. The reminders may have helped to keep health-related issues closer to the forefront of the participants' minds, thus improving their abilities to carry out health-related plans.

Although texting reminders are useful in rural and less economically secure areas, they have also gained popularity in more economically successful regions where the majority of the population possesses mobile phones. Adolescents with cell phones are much more inclined to be adherent when given SMS reminders (de Niet et al., 2012) and a wide range of screening, preventive, and disease management behaviors have been shown to improve with the use of electronic reminders, including oral contraceptive and other medication use; mammograms fecal occult blood screenings, and cholesterol screenings; smoking cessation; exercise; and weight loss (Castaño, Bynum, Andŕes, Lara, & Westhoff, 2012; Cole-Lewis & Kershaw, 2010; Ornstein, Garr, Jenkins, Rust, & Arnon, 1991). Texting reminders would likely be useful for elderly adults, as well, since they may forget to take their medications or to come in for appointments; but there is little data on elderly patients and their experiences with text messages and other SMS technologies. This may be due, in part, to the relatively lower level of technological sophistication in this age-group but these age-related differences are rapidly diminishing.

Despite the promising nature of SMS and related technologies, the evidence for their effectiveness is by no means unequivocal. Recent reviews have found that medication adherence and appointment attendance are generally improved with electronic reminders (Gurol-Urganci, de Jongh, Vodopivec-Jamsek, Atun, & Car, 2013; Vervloet et al., 2012), but it is less clear that such interventions are as consistently effective at improving self-management of chronic diseases such as diabetes and asthma, although many studies to show promising results (Cole-Lewis & Kershaw, 2010; de Jongh, Gurol-Urganci, Vodopivec-Jamsek, Car, & Atun, 2012). Taken in total, the evidence suggests that automated reminders and SMS-style approaches may be most useful as supplements to more traditional, in-person communication (e.g., Granger & Bosworth, 2011).

Remote Videoconferencing and Telehealth. Another tool that aims to improve communication, strengthen clinician-patient relationships, and foster adherence is remote videoconferencing or telehealth. Remote videoconferencing can be convenient for both patients and clinicians since the parties can "meet," share information, ask questions, and discuss concerns without the time-investment associated with traveling to meet physically in a single location. This technology has been shown to be particularly useful for patients who are chronically ill and find it difficult to leave home or patients who have diseases or infections about which they fear social stigma. For example, HIV-positive patients report that videoconferencing effectively meets their needs and concerns (Lillibridge & Hanna, 2009; Saberi, Yuan, John, Sheon, & Johnson, 2013). HIV-positive patients using telehealth technology reported that it was more convenient and more cost effective than regular doctor meetings and they also reported being more comfortable and less intimidated than in face-to-face meetings (Saberi et al., 2013). These patients felt that videoconferencing provided a quick and convenient way to get their questions answered while also helping them feel comfortable talking to their medical specialist as they felt less judged and stigmatized than when communicating in person.

Videoconferencing has also been shown to be useful for patients who have transportation constraints or are discouraged by distance from making regular doctor visits. Distance and geographical terrain can be a challenge for patients; living in a rural area where health services are difficult to access creates a real deterrent and, in many cases, videoconferencing can mitigate the problem. Research in pediatric care with children who live in rural areas shows that video conferencing eliminates the barriers of travel and unavailability of healthcare personnel for patients living with asthma (Chan, Callahan, Sheets, Moreno, & Malone, 2003). It can also enhance the success of early intervention techniques with patients who have disabilities such as spina bifida or Down syndrome, as daily-care providers can more easily interface with the clinicians providing physical and occupational therapy coaching and those clinicians can suggest ways to enhance treatment while they are watching the parent-client interact in real time, in their home environment (Olsen, Fiechtl, & Rule, 2012). Thus, videoconferencing can improve treatment adherence by increasing patients' knowledge about what they are supposed to do, and by creating an environment in which patients feel comfortable and problems likely to be encountered in the home environment may be more readily apparent to the clinician. With personnel available in real time, videoconferencing allows patients to ask questions clarify any confusion or doubts they may have about their treatment.

Telehealth has not only been used by physicians but also by psychologists and their clients—in mental/behavioral health settings this technology may be referred to as "telemental health" (Baker & Bufka, 2011). There has been discussion about the degree to which it is appropriate to incorporate telehealth into psychological practice, mainly due to concerns over privacy and the lack of in-person, face-to-face interaction which has been the foundation of psychological therapeutic practice. Despite these concerns, early indicators seem promising and there are potential benefits associated with psychologists' ability to conduct therapy and assessments by telephone and videoconference (Maheu, McMenamin, Pulier, & Posen, 2012). As in many traditional

medical encounters, psychologists can use videoconferencing therapy with clients who live in remote locations—eliminating the requirement that both parties be in the same location widens the opportunities for appropriate matches between therapist and client (Nelson & Velasquez, 2011), and clients are able to engage in therapy without leaving the comfort of their own homes. Videoconferencing in therapy has been shown to reduce hospitalization and thus seems to be an effective tool for managing mental health. A nationwide study by Godleski, Darkins, and Peters (2012) showed that, in a sample of 98,000 mental health patients being served by the Department of Veterans' Affairs, a 25 % reduction in hospitalizations occurred between the time of implementation of a videoconferencing telemental health system in 2006 and the follow-up in 2010. Thus, telemental health services represent a promising possibility for improving outcomes for those with a variety of mental health problems.

Videoconferencing in telemental health is also beneficial because computer technology allows therapists to gain additional information that may be difficult to obtain in face-to-face encounters but which can meaningfully inform the therapy. For example, with proper lighting therapists are able to zoom in to view nonverbal behaviors such as facial expressions, tics, and other physical manifestations in more detail (Nelson & Velasquez, 2011). This gives telemental health therapists an edge over those relying on traditional techniques since they may be able to detect cues, at the moment they occur, that would have been missed in face-to-face interactions.

Although the future of telemental health services looks bright, there is controversy over the use of these technologies. Perhaps the most serious critique of telemental health services and videoconferencing is the risk, real or perceived, to privacy. Clients may worry that since they are seen through video, that they may also be recorded; or that other people may be observing or listening to the encounter. If a patient believes that someone other than the therapist is listening, she or he might not feel comfortable sharing intimate information. This highlights the importance of building a strong bond with patients—perhaps especially with those being seen for mental health issues—prior to implementing telemental health approaches. And, therapists must be sure to follow the guidelines of informed consent and other ethical considerations when using video or audio therapy (Baker & Bufka, 2011; Maheu et al., 2012). Video recording in videoconferencing is also a confidentiality challenge that therapists and clients must be aware of. Guidelines for videoconferencing and other telemental health services are uncertain, as the use of these technologies is a fairly new approach in the clinical health field. Other potential concerns include technological disruptions due to inadequate internet service, poor video quality, and lack of referral services in patient's areas (Baker & Bufka, 2011). However, these technological services may prove to be very effective with more practice and as models for how therapists and providers should approach these technology-mediated interactions are refined.

Online Support Groups. Another useful strategy by which clinicians can support adherence and positive health outcomes is referral to online support groups. One good predictor of adherence is support from family, friends, or a caregiver. Particularly for those who have less in-person support from friends or family, these support networks can serve a vital function. And, even for those who have adequate

in-person support, these groups can provide the type of camaraderie, social comparison, and encouragement that can be so important to sustaining one through the ups and downs of treatment. Individuals who are struggling with the same issues may be able to make practical suggestions and troubleshoot in ways that even the most supportive non-sufferer cannot. For example, research on cancer support groups concludes that they are effective for enhancing the delivery of treatment information, of emotional support, and for encouraging active participation in decision-making (Beaudoin & Tao, 2007; Huber et al., 2011). The emotional support and peer-to-peer discussion of treatment options and coping strategies with others who are undergoing (or have conquered) similar obstacles can be of great benefit; clinicians who are able to facilitate connections to such groups may be doing their patients a great service.

Online support groups have not proved to be as effective for people with mental health issues such as depression, however (Griffiths et al., 2012; Melling & Houguet-Pincham, 2011). Much of the research on online support groups specifically for depression contains anecdotal evidence with little empirical evidence of efficacy. Although online support groups are helpful for some people, more research is needed to better understand the limitations for particular groups, and to identify cases in which online networks may be detrimental. Nevertheless, online support groups have generally been shown to associate with positive outcomes through their enhancement of emotional support and provision of environments conducive to the discussion of various aspects of treatment and coping.

Tracking Apps. As interfaces with technology become more seamless, mobile apps are likely to gain prominence as desirable tools for engaging patients in their own care and improving adherence. Although many of these apps are new and still being refined, there is a good deal of enthusiasm about the possibilities they suggest. One kind of app that is said to improve treatment adherence is MediSafe Project's *mobile pillbox*. The mobile pillbox health app has now gone through several trials and Horowitz (2013) reports that, using the app, patients with Type 2 diabetes are able to improve their adherence rates to about 80%. The pillbox app is set up to remind patients when to take their medication and sends an alert to someone close to the patient such as a family member or caregiver if a dose is missed. Once the patient indicates on the app that the dose of medication has been taken, the app stores the data to accurately report adherence rates. Caregivers can monitor patient adherence through the app's stored data, which can also be synced to the caregiver. Intel is also working with researchers on refinements to similar mobile apps to enable location sensors to remind patients about their medications at the most appropriate places and times (Janet, 2006).

Mobile apps that not only remind the user, but also engage the supportive community, tackle two large predictors of adherence at the same time: forgetfulness and lack of support. With this combination, patients are more likely to adhere to their recommended treatments as they are not only prompted to adhere but the supportive network that might foster the desired behavior is also cued to act. Despite the promise of apps like the mobile pillbox, only a small percentage of caregivers currently use adherence technologies to track patients' medication (Horowitz, 2013). Reasons

for this are not clear, but probably include varying levels of comfort with technology on the part of both clinicians and patients; concerns over integrating data from these systems with existing clinical software; and worry that more automation will decrease the hands-on, personal aspects of care. As these apps become more integrated into everyday care, however, it seems likely that they may not only be recognized as a useful tool in their own right but also as a means of facilitating conversation, partnership, and engagement in active decision-making for clinicians and their patients.

Moving from the high-tech to the ultra-high-tech, smart pills (or wireless motility capsules) can be swallowed like regular pills and used to track a variety of indicators including adherence. Along with an epidermal patch that must be worn and smartphone app specifically used for the pill, the smart pill can track medication taken, body temperature, and heart rate (Heart Beat, 2012). Since the FDA approved the wireless motility capsule in 2006, researchers and physicians have been using this device to track medication adherence, internal pressure, pH, and body temperature (Saad & Hasler, 2011). The pill has been primarily used with people who have delayed gastric emptying, but the pill has been receiving attention from providers and researchers who want to track other elements of patient health and treatment adherence. Although more invasive, this technology has the ability to do more than simply remind—it can accurately report on what a patient has (or has not) done, and record the body's responses. This can provide a solid foundation for beginning or continuing a discussion about the best ways for a patient to improve his or her health.

Leveraging Technology to Engage Patients

The integration of technology into one's practice to best serve the patient's needs is truly an art. It requires that the clinician be personally engaged and know the patient as an individual to achieve the best match. Some patients will move quickly to embrace new tools and others will be more hesitant; taking the time not only to think about one's recommendation but to explain its importance and utility (much as one might explain a new medication) is crucial. Making recommendations about technologies that help patients to self-monitor and self-manage sends an important message—that the clinician supports and sees the value in these actions. This strengthens the sense of shared commitment to and responsibility for patient health outcomes.

Many patients *will* use apps and various websites to garner information about their ailments and possible treatments; thus, it makes sense for clinicians to make recommendations about these. Without recommendations to reputable sites and products, patients may select suspect or even dangerous options and quality is likely to be low.

Clearly technology cannot, and should not, replace the relationship between the patient and his or her clinician. Technology should, however, help to maximize the

knowledge, autonomy, and confidence that each party brings to the encounter. It should help patients to be more accurate in their reports of their own behaviors, and to more effectively carry out the commitments they make regarding their health. And, it should facilitate the communication and partnership between the health care provider and the receiver of that care.

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