The Issue Is...

More Than Good Intentions: Advancing Adherence to Therapy Recommendations

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- behavior therapy
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- patient compliance

Everyone who has tried to change their behavior can appreciate the difficulties in sustaining this effort despite their best intentions. Imagine, then, the effort required to adhere to occupational therapy recommendations after the onset of disability when the associated everyday changes are not necessarily of one’s own choosing. Many people who receive occupational therapy services face this scenario, especially those with chronic health conditions. Many patients with stroke, brain injury, and spinal cord injury do not follow discharge recommendations or prescribed therapy protocols (Andrews & Stewart, 1979; Ditor et al., 2003; O’Brien & Bailey, 2008; Schönberger, Humle, Zeeman, & Teasdale, 2006; Wallenbert & Jonsson, 2005) even though doing so is associated with optimal outcomes of care (Clay & Hopps, 2003). The rates of nonadherence to chronic illness regimens are estimated at 30%–60%, which is significantly worse than those for acute illness treatments (Christensen, 2004).

Despite the evidence that people with chronic health conditions may not adhere to their health care providers’ recommendations, the issue of nonadherence remains largely ignored by occupational therapy clinicians and researchers. The term itself is omitted from the profession’s official vocabulary (American Occupational Therapy Association [AOTA], 2008), and the enterprise is not represented in conceptualizations of the service delivery process (AOTA, 2008). Occupational therapy research is equally lacking in this area. A small number of publications have primarily focused on adherence as a secondary or ancillary issue; few studies have specifically examined adherence-promoting strategies. Moreover, this gap in occupational therapy adherence research was not specifically mentioned in the recently developed AOTA/American Occupational Therapy Foundation research agenda (AOTA, 2009).

The purpose of this report is to bring the problem of nonadherence into the occupational therapy professional fold and clinical conversation. To that end, I describe the complexities associated with adherence to medical recommendations and summarize the small literature specific to adherence and occupational therapy. I use an ecological model of adherence in rehabilitation to propose adherence-promoting strategies for clinicians and conclude with directions for occupational therapy research.

Adherence Defined

Adherence has been defined as “the degree to which patients and research participants act in accord with the advice of their clinician or researcher” (Moseley, 2006, p. 662). This term replaces the use of the word compliance, which connotes patient passivity and obedience (Levensky & O’Donohue, 2006) and suggests behavioral change without internal acceptance (Johnson & Johnson, 2006). Low adherence to medical recommendations takes many forms (Levensky & O’Donohue, 2006). People may miss or come late to appointments, not initiate (or partially implement) a recommended treatment, not complete behavioral recommendations (e.g., exercise changes), make adjustments in medication regimens (e.g., taking too many or too few pills or doing so at incorrect times), or prematurely discontinue therapy.
Adherence and Occupational Therapy

Limited adherence to medical recommendations should come as no surprise. Most medical and rehabilitative interventions require people to make some degree of behavior change (Levensky & O’Donohue, 2006), which even under ordinary circumstances is difficult for people to maintain (Prochaska, DiClemente, & Norcross, 1992). The potential for poor adherence to therapy recommendations should be of particular concern to occupational therapists because of their clients’ characteristics and the nature of occupational therapy intervention. Most service recipients have chronic rather than acute health conditions that interfere with their functioning and are, therefore, at significant risk of low adherence (Christensen, 2004). People with chronic conditions may experience treatment fatigue in which they do not adhere to recommendations, in part, because they have little confidence that the treatment will make a difference (Jaarsma, Abu-Saad, Dracup, & Halfens, 2000). Some of the sequelae associated with chronic neurological disability may compound the adherence challenge. For example, one of the consequences of acquired brain injury is lack of awareness of cognitive deficits (Prigatano, 1991), and it is particularly difficult to help people adhere to treatments or recommendations for problems they do not know they have (Schöenberger et al., 2006; Trahan, Pepin, & Hoppes, 2006). Moreover, most occupational therapy intervention approaches involve teaching people strategies (exercises, activities, equipment use, environmental modifications) that enable them to advance their own healing, adaptation, wellness, and quality of life. Patients are rarely “fixed” at clinic sessions. Therefore, even evidence-based occupational therapy interventions and recommendations will be ineffectual if clients cannot or do not adhere to them at home.

The small occupational therapy literature associated with adherence has affirmed that adherence is important to therapy outcomes. Adherence to therapy recommendations was positively associated with occupational therapy outcomes for cancer-related lymphedema (Johnstone, Hawkins, & Hood, 2006). Even modest levels of adherence to occupational therapy recommendations given to caregivers of people with Alzheimer’s disease appeared to differentially ameliorate caregiver burden (Dooley & Hinojosa, 2004). Most of the occupational therapy literature has described influences on patient adherence. For example, adherence to resting splint use by people with rheumatoid arthritis was found to be linked to comfort (hard vs. soft splint; Callinan & Mathiowetz, 1996). Similarly, patients made decisions regarding whether to wear pressure garments to treat burn injuries on the basis of the garments’ appearance and construction (Stewart, Bhawanjee, Mbakaza, & Binase, 2000). Chen, Neufeld, Feely, and Skinner (1999) found that self-efficacy and internal locus of control predicted adherence to an upper-extremity home program use. Availability of family help and an optimistic expectation for results was found to predict implementation of home modification recommendations to prevent falls (Cummings et al., 2001). Only two studies evaluated the use of adherence-promoting strategies on adherence and outcomes, both of which examined patient education methods. Feinberg (1992) found that adding adherence-enhancing strategies such as using learning principles and shared expectation was linked with greater use of resting hand splints than was standard care. Hammond and Freeman (2004) also demonstrated that the nature of client education for joint protection made a difference in terms of adherence at 4-yr follow-up. The people with rheumatoid arthritis who were randomly assigned to the behavioral approach (practicing strategies, goal setting, planning home programs) had significantly better joint protection adherence, less morning stiffness, and higher activities of daily living (ADL) scores than those who received standard care.

Recommendations for Practice

In the absence of extensive direction from the occupational therapy literature, I propose several possible strategies to enhance clients’ adherence to occupational therapy recommendations. These strategies are based on two central assumptions.

First, adherence can be viewed as an ecological enterprise, as depicted by the Ecological Model of Adherence (Figure 1; Radomski, 2007). Based in part on the combined work of Clay and Hoppes (2003); George, Kong, Thoman, and Stewart (2005); Ryan and Wagner (2003); Sankar, Luborsky, Schuman, and Roberts (2002); Wehmeyer (1999); and Wehmeyer, Kelchner, and Richards (1996), this model suggests that adherence for people with chronic health problems, disability, or both is a function of person, provider, and intervention factors that are set in the context of environmental, social, and technological constraints or enablers. Person, provider, intervention, and related contextual factors are synthesized, shaped, and actuated through self-determination (personal choice) and learning (skill acquisition and employment).

Second, I suggest that adherence is a process involving a sequence of interrelated patient-therapist decisions and actions rather than an on-off switch (Figure 2). Consequently, occupational therapists shoulder at least some of the responsibility for whether service recipients adopt occupation-enhancing recommendations.

Therefore, although appreciating the complex and interactive aspects of the ecologically based adherence enterprise and process, I highlight three categories of adherence-promoting therapist activities: (1) selecting and right-fitting the intervention recommendation, (2) advancing self-determination and learning, and (3) supporting implementation of recommendations and habit formation.

Selecting and Right-Fitting the Intervention Recommendation

Adherence is optimized when the recommended activity, behavior, or regimen is in sync with patient priorities, preexisting routines, and available supports and enablers. Therefore, before specifying any recommendations, occupational therapists must build the kind of therapeutic relationship that sets the stage for an honest dialogue about these critical adherence
Figure 1. Ecological model for adherence in rehabilitation.

factors. A solid emotional bond between practitioner and client influences adherence by providing a secure framework within which a client can come to terms with a new diagnosis, condition, or limitation, insights that are prerequisite to adherence to treatment recommendations (Schönberger et al., 2006). Incorporating structured interviews, such as the Canadian Occupational Performance Measure (Law et al., 1994) and motivational interviewing (Miller & Rollnick, 2002), into the evaluation process can help the therapist figure out how to link therapy recommendations to what really matters to patients. Finding out detailed information about the client’s everyday routines, such as talking through the patient’s typical day (Radomski, 1995), is equally as important in selecting appropriate recommendations. That people with stable daily routines seem to be better able to adhere to recommendations is well-established (George et al., 2005; Roberts, 2000; Ryan & Wagner, 2003). Adherence is optimized if the person can link the recommended behavior, medication, or therapeutic activity with specific routine daily events, such as eating breakfast or watching a television program (Ryan & Wagner, 2003; Segal & Beyer, 2006), so that it ultimately becomes automatic (Roberts, 2000). Morning routines are particularly important to adherence because they are more regimented for most people; evenings tend to be more varied and less structured (Ryan & Wagner, 2003).

If therapy adherence involves modifying existing routines or developing new ones, therapists must try to understand the patient’s readiness to make the large or small everyday changes that may be necessary. The Transtheoretical Model of Stages of Change (Prochaska et al., 1992) proposes five stages of change: (1) precontemplation, (2) contemplation, (3) preparation, (4) action, and (5) maintenance. Therapists may use informal interview methods to explore patients’ readiness to change associated with specific recommendations. Specifying an actionable therapy recommendation is pertinent only for those in the action or maintenance stages, although therapists may help patients transition toward these change stages through the use of various motivational strategies. (See Miller, 2003, for a full discussion of these stage-specific strategies.)

Before specifying a therapy recommendation, therapists should formally assess the status of environmental, social, and technological constraints and enablers of adherence. For example, distance of treatment from residence and architectural barriers appear to influence adherence (Clay & Hopps, 2003), and having a stable place to live is critical (Sankar et al., 2002; Stone, 2001). People who have family members or friends who are both knowledgeable and supportive of the recommended treatment will be more successful in adhering than those who do not have this kind of support (Stone, 2001). Moreover, access to technology even as basic as a telephone may enable adherence. Automated and individualized telephone calls have been used to improve adherence to many health-related interventions (McBride & Rimer, 1999), including behavior changes associated with sleep apnea (DeMolles, Sparrow, Gottlieb, & Friedman, 2004) and substance use disorders (McKay et al., 2005). Use of text messaging and mobile technologies has also been demonstrated to advance adherence, especially if combined with identifying implementation intentions such as planning when, where, and how a client will perform goal-directed behaviors (Prestwich, Perugini, & Hurling, 2009).

Finally, in selecting and right-fitting an occupational therapy recommendation, the therapist must appreciate that the characteristics of the recommended intervention itself (behavior, regimen, or activity) influence the extent to which a person implements it in daily life (Clay & Hopps, 2003), including the total number of recommendations (the fewer the better; DeForge et al., 2008), treatment complexity and demands, aversive tasks and side effects associated with treatment, and its duration and cost (Clay & Hopps, 2003). Clinicians must override the default perception of treatment regimens as rigid and immutable and, instead, try to isolate the critical, outcome-essential elements (or “active ingredients” as proposed by Whyte & Hart, 2003) in an evidence-informed intervention and then adapt some aspects of treatment to fit the unique demands of patients’ lives (Clay & Hopps, 2003).

Advancing Self-Determination and Learning

Self-determination refers to the superordinate human right of “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s
quality of life free from undue external influence or interference” (Wehmeyer et al., 1996, p. 632). Once a therapy recommendation is proffered, reciprocal processes of self-determination (self-reflection, self-efficacy, self-regulation) and learning (acquisition of knowledge and skills, application, routinization) appear to drive the patient’s decision on whether to adopt it. Research on adherence to long-term regimens associated with HIV and chronic obstructive pulmonary disease has found that patients’ understanding of their condition and beliefs about treatment, its efficacy, and their ability to comply with the regimen (i.e., self-efficacy) appear to influence adherence (George et al., 2005; Sankar et al., 2002).

Occupational therapists are challenged to optimize their communication style and skills because patients tend to implement medical or rehabilitation recommendations when they know what to do and why (Sankar et al., 2002). Direct statements that specify the desired action are more adherence advancing than indirect or inferred communication (Smith, DeVellis, Kalet, Roberts, & DeVellis, 2005). After ensuring that clients acquire declarative knowledge related to the whats and whys of the recommended regimen, occupational therapists teach the how-tos of tasks that clients are asked to perform at home and provide opportunities for repeated and supervised practice to ensure competence in the new skill. Finally, as the patient determines to implement the recommended regimen and demonstrates proficiency in the skills needed to do so, adherence is likely optimized as the occupational therapist and client talk about the normal and typical problems most people have in following through on their best intentions. By normalizing the issue, the therapist sets the stage for future disclosure and problem solving should low adherence occur. By acknowledging the challenge in an upfront manner, occupational therapists increase the likelihood of follow-through by helping patients establish implementation intentions (Gollwitzer, 1999). Whereas a goal merely specifies a desired endpoint, an implementation intention specifies when, where, and how the goal-directed response will be executed (Gollwitzer, 1999).

Supporting Recommendations Implementation and Habit Formation

Once the patient decides to implement a given therapy recommendation, he or she must still remember to routinely perform it as instructed (correctly and at the appropriate time) outside of the clinical setting. Adherence may be optimized by teaching the client to use timers and alarms, checklists, or notes in day planners to prompt initiation of the desired regimen. Clients tend to continue adhering if they determine that the regimen is having the desired impact or outcome. Because some intervention regimens involve slow, incremental improvements in function, patients may not be able to detect their own progress. Therefore, adherence may be better sustained if therapists provide feedback in the form of measurable or instrumented indicators of progress. Finally, by
building in follow-up, support, and reinforcement, therapists help clients adhere to long-term treatment recommendations that are typical of chronic health problems and develop new habits around recommended behaviors, regimens, or activities.

Recommendations for Research

This in-depth consideration of a multi-step process nested in an ecological model suggests that adherence involves patients and therapists collaborating as equals (Löfman, Häggman-Lahtila, & Pietilä, 2008) on recommended interventions, establishing agreement on a proposed course of action (Hobden, 2006), and together trying to anticipate the kinds of supports that will enable patients to adhere to therapy to meet their own goals. However, few if any of these strategies have been evaluated empirically in the context of occupational therapy intervention; more research is needed regarding each strategy and segment of the adherence process. Given practitioners’ and researchers’ appreciation of the multifactor and contextually driven nature of performance (Law et al., 1996; Trombly Latham, 2008) and emphasis on client-centered assessment and intervention (McColl & Pollock, 2005), they also have much to offer those outside of the profession who are concerned with the larger medical and societal implications of nonadherence. The health and rehabilitation communities need more knowledge to inform practice in every aspect of the earlier-mentioned adherence process, such as specifying or analyzing what patients are being asked to adhere to (including the impact of receiving recommendations from many individuals on a multidisciplinary team); determining how patients perceive clinician recommendations (as options or imperatives); evaluating the practices used to determine whether patients understand and can perform recommendations; and determining how much and what kind of supports are effective in linking a new health or therapy recommendation to a preexisting routine.

In conclusion, I suspect that occupational therapists have neglected this important aspect of occupational therapy practice and research because they have minimized the complexities involved in adherence and simply assumed that adherence takes place by virtue of their good ideas and intentions. I hope that I have made the case that this is not so. People with chronic conditions seem to adhere to therapy recommendations when clinicians use adherence-promoting strategies throughout the service delivery process. Even as clinicians are challenged to incorporate these strategies in everyday practice, a professional response is also in order. Occupational therapists must include the adherence enterprise in their conceptualizations of the occupational therapy process (including the process outlined in the Occupational Therapy Practice Framework, 2nd ed.; AOTA, 2008) and specify the issue as a priority in their newly formed research agenda. Moving adherence from good intentions to planned and deliberate actions will advance occupational therapy outcomes of care and position occupational therapy philosophy and science at the vanguard of addressing the even larger societal challenges associated with people’s inability to stick with health-promoting lifestyle changes even when they know better (King, Mainous, Carmona, & Everett, 2009).

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