ADOLESCENTS AND ADHERENCE TO MEDICATION PROTOCOL: AN EVIDENCE-BASED APPROACH

By Eric Brown and Marissa Morris-Jones

This article utilizes a case example to illustrate the process of developing an evidenced-based clinical intervention for an adolescent client who presents with nonadherence to a medication protocol. The process encompasses a literature search guided by the Client-Oriented Practical Evidence Search (COPES) methodology; the development of an intervention comprised of psychoeducation and behavioral methods; and the creation and adaptation of instruments to monitor and evaluate the effectiveness of each intervention chosen.

Evidence-based practice (EBP) has evolved within the field of social work over the last 50 years (Reid, 1994). According to Leonard Gibbs (2003, p. 6), evidence-based clinical practice for social work practitioners encompasses "a process of lifelong learning that involves continually posing specific questions of direct practical importance to clients, searching objectively and efficiently for the current best evidence relative to each question and taking appropriate action guided by the evidence." The initial shift towards EBP occurred during the 1960s, as the federal government required social workers to prove the effectiveness of clinical interventions (Reid, 1994). Critics of this mandate suggested that the movement towards EBP resulted in routinized clinical interventions and the loss of the flexibility that would enable professionals to tailor these interventions to the needs of their clients (Reid, 1994). Today, EBP is viewed as a method for formulating clinical interventions by integrating the client's values and expectations for treatment with evidence found in the research literature (Mullen and Streiner, 2006). This article uses case material to demonstrate the process for developing an evidence-based

clinical intervention with an adolescent client who presents with nonadherence to a medication protocol.

CASE DESCRIPTION

John is a 13-year-old male who has been diagnosed with Wegener's disease.¹ Wegener's disease, or Wegener's granulomatosis, is a chronic illness that affects his kidneys. The National Institutes of Health (n.d.a) describe it as "an uncommon disease in which the blood vessels are inflamed (vasculitis). This inflammation damages important organs of the body by limiting blood flow to those organs or destroying normal tissue. Although the disease can involve any organ system, Wegener's mainly affects the respiratory tract and the kidneys." During a routine visit to the outpatient nephrology clinic, John's mother reports that he is not taking his medication as prescribed. The physician requests a consultation with a social worker to assess the circumstances surrounding John's instances of nonadherence. In conducting a biopsychosocial assessment, the social worker discovers that John is given complete independence to take his medication in the morning and evenings when he is at home. The nurse at school administers John's afternoon dose and confirms that he actually swallows the medication. John also reports that he often forgets to take his medication on time at home and sometimes skips a dose. John indicates to the social worker his belief that if he is not experiencing physiological symptoms, there are no repercussions for missing or skipping a dose of medication.

John is close with his parents and believes they are supportive. However, he also feels that they "nag" him too much by "telling him what to do." John reports being the only individual in his peer group who has a chronic illness. As a result, he reports that he feels different and alienated from his friends. He also reports low self-esteem. He has gained some weight as a result of the prescribed medication and expresses feeling self-conscious about his body changing. According to his mother, John's parents have given him complete freedom at home to take his medication because they understand his need to be independent. However, they are concerned that these instances of nonadherence will complicate his long-term prognosis. John's parents want him to be responsible, and they are sensitive to his accusations of "nagging." They want to figure out a method for encouraging him to take his medication without being overbearing towards him.

John Rolland (1994) outlines a model for understanding how family characteristics interact with characteristics of an illness within a systemic context. The determination of a psychosocial typology for Wegener's disease is

important for illustrating the demands this illness places upon John's family system. The psychosocial typology of an illness refers to the "relationship between family or individual dynamics and chronic disease" (Rolland, 1994, p. 23). According to Rolland (1994), the psychosocial typology encompasses five characteristics of the illness (onset, course, outcome, type and degree of incapacitation, and degree of uncertainty), as well as the impact of these characteristics on the challenges a family system has to contend with over the time phases of the illness (crisis, chronic, and terminal). The initial onset of John's illness was acute and characterized by biological changes over a brief period of time. These changes culminated in his presentation at the hospital with symptoms and eventual diagnosis. The course of John's illness is relapsing or episodic, as he experienced a period during which his symptoms flared-up, and this was followed by a period of stability. Although John is not physically incapacitated as a result of his chronic illness, Wegener's disease can be fatal. The current period of stability that John experiences is managed with use of a continual medication protocol. The experience of relapse largely underscores John's parents' concern regarding his instances of nonadherence. John's illness is currently in the chronic time phase. Helping his family to continue effectively managing the demands of his illness can prevent the illness from transitioning to a terminal phase and becoming fatal for John.

At the conclusion of an interview with John and his mother, the social worker determines that John's instances of nonadherence may stem from a lack of adherence monitoring at home. His parents desire to be supportive of John while respecting and encouraging his need to feel independent. At the same time, they are concerned that his decisions to take his medication inconsistently might cause a relapse of his illness.

John is simultaneously contending with the demands of adolescence and managing his chronic illness. The illness has isolated him from peers, and the side effects of his steroid medication include weight gain (National Institutes of Health, n.d.b). John can benefit from having increased social support as well as an increased understanding of how taking his medication as prescribed affects the progression of his illness. The family's current communication style does not allow them to meet the demands of helping John to adhere to his medication protocol. As part of a family system experiencing John's illness, John and his parents could benefit from improved communication and accountability. These features would allay John and his parents' concerns that his illness might relapse while enabling them to continue encouraging John's need for independence. Additionally, reframing their relationship within a cooperative context could help John understand his parents' concern as supportive rather than authoritative.

ADHERENCE: LITERATURE REVIEW

The case description raises the following research question: For adolescents who require the continual use of medication to manage a chronic illness, what is the most effective intervention to increase adherence to a medication protocol? The review of the research literature for this article is informed by the Client-Oriented Practical Evidence Search (COPES) methodology, which is employed to outline the extent to which various clinical interventions can be utilized effectively to pursue the resolution of a problem that presents in clinical practice (Yeager and Roberts, 2006). The three essential criteria for a COPES question include: (1) focusing on issues that matter to the client's welfare in the development in the question; (2) addressing a problem that is relevant to clinical practice; and (3) specifying the question adequately to generate pertinent resources in an electronic search for a literature review (Yeager and Roberts, 2006).

Adherence describes the extent to which patients follow the instructions they are given for prescribed treatments from physicians (Haynes et al., 2005). Robin DiMatteo (2004b) reports that typical adherence rates for prescribed medications are approximately 25 to 40 percent, although studies report that rates can vary from 0 to 100 percent (Anderson, and Collier, 1999; DiMatteo, 2004b; Haynes et al., 2005; Lyon et al., 2003). Medication adherence rates are lowest among individuals with a chronic illness and among individuals who require continual use of a medication protocol to manage symptoms (Lyon et al., 2003). In comparison to the general population, adolescents face more challenges with adherence. The challenges are due to developmental factors associated with an increased need to assert their independence and the need to identify with peer groups (Anderson and Collier, 1999; DiMatteo, 2004b).

It is important to understand common forms of nonadherence because an awareness of these factors clarifies areas that might be instrumental in bolstering adherence rates among clients. The types of nonadherence identified in the research literature include: (1) self-determination (i.e., client chooses not to take medication); (2) improper dosage as a result of misunderstanding the instructions; (3) missed doses; (4) increasing or decreasing a medication dosage; and (5) using medications for the wrong purpose or using outdated medications (Anderson and Collier, 1999; DiMatteo, 2004b). In a study of electronic devices that monitor medication adherence, findings reveal that nonadherence most commonly takes the form of missed doses and not taking doses at the prescribed time (Osterberg and Blaschke, 2005). The frequency of dosage also has an affect on adherence rates. Lars Osterberg and Terrence Blaschke (2005) cite a systematic review of 76 clinical trials that use electronic

medication monitoring. In that review, adherence was found to be inversely proportional to frequency of dosage; hence, medications prescribed at one dose per day are found to maximize adherence. Osterberg and Blaschke (2005) also state that the potential to experience no relief from symptoms is much more of a significant predictor of nonadherence than are such demographic factors as race, sex, and socioeconomic status.

Research also identifies risk factors and mediating factors relevant to nonadherence among the adolescent population. Common barriers related to medication adherence among adolescents include: problems with the medication regimen (such as adverse side effects), unclear or confusing instructions, an inadequate patient-provider relationship, poor patient memory, patient denial of need for medication, patient transportation difficulties, language barriers, inability to pay for care or supplies, the need to take too many pills, the taste of pills, and not feeling sick (Anderson and Collier, 1999; DiMatteo, 2004a; Haynes et al., 2005; Lyon et al., 2003). However, a number of factors promote medication adherence for adolescent clients. DiMatteo (2004a, p. 207) suggests that support from friends and family can increase adherence "by encouraging optimism and self-esteem, buffering the stresses of being ill, reducing patient depression, improving sick-role behavior, and giving practical assistance." Additionally, Thomas Campbell (2003, p. 265) cites a number of family factors associated with positive health outcomes: "Family closeness or connectedness, caregiver coping skills, mutually supportive relationships, clear family organization, and direct communication about the illness." The intervention developed for John's family should consider two factors that are highlighted by the research literature and that pertain to his case. John can benefit from additional peer support, which he does not receive from his current peer group. The family's communication style is largely avoidant concerning when John takes his medication. Troubleshooting around this area could involve developing a more open communication style that respects existing family dynamics.

The research literature does not identify any one intervention as effective in addressing all forms of nonadherence. R. Brian Haynes and associates (2005) found that, out of 58 interventions reported in 49 randomized control trials, only 26 interventions were associated with improvement in adherence, and only 18 of these 26 led to improvement in at least one treatment outcome. Haynes and associates (2005) found that, among the 26 successful interventions identified, some interventions improve short-term adherence and others improve it for long periods. Counseling, written information, and personal phone calls produced increases in short-term adherence, but complex interventions

were necessary to improve long-term adherence (Haynes et al., 2005). The study suggests that long-term adherence is increased by combining convenient medical care, information, counseling, reminders, self-monitoring, reinforcement, family therapy, psychological therapy, crisis intervention, telephone follow-up, and additional supervision or attention (Haynes et al., 2005). In addition, Andrew Peterson and associates (2003) suggest that educational interventions are more effective among patients who are invested in and willing to take their medication than they are among patients who are not motivated to adhere or who forget to take their medication.

Maureen Lyon and colleagues (2003) and Carolyn Anderson and Julie Collier (1999) studied interventions to increase medication adherence among adolescents. Lyon and associates (2003) tested an intervention that involved parents and peers as "treatment buddies" (p. 299) and sources of social support for adolescent clients with a chronic illness. Ninety-one percent of the clients reported that their adherence increased after completing the program. Despite the presence of many interventions, including peer support groups, family support groups, and psychoeducation, participants identified the multiple-alarm watch as the most effective intervention to prevent missing a dose (Lyon et al., 2003).³ Anderson and Collier (1999) examined an intervention for adolescents who were in the hospital due to medication nonadherence. Their intervention focused primarily on psychoeducation and behavioral efforts that involved the adolescent as well as his or her family.

Both studies utilize interventions that operate within a developmentally appropriate framework in which adolescents were encouraged to take responsibility for and control of their own treatment and health (Anderson and Collier, 1999; Lyon et al., 2003). Osterberg and Blaschke (2005) suggest that in order to provide a developmentally appropriate intervention, successful adherence interventions with adolescents should involve the patient's family members as well as school personnel. Furthermore, the use of behavioral interventions to increase medication adherence for adolescents is cited as an effective practice in their study (Osterberg and Blaschke, 2005). A most notable common component among these interventions is the token reinforcement system. This system provides token rewards, incentives, and privileges to adolescent patients for taking medications as prescribed (Osterberg and Blaschke, 2005).

Much of the literature on successful interventions to increase medical adherence is hindered by small sample sizes and the reliance upon client self-reporting to determine results (Anderson and Collier, 1999; Haynes et al., 2005; Lyon et al., 2003). The task of increasing adherence among adolescent

clients is confounded by the developmental tasks associated with adolescence. Findings from studies on general adherence provide some direction, but successful interventions with adolescents should also increase social support within the family system to assist adolescent clients in adhering to medication protocols (Anderson and Collier, 1999; DiMatteo, 2004*b*; Lyon et al., 2003). Forming an alliance between clients and caregivers, as well as providing psychoeducation, comprise the bedrock of these interventions. Behavioral interventions, such as token reinforcement systems, can be built in to existing interventions to maximize the chances for successful adherence rates among this group.

AN EVIDENCE-BASED INTERVENTION TO INCREASE ADHERENCE

For this study, the authors drew upon evidence-based interventions to address an adolescent client's nonadherence to a medication protocol. The target areas and goals of the intervention were identified through an examination of data from the case. These objectives are presented in a logic model (see Appendix A) that enables the social worker and physician to plan and map the interventions that will occur throughout John's care. The logic model has several different components. First, it identifies the antecedent condition or the problem (McCracken and Rzepnicki, in press). For John, this is that he is not adhering to his medication protocol, which subsequently places his health in jeopardy.

The second component identifies the objectives to be accomplished (results, changes, goals; McCracken and Rzepnicki, in press). For John, this includes increasing the rate of medication adherence and increasing his sense of social support. The model's third component identifies the methods that will be utilized to accomplish the objectives (McCracken and Rzepnicki, in press). For John, some of the methods utilized include participating in a support group, receiving a text message reminder to take medication, and creating a token reinforcement system to provide incentives for adherence. The next component (input) identifies the resources that will be utilized to accomplish the aforementioned goals (McCracken and Rzepnicki, in press). In John's case, some of the resources include: a physician, a cell phone, and a therapeutic relationship with a social worker. Finally, the logic model provides a visual map of how each of these components relates to the others (McCracken and Rzepnicki, in press).

After creating a therapeutic alliance with John and his family, the physician and social worker provide education about John's illness and medication to

both John and his family. The social worker also provides psychoeducation for John. This helps John to increase his problem-solving abilities and coping skills in order to address the stress associated with being an adolescent who has a chronic illness. In this intervention, medication education and psychoeducation are provided to John independently of his parents in order to support him in taking more responsibility for his own care. Additionally, the social worker can help John to have an understanding of how his illness impacts the entire family system.

John's role in the family system is clarified by the intervention's emphasis on explaining the importance of communication between John and his parents. It is also clarified by the focus on accountability as it relates to John's independence and adherence to his medication protocol. His parents' role is clarified as that of supportive monitors (rather than authoritarian parents) who cooperate with him to achieve a goal. Medication education and psychoeducation with John's parents reacquaint them with the details of John's medication protocol and provides a description of the interventions to increase adherence. Their willingness to allow John some independence is affirmed. The emphasis on their role as monitors highlights the need for balance between independence and interdependence within the family system.

A pretest is administered before John and his parents are provided with educational information by a physician and social worker. This information is then followed by a posttest. The same test, which is presented in Appendix B, is used at both rounds. The use of the pretest and posttest instruments enables practitioners to gauge whether education improves the client and parents' knowledge about the medication protocol. It also provides an entrée for social workers to conduct psychoeducation around some of the family's misperceptions about the illness, medication, and importance of developing problem-solving capacities to meet the demands of an illness. According to Campbell (2003), family psychoeducation helps families cope effectively with an illness by providing specific problem-solving skills. In this case, the family's communication style prevented the parents from being involved with John's care and from providing optimal support for medication adherence at home. The collaborative process of redefining their roles and the addition of the adherence checklist help to facilitate improved communication. John's parents know that he has taken his medication because he brings the checklist to either parent for a signature. John, in turn, does not feel "nagged" because they are not asking him about taking his medication.

An additional aspect of the intervention involves the use of a token reinforcement system. A token system is operationally defined as rewards or

incentives that are given to clients for taking medication successfully. This type of behavioral intervention is cited in the literature as an effective method for improving adherence among adolescents (Osterberg and Blaschke, 2005). The social worker will work directly with both John and his parents to create a token reinforcement system that is cost-effective for John's parents, motivates John, and provides him with incentives. The client receives a weekly medication adherence checklist (see Appendix C) that outlines the day and time when he is to take the medication. John is responsible for taking his medication; however, he must also obtain signatures from his parents and the school nurse to attest to the fact that they have seen him take his medication. The checklist facilitates accountability and communication between John and his parents. John takes the initiative to demonstrate to his parents that he is being responsible by taking his medication in front of them. His parents commit to rewarding him with an incentive for following his medication protocol as prescribed.

The checklist is returned to practitioners at the weekly support-group meeting. The client receives a point for taking the prescribed dosage of medication on time. These points are redeemed for rewards at home (rewards are determined by parents and client in collaboration with the social worker, as stated above). It is important to note that the token reinforcement system not only incentivizes adherence but also supports the client's responsibility for his own care. The token reinforcement system also establishes a partnership between John and his parents. The partnership respects his independence while allowing his parents to be more involved with his care. In other words, John is ultimately responsible for adhering to his medication protocol but understands that his parents are functioning in a supportive role as monitors rather than in an authoritarian role as parents telling him what to do.

As the preceding discussion briefly mentions, the client also enrolls in an adherence support group for adolescent clients seen in the outpatient nephrology clinic. The group meets on a weekly basis for 12 weeks. Social workers facilitate the support group and specifically address developmental characteristics that contribute to nonadherence among adolescent patients. Group participants have chances to build relationships as well as to provide and receive support from peers who also have a chronic illness that requires medication management. Support-group attendance is noted on the medication adherence checklist, and the client earns additional points toward rewards by attending group sessions. Clients are also responsible for identifying at least two group members whom they can contact for support. Each week, a different group member bears the responsibility of sending a text-message reminder to the individuals identified as his treatment buddies. Text-messaging is an

inexpensive approach to leverage the technology that the adolescent clients already possess. It also enables the intervention to draw upon the research findings concerning the effectiveness of alarm-watch reminders in interventions to improve adherence. In 2007, the Center on Media and Child Health (2007) reported that over 60 percent of adolescents have cell phones, and the current intervention assumes that John has a cell phone. This aspect of the intervention is cost-effective because it does not require clients to purchase a costly alarm watch in order to participate. Furthermore, text-messaging can serve as a pathway for adolescent clients to build relationships with other individuals who have a chronic illness. Such relationships may decrease clients' sense of social isolation and low self-esteem.

MEASUREMENT

The measurement used to assess this intervention reflects the intervention's single-subject design. In order to capture how John responds to the intervention, the measure must collect data on his adherence rates and self-esteem during the baseline (4 weeks) and treatment (12 weeks) phases. The baseline phase for collecting data occurs while client and parents are provided with medication education and psychoeducation. Under normal circumstances of nonadherence, medication education would be provided to families. The redefinition of family roles is necessary for implementing the successive interventions. During this period, data are collected to enable a comparison of the pretreatment phase to the treatment phase, when the text-message reminder, token reinforcement system, and support-group interventions are implemented. The adherence monitoring checklist and results from the Rosenberg Self-Esteem Scale (Rosenberg, 1965) will be analyzed on a weekly basis to determine how the client is responding to the interventions. The analysis of the checklist also facilitates the process of monitoring because the social worker can identify, on a weekly basis, whether instances of nonadherence coincide with an absence of signatures, noncompliance with text-messaging responsibility, nonattendance at support-group meetings, or a combination of these three factors.

CONCLUSION

This article proposes the importance and process of creating an evidence-based intervention, as well as a model of intervention with adolescents who present with nonadherence to a medication protocol. An evidence-based approach is utilized to ensure that the interventions have been shown to be effective. Evidence-based practices enable clinicians to combine research, evaluation, and clinical decision-making in a way that meets the client's individual needs.

The interventions mentioned in this article, as well as other interventions highlighted in the research literature, can be implemented under circumstances where: (1) the client and family show a willingness to participate in an intervention; (2) the agency setting is flexible and supports the use of innovative social work interventions; and (3) the collaborative relationship between physician and social worker on a multidisciplinary team is characterized by a mutual respect and understanding of how differences in training inform approaches to interventions with clients and families.

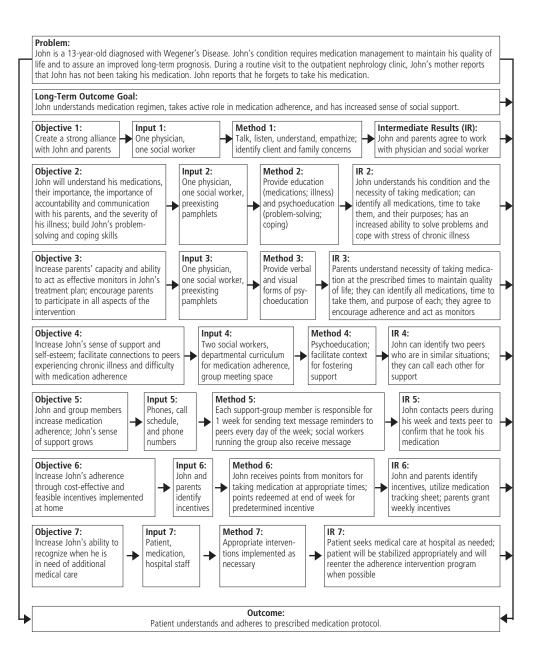
This particular intervention was individualized on multiple levels. It works with John and his family to create a token system that is effective for their lifestyle. It utilizes creative interventions determined by the social worker while providing psychoeducation sessions that engage John. These sessions also enable him to increase his problem-solving and coping abilities. John's family possessed the resources to facilitate his participation in other interventions, such as text-messaging and the support group. If John's family circumstances differed, the social worker would develop alternatives that increase social support but do not require technological devices or the use of personal modes of transportation. For example, the social worker might cultivate support within the client's existing family and social network.

APPENDIX A

LOGIC MODEL

This logic model makes the following assumptions:

- 1. Client and parents understand his medical condition.
- 2. Client has family support.
- 3. Parents will assist with monitoring to ensure accuracy.
- 4. Trust of parent and patient to self-report with honesty.
- 5. Patient has a mobile phone.
- 6. Patient and parents are motivated to participate in all aspects of the intervention.



APPENDIX B INSTRUMENT FOR PRETEST AND POSTTEST

Medication	Dosage	Frequency

Questions

- 1. Is it permissible to skip a dosage of medication? Why or why not?
- 2. Is it permissible to double-up on medication when a dosage is missed?
- 3. In what instances can I increase or decrease a dosage of my medication?
- 4. How does taking medication affect my illness?
- 5. What are some possible side effects my medication may cause?
- 6. Who should I notify if I experience intolerable or painful side effects?

APPENDIX C

MEDICATION ADHERENCE CHECKLIST

Part A (To be completed by monitors)

Instructions for Monitors: Please initial the appropriate box to indicate that the client has taken the prescribed dosage of medication. Include any relevant notes (e.g., side effects, reasons for missed dosage).

Day	Morning	Afternoon	Evening	Notes
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				
Saturday				
Sunday				

,							
Part B (To be completed by social worker at weekly support group)							
Weekly adherence rate (points equals adherence percentage):							
•	•	-	- 0				
Text message reminder sent:							
Peer support-	group attendance	e:					
Total points a	warded (sum of	all points):					

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NOTES

¹The client's name has been changed to protect his confidentiality. In addition, details that could potentially identify the client, family, or agency setting were omitted from the case description in order to ensure privacy and protect confidentiality.

² Treatment for Wegener's Disease usually involves a combination of steroids and cytotoxic medicines. A common side effect of steroid medication is weight gain. Approximately half of all people diagnosed with Wegener's can experience a return of the disease; however, treatment improves the long-term prognosis (National Institutes of Health, n.d.b).

³The multiple-alarm watch is a device that enables an individual to program different alarms on the same watch. The alarm rings throughout the day to remind the individual to take the scheduled dose of medication (Lyon et al., 2003).

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