

ADOLESCENT SELF-MANAGEMENT OF PSYCHOTROPIC MEDICATIONS FOR
POST TRAUMATIC STRESS DISORDER

BY

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Abstract

A relatively high rate of emotional, behavioral and/or psychiatric disorders occurs among children and adolescents in the United States, and often these disorders are treated with various types of psychotropic medications. A review of the literature about adolescent medication self-management reveals limited information, especially for adolescents, with psychiatric disorders. Self-management appears to be the safest and most accurate method of managing a medication regimen, especially for psychotropic drugs. This study examined an intervention to increase skills for self-management of psychotropic medications prescribed for post traumatic stress disorder with adolescents who lived in a residential program for emotionally disturbed adolescents.

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Introduction

Emotional, behavioral and/or psychiatric disorders occur at a relatively high rate among children and adolescents in the United States. According to the National Health Interview Survey published by the Substance Abuse and Mental Health Services Administration (SAMHSA) for the years 2001 through 2003, 5% of all children and adolescents between the ages of 4 to 17 years had definite and severe emotional and behavioral problems. Of those children, 48.8% were prescribed medication for those problems (<http://www.oas.samhsa.gov/NSDUH/2k6NSDUH.html>).

Some of the most common psychiatric disorders that children and adolescents are diagnosed with in the United States are major depressive disorder (33%) and attention deficit disorder (25%) (<http://www.surgeongeneral.gov/topics/cmb/childreport>). Harris (2005) reviewed admissions to a psychiatric hospital for children and adolescents ages 3 to 13 years during a three month period and found that 25% of those children were diagnosed with juvenile bipolar disorder. Some of the most common medication types that have been prescribed to treat these disorders are: (a) antidepressants for depression (Thomas, Conrad, Casler & Goodman, 2006), (b) stimulants for attention deficit disorder (Thomas, Conrad, Casler & Goodman, 2006), and (c) divalproex sodium and/or lithium carbonate for bipolar disorder (Harris, 2005).

At least three potential problems are associated with using psychotropic medications to treat adolescents who have been diagnosed with psychiatric disorders. First, the effectiveness of the medications for treating adolescents has, until recently, been largely untested (with the exception of stimulants for attention deficit hyperactivity disorder). Second, if psychotropic medications are potentially effective in treating these disorders, we do not know the medication regimens needed to achieve maximum effectiveness. In fact, the levels of medication needed may be determined by the individualized responses

of patients to dosing regimens. Third, idiosyncratic responses to a medication such as adverse drug reactions (negative side effects) can occur and must be monitored carefully. For these reasons it is important that there be a dialogue between the physician and the adolescent with emotional and behavioral disorders. Patient self-report is an important part of determining whether a psychotropic medication is having a desired effect. Behavior needs to be measured as well, but self-reports are relied on a great deal by physicians. Because of this, the adolescent needs to be able to clearly state whether the medication is having a good or bad effect.

Levison (1991) asserted that adolescents do not typically talk with their health care provider about the effects of medications and recommended that physicians should include adolescents as members of the health management team as quickly as possible to ensure that the adolescent will take responsibility for using medication in a safe and effective manner. A critical factor influencing the variability of medication effectiveness may be the lack of self-report provided by patients about the efficacy of the medicine.

Krypel (2006) recommended that a curriculum should be developed for pharmacy students to teach them skills for obtaining information from patients about the effects of their medication. Krypel also proposed that the curriculum should include teaching the pharmacy students how to ask patients open-ended questions to obtain better patient reports about the effects of the medication, to listen to what patients say, and to ask additional questions for clarification or to obtain additional information. The author asserts that good listening skills are essential for gathering information about patient responses to medications. No data, however, were provided to support the author's recommendation.

In conjunction with increasing the questioning and listening skills of pharmacy students (and, perhaps pharmacists and physicians as well), it might also be useful to

teach the adolescent patients how to record and report the effects of the medications that they are taking. An example of such an effort was a study by Meade, Creer and Mahan (2003). Although the study was done with renal transplant patients, it described a possible method of improving self-report from adolescents who were taking medications for psychiatric problems.

The purpose of the study by Meade et al.(2003) was to teach nine adolescent participants, ages 11 to 17 years old, to become members of their medical teams in order to manage their transplants more effectively. One of the skills taught to the adolescent patients was to communicate effectively with health care professionals. This skill was taught by having the participants prepare two questions for their doctor and two questions for their nurse about the participants' treatment concerns. These questions were practiced using passive, aggressive, and assertive styles as patients assumed both the patient and the doctor role. Effective communication was modeled by facilitators. Then, the patients had the opportunity to ask the doctor and the nurse the questions. A post-study evaluation was filled out by the participants immediately after the final session. The evaluation consisted of seven multiple choice questions, nine questions using a Likert scale to rate various aspects of the program, and three open-ended questions to obtain their opinions about the program. Learning to question the doctor and the nurse about transplants and the medications were two components that were rated by the participants as "very helpful" (the highest rating possible on the accompanying Likert scale). In spite of the fact that the study did not obtain pretest measures of patient satisfaction and did not report whether the skills taught were correlated with improved health outcomes, similar interventions might be useful to increase the participation by adolescents in the treatment procedures used for psychotropic medications.

The study reported by Meade et al. (2003) might also be expanded in several ways. Adolescents, for example, might report whether they are taking medications as prescribed, whether the effects of the medications are more evident at some times than others, what moods are affected, and what behaviors (both desirable and undesirable) they display that seem related to the medications. Additionally, adolescents might record and graph their own behaviors that seem to be related to the medications they are taking.

In the study by Meade et al. (2003) and in additional suggestions listed above, the information provided to medical personnel is based entirely on patients' self-reports. This can present a serious difficulty. Currently, it is not possible to determine the accuracy of most types of self-report. For example, patient reports of mood changes and how the drug seems to affect the patient cannot be verified by anyone else. In some cases, however, a patient's self-report of whether or not he/she took the medication at a certain time and at a certain dose, potentially, can be verified by observations of other people. Although many measures of the effects of medication are based solely on self-reports, these self-reports appear to be the only practical method available until we can conduct studies with appropriate double-blind and placebo controls that evaluate whether certain drugs at certain dose levels seem to produce consistent verbal reports within each patient. In spite of the questionable status of patient self-report, the use of these reports seems to be an advance over not obtaining any information from the patients. These issues and other issues have been part of a larger field of inquiry that has examined self-management skills for chronic disease to improve health outcomes.

Self-management Training to Improve Health Outcomes for Adolescents

DeMonaco and von Hippel (2007) suggested that a definition of self-management includes: (a) engaging in activities that protect and promote health; (b) monitoring and

managing symptoms and signs of illness; (c) managing the impacts of illness on daily routines; and, (d) adhering to treatment regimens.

Two major reviews examined interventions to improve adolescent management of psychiatric disorders. Ong and Caron (2008) systematically reviewed the literature on the efficacy of interventions using education and training for the family and the adolescent who had been diagnosed with mood disorders. The authors concluded that the purposes of the interventions that were reviewed were to help the adolescent and his/her family make informed treatment decisions and to cope with the illness and its complications. The authors found eight studies relevant to these issues. In these studies, investigators used workshop formats to teach information about mood disorders, to discuss that information, and, in some cases, to train the participants in specific skills related to mood disorders. The authors observed that the lack of randomized control trials made it difficult to draw conclusions about the effectiveness of the interventions reviewed. In addition, the models used in each intervention differed greatly so comparisons were not possible.

Feeny, Foa, Treadwell and March (2004) reviewed another body of literature that addressed the treatment of post traumatic stress disorder in adolescents. Some of the studies reported improved symptom management using techniques that were taught to the adolescent to manage those symptoms. Those techniques for symptom self-management included muscle relaxation, diaphragmatic breathing, and problem solving techniques to control anger. At the same time, the authors suggested that the results from these studies needed to be viewed with caution because there had been no use of control groups, there were no comparisons within the studies to other types of interventions, and there were no clear empirical data on the effects of these interventions on health outcomes.

Thus, the available research on the interventions to improve the self-management of psychotropic medications for adolescents is very limited, and, as a result, this current

literature search was expanded to include self-management interventions for adolescents with other forms of chronic disease.

Four published reviews have summarized a great deal of the information available about self-management for adolescents with chronic diseases other than a mental health diagnosis (Goodall & Halford, 1991; Costello, Wong & Nunn, 2004;; Wysocki, 2006; and Kahanna, Drotar & Frazier, 2008). These review articles suggest a number of possible interventions to improve self-management of chronic illness. Goodall and Halford (1991) found that interventions that were reviewed provided information to the parent and child. Costello, Wong and Nunn (2004) reported attempts to: train pharmacists about specific child medication regimens, use pharmacist consultations with the patient about specific medications that were prescribed for the patient, and train children how to use asthma medication. Wysocki (2006) reported the use of interventions to teach parent-child communication skills, problem solving skills and communication about diabetes skills. Kahanna, Drotar and Frazier (2008) reviewed interventions to develop individual self-management plans, educate the caregiver and the child, learn problem-solving techniques and social skills, develop social supports, and learn to use technology based interventions.

At the same time, those same authors noted that the following recommendations should be addressed in future studies: (a) more studies are needed to demonstrate that measurable improvements in self-management are correlated with empirical data showing improved health outcomes, and that more precise measurement of this relationship should be attempted (Goodall & Halford, 1991); (b) studies need to examine the long-term effects of self-management on health outcomes (Costello et al., 2004); (c) critical elements of some of the modestly successful interventions were not clearly described, and as a result, would be difficult to replicate (Wysocki, 2006); (d) studies

lacked uniformity of design and measurement, did not report information about participant health outcomes as a result of interventions, and neglected to report measures of fidelity to the interventions (Kahanna et al., 2008); and, (e) fewer than 25% of the studies reviewed provided any follow-up data (Wysocki, 2006).

Four published studies were not included in the review papers cited above, but did address the relationship between self-management and health outcomes for adolescents with a chronic disease (Amari, Grace & Fisher, 1995; Bruzzese, Unikel, Gallagher, Evans, & Colland, 2008; Buckingham, Beck, Xing, & Kollman, 2007; Wysocki et al., 2006). The first study by Amari, Grace and Fisher (1995) attempted to reduce seizures of a 15-year old female with intractable epilepsy by teaching her to maintain a diet that would contribute to seizure reduction. A stimulus-choice procedure was used to assess the adolescent's preferences for 33 foods that were part of a strict diet implemented to reduce the number of seizures. The adolescent was given a high preference food to eat after she ate a low preference food (both foods were from the recommended diet). Observations of the food intake and weighing of the plate after eating were used to measure amount of food consumption. The procedure was successful in increasing compliance to the diet from 60% at baseline to 97% after the intervention, and resulted in a 40% reduction in seizures, which was, according to the authors, an important health outcome.

Wysocki et al. (2006) taught adolescent participants self-management skills for chronic disease and evaluated the effects of self-management training on health outcomes. The authors randomly assigned 104 adolescents with Type I diabetes to a control group or to one of two intervention groups. The measure of self-management was a self-report survey and the primary health outcome was glycemic control that was monitored using a standard measure (HbA1c levels) during baseline, at six months and at

18 months post intervention. The control group received standard care which consisted of: (a) a meeting with a physician three or more times a year to review glucose levels; (b) daily injections of mixed intermediate and short-acting insulin; (c) diabetes self-management training; (d) dietary and exercise instruction; and, (e) annual evaluations for long-term diabetic complications. The second group of participants received the Behavioral Family Systems treatment intervention that consisted of standard care plus 12 sessions during which the family and the adolescent were trained in problem-solving, communication skills, and behavioral contracting techniques related to diabetes self-management. The third group was called the “education and support group”, and received all of the standard care as well as 12, 45-minute presentations from a manual by the American Diabetes Association. The study intervention lasted for six months.

The difference between the average scores on the self-report measure of self-management taken at baseline and at 6 months (immediately post-intervention) indicated a higher and statistically significant difference ($p=.03$) for the Behavioral Family Systems group for a subset of participants who had a baseline measure of glycemic control greater than 9 (considered to be poor control). But, all three groups improved the health outcome of glycemic control for participants whose glucose levels were greater than 9. Training parents and adolescents in problem-solving, communication skills, and behavioral contracting techniques was related to better health outcomes as measured by improved glycemic control for adolescents with previously poor glycemic control (baseline of HbA1c greater than 9).

Bruzzese, Unikel, Gallagher, Evans, and Colland (2008) tested the effects of a school-based intervention for 25 adolescents with asthma. Each participant had an asthma diagnosis from a medical provider, used asthma medication or had a prescription for the medication, and had exhibited asthma symptoms (based on self-report) an average of

three times per month over the last 12 months. Participants and their caregivers were randomly assigned to either an intervention or control group. Participants in the control group received no additional services from the experimenters. Participants in the intervention group attended six, weekly 75-minute sessions during which information and training were presented about asthma and asthma medication, prevention and management of asthma symptoms, problem-solving and coping with asthma, and communication skills about asthma treatment. Caregivers of participants attended five 90-minute sessions that addressed general parenting strategies for children with asthma and asthma management.

The participant and his or her caregiver jointly rated the participant on a measure of asthma self-management and a measure of asthma-related health outcomes. These two reports were taken before the intervention, at study completion and 2 months after the intervention. The first report was of the number of steps the patient completed to prevent symptoms (of 18 possible steps), and the second report was of the number of nights the patient was awakened by asthma symptoms during the prior two-week period.

The intervention group reported taking 1.5 additional steps (baseline 8.1 and post intervention 9.6 steps) to prevent asthma symptoms. The control group reported taking .8 fewer steps (baseline 7.7 and post intervention 6.9 steps). The difference was small but statistically significant between the two groups ($p < .05$). Two months after study completion, the intervention group reported an average 67% reduction in the number of nights awakened by asthma symptoms during the prior two week period compared to the control group's average increase of 19% ($p < .01$). The authors concluded that training in information about asthma and asthma medications, management and problem solving skills related to asthma, and communication skills for asthma self-management contributed to improved health outcomes for the participants.

Buckingham, Beck, Xing, and Kollman (2007) studied the effect of the use of the Continuous Glucose Monitoring System (Navigator) for prompting medication self-management for adolescents and children. This is a device inserted under the skin to monitor a person's glucose level every 60 seconds. The device sounds a beeping noise if glucose levels are out of the acceptable range and presumably, prompts participants to take additional insulin. Thirty participants between the ages of 4 and 17 years used the Navigator for 13 weeks. Phone calls to the participants and their caregivers occurred half way through the first week and at 2, 4 and 8 weeks to review data on glucose levels and Navigator use. Glucose levels recorded during office visit at weeks 3, 7, and 13 decreased from an average of 7.1% at baseline to 6.8% at the end of 13 weeks ($p=.02$). The authors asserted that the reductions in glucose levels were due to better self-management for timing the dose and measuring the dosage needed as a result of using the Navigator.

The studies cited above provide modest evidence that teaching self-management procedures can positively affect health outcomes. Only two of the studies, however, (Wysocki et al., 2006; Bruzzese et al., 2008) used an adequate experimental design to evaluate the effects of the intervention. And, only one of the studies (Wysocki et al., 2006) provided data on long-term outcomes. Perhaps, the most important issue, however, is that these studies included attempts, however modest, to measure improvements in participant self-management of health care routines together with measures of health outcomes. Similarly, the use of interventions that teach self-management skills might well provide more effective ways of addressing problems with psychotropic medications prescribed for adolescents and possibly contribute to improved health outcomes.

Methodological Recommendations

The first methodological issue that needs to be addressed in evaluating whether developing self-management skills affects the health outcomes of adolescents who are

prescribed psychotropic medications for psychiatric problems is defining what medication compliance is.

Definitions of medication compliance can be problematic. A definition provided by Haynes, McKibbin and Kanani (1996) was that compliance was the extent to which a patient's behavior coincided with medical advice. Osterberg and Blaschke (2005) defined medication compliance as the extent to which a patient correctly takes medication as prescribed by his/her health care provider. Roberts et al. (2004) proposed that medication compliance be defined as taking medication in the right dosage, at the time that the medication was scheduled to be taken and at the correct rate over time by the person for whom the medication was prescribed. Murphy et al. (2005) and Bernstein et al. (2000) defined medication compliance as how frequently the drug was taken over a period of time compared to the frequency that the patient was supposed to take the drug.

Thus, in all of the definitions, the prescription essentially defines what the elements of compliance are although some definitions are more stringent than others. The most stringent definitions include taking the medication (a) as frequently as prescribed over some period of time, (b) in the prescribed amount, and (c) at the times the prescription indicated that the medication should be taken.

Even the most stringent definition of medication compliance, however, does not provide clear guidance as to what amounts of compliance are necessary to achieve positive treatment outcomes. For example, in one study, the definition of medication compliance was taking the medication 75% of the time as prescribed (DelBello et al. (2007). In another study, medication compliance was defined as taking the medication 100% of the time as prescribed (Mears, Charlebois & Holl, 2006). Thus, although the prescriptions and the various definitions of medication compliance provide a basis for

measuring compliance, the definitions still leave open questions about the amount of compliance required to be considered adequate compliance for positive health outcomes.

Ideally, an adequate definition of medication compliance would be based on solid empirical information as to what amounts and at what times a medication should be taken to produce positive health outcomes. Unfortunately, the necessary empirical information has not been published, especially for psychotropic medications for adolescents.

Additionally, an optimal definition of compliance may need to be determined individually for each patient. Currently, actual drug prescriptions typically are the best available estimates of what will be effective. Systematic follow-up with the patients may then allow prescriptions to be modified based on laboratory tests and patient reports of the effects of the medication.

A second methodological issue is that the experimental designs that have been used in studies of self-management have been problematic. In some studies, for example, authors simply recorded baseline measures of the dependent variable and then reported any changes in measures of those variables after the interventions were put into place (e.g. Bruzzese et al. 2008). Studies that have included rigorous experimental designs most commonly used group designs, where, for example, participants have been assigned (sometimes randomly and sometimes not) to one or more experimental groups or to a control group. These types of designs are useful in evaluating the extent to which one or more variables can affect the group averages, but they have been limited in their ability to provide the kind of evidence needed to discover procedures that are likely to be highly effective. This is apparent in the existing literature.

In developing procedures that are more likely to be effective, it seems that there are substantial benefits to using single subject designs in the initial stages of “discovery”. There are several reasons for this. First, single subject designs, such as reversal designs,

are less costly and cumbersome than group designs thus permitting more efficient evaluations of many more variables, singly and in combination, than group designs.

A focus on single subject designs is to reduce variability, a seemingly constant characteristic of medication self-management. Single subject designs may be a better tool for reducing variability because interventions are often used to reduce individual variability, whereas, group designs treat variability as an inherent characteristic of behavior. This is a very serious issue for the self-management of psychotropic medications not only because the self-management behavior that is necessary is highly variable and may be controlled by a number of different variables, but also because the effects of the medications themselves, especially medication for psychiatric problems, appear to have widely different effects across people and sometimes different effects within people at different times. A functional assessment could be done with each individual to determine problematic behaviors and responses to the medication. Thus, experimental designs that permit economical exploration of the effects of a variety of environmental conditions as well as the variety of effects of the medications would seem to have an advantage as a “discovery” strategy. Promising procedures that are “discovered” using single-subject designs may then be evaluated to determine their “average” or “actuarial” effects within suitable group designs across different populations of people.

A third methodological issue is the lack of replications of interventions to improve medication self-management. A demonstration of the functional relationships between interventions and changes in self-management behaviors is critical. Most published studies on adolescent self-management, however, do not contain the information that is needed to replicate studies. In general, what seems to be needed for replication are clearer definitions of what constitutes self-management for psychotropic medications, well

specified and complete descriptions of intervention procedures, and the inclusion of fidelity measures that insure that the procedures were implemented as described.

Enhancing Adolescent Self-management of Psychotropic Medications

The existing literature on improving adolescent self-management of medication for a chronic illness has not provided clear examples of strong and effective methodologies for producing self-management skills or for better health outcomes. The use of more accurate and reliable measures, rigorous experimental designs and more replicable procedures may lead to some improvement. This alone, however, is not likely to be enough. More effective interventions are needed. Some suggestions for more effective interventions may be found in the descriptive literature about environmental conditions that are associated with high and low levels of self-management of medication.

The variables that have been associated with higher levels of effective self-management of medication and that seem to be definable and modifiable include: (a) the degree to which prompting and monitoring is provided by natural supports such as parents (Modi, 2008; Leslie et al. 2003) and school personnel (Rogers & Bullman, 1995); (b) the amount of positive social consequences that can be provided (Hovell et al., 2003); and, (c) the degree of “fit” between the self-management regimen and the adolescent’s daily routine (Bender, 2002). The variables that have been associated with low levels of successful self-management of medication that also seem to be both definable and modifiable include: (a) negative side effects of medications such as rapid weight gain; (b) a denial of the diagnosis (Asadi-Pooya, 2005); and, (c) the cost of the medication (Jenkins, 1977).

Thus, interventions to improve adolescent self-management of medication might include prompts and reminders from parents or siblings to take prescribed medications as well as positive social consequences for taking medication appropriately. Careful

planning and inclusion of the adolescent in the planning process for the self-management routine might increase the probability that the medication regimen fits well with the adolescent's daily life. Finally, the development of systematic ways for adolescents to provide input about the positive and negative effects of medications and other problems associated with the medication might lead to greater efforts to minimize the negative side effects of medications by changing dosing levels or by trying alternative solutions.

The teaching of medication self-management skills to adolescents with a psychiatric diagnosis is important for two reasons. First, adolescents are often at the point in their lives where they are becoming more independent and are taking greater control over some aspects of their daily lives. This increased independence includes the responsibility of taking their own medications and developing their own patterns of behavior that either promote or do not promote healthy lives as they become adults. Patterns of behavior that are developed relatively early in life often persist into later life. Thus, the establishment of health-promoting patterns of behavior in adolescents may help increase the number of health promoting behaviors that are sustained throughout an individual's life.

Second, there is evidence to indicate that adolescent medication management is lower than for that of children who presumably rely more on their parents or other caregivers to support and prompt medication management. The literature about procedures to improve self-management for chronic disease and other medical problems also contains information about variables that may be useful in enhancing self-management of psychotropic medications for adolescents. The principles of learning also provide a structure to develop procedures that have been shown to be somewhat effective including: (a) training in problem-solving and communication skills and behavioral contracting techniques (Wysocki et al., 2006); (b) training about asthma and asthma medications, prevention and management of asthma symptoms, training in problem-

solving and communication skills specific to asthma treatment, and relaxation exercises (Bruzzese et al., 2008); (c) using a stimulus choice procedure to assess preferences to be used as reinforcers for low preference behavior (Amari et al., 1995); and, (d) improving monitoring for timing the dose and measuring the dosage needed by using a monitoring device (Buckingham et al., 2007).

Problems with Psychotropic Medications for Adolescents

If psychotropic medications are to be effective in treating psychiatric disorders then more reliable methods are needed to produce safe and effective regimens. The few studies, however, that have examined the effects of psychotropic medications report lower efficacy in children and adolescents than in adults (Ingersoll, Bauer & Burns, 2004). Efficacy or the extent to which psychotropic medications really address the problems for which the medications are prescribed for adolescents is not well established in the literature. Currently, there are a large number of factors that may cause variability in the effects of medications prescribed for psychiatric disorders of adolescents, such as: (a) whether or not adolescents take medication as prescribed; (b) what the effects and side effects are (as well as, the intensity of those effects); (c) what dosage levels of medications are needed to produce beneficial effects (and to minimize undesirable side effects); and, (d) what the effects are of different drugs being simultaneously prescribed. The ability to determine the extent to which adolescent psychiatric disorders respond to medication is directly related to finding ways to reduce these sources of variability.

Purpose of the Present Study

The purpose of this study was to teach adolescents who were diagnosed with post traumatic stress disorder to use self-management skills with respect to the medications that were prescribed for that disorder. Treatment of post traumatic stress disorder is particularly challenging because the symptoms are often very problematic, such as

physiological reactivity to certain stimuli in the environment that are associated with a traumatic event (associated with periods of high respiration and heart rate), reports of “flashbacks” and nightmares, sleep disturbance, avoidance of stimuli that are associated with the event, avoidance of normal activities and routines (sometimes diagnosed as depression), and increased levels of aggressive behavior or hyperarousal (American Psychiatric Association, 2000). Additionally, different psychotropic medications have been used to treat adolescents exhibiting the different symptoms associated with post traumatic stress disorder, but no randomized, control treatment studies have reported successful, long-term outcomes using those medications, nor have any of those studies been replicated (Cohen et al., 2010).

In addition, adolescents do not take prescribed medications for a multitude of reasons, and they often avoid taking psychotropic medications in particular. Some of these reasons may revolve around a lack of knowledge about the likely effects of the medications and some may be related to the undesirable side effects of the medications once the adolescents try taking the medications. Additionally, adolescence is a time when young men and women are increasingly attempting to become more independent and take greater control over their lives. Often, these attempts are evidenced by refusals to follow adult instructions. With respect to prescribed medications, the only way adolescents may be able to exert control over the treatment process is to refuse to take the prescribed medications. If any of these factors are relevant to the lack of participation in treatment that health care providers experience when working with adolescents with psychiatric disorders, perhaps teaching the adolescents skills to exert more control over what medications they are prescribed and the medication regimen itself would result in increased participation in the treatment process. Several possible avenues may be explored to address how to include the adolescent in the treatment process. One

possibility is to have a systematic educational program for adolescents so that they are informed as to what medications are being considered for them, what the effects and side effects of these medications are, and how the negative side effects might be minimized or even avoided by taking different medications. Additionally, adolescents need to be taught how to measure or evaluate both the benefits of the prescribed medication, and the severity of the negative side effects, and how to present this information to health care providers in order to advocate successfully for maintaining current medications, stopping the medication, changing the dose of the medication, or changing types of medications.

Methods

Participants

The participants for this study were adolescents 13 to 17 years old with a diagnosis of post traumatic stress disorder. All participants were patients at Crittenton Children's Center (CCC), a residential program for adolescents with serious emotional disturbances. Prior to the study and independent of the study, all participants had psychotropic medications prescribed to help with their problems, which was part of the standard intervention procedures at CCC.

All residents who were admitted to CCC during June of 2008 for treatment, and met the diagnostic and age criteria were offered the opportunity to participate in this study. All adolescents who indicated an interest in participating in the study and their parents or guardians were provided information about the study. The first 14 adolescents who assented to participating in the study and whose parents or guardians provided consent for the adolescents' participation were included in the study. The parent/guardian consent form and the participant assent form are shown in Appendix A.

Although a total of 14 adolescents were recruited to participate in the study, four adolescents did not complete the study. These four adolescents did not participate

because they were discharged prior to the starting date for the group to which they had been assigned. The demographic characteristics of the participants who completed and did not complete the study are shown in Table 1.

Experimental Design

A multiple baseline design was used to assess the effects of the intervention. The first seven participants recruited were in Group One and the second seven participants recruited were in Group Two. As noted previously, four participants (two in each group) did not complete the study. For Group One participants, weekly sessions that constituted the intervention started after an 8-week baseline period. Thus, for these participants, data were collected during 8 weeks of baseline, during the 8-week intervention, and for 8 weeks immediately following the intervention. For Group Two participants, data collection started and continued through a 16-week baseline, during the 8-week intervention, and for 8 weeks immediately following the intervention.

Procedures

The intervention was a series of eight educational class meetings (one a week) that were one hour and 15 minutes long. Each participant signed an attendance sheet at the beginning of the class. Classes included information about post traumatic stress disorder, medications for post traumatic stress disorder, the effects and side effects of the various medications discussed how to measure and record the effects and side effects of the various medications discussed, what types of questions participants might ask the advanced practice nurse who was responsible for conducting the monthly treatment review, how to present information to the advanced practice nurse, how to tell the advanced practice nurse that the medication prescribed was working effectively or was not effective, and how to make requests appropriately for changes in medication. The completion of class activities by each participant was observed and recorded by the

therapist who assisted the researcher in facilitating the group. The last 15 minutes of each class was a “party-time” during which healthy snacks chosen by the the participants were served and participants were free to discuss whatever they wanted to discuss. A more detailed description of the curriculum is available in Appendix A.

As part of the usual treatment program provided at Crittenton Children’s Center (CCC), all participants met individually with an advanced practice nurse and the participant’s therapist for one-half hour, once every 4 weeks at a treatment review to assess the participant’s progress and to discuss whether or not to change or adjust medications. These treatment reviews began within the first month of admission to CCC and continued during baseline, the intervention, and follow-up.

As part of the intervention, a motivational system (a point system) was used during the last two treatment review sessions to reward participants for their statements during the last two treatment reviews to the advanced practice nurse about their satisfaction and/or dissatisfaction with their current medication regimen. The researcher recorded the statements by participants of satisfaction or dissatisfaction with the medication regimen as the statements occurred during the treatment review. Immediately after the treatment review, the researcher told participants how many points they earned. A total of 500 points was possible. These points could be exchanged for the participant’s choice of prizes that were available at the Points Canteen at CCC. A total of 500 points could purchase an item at the Points Canteen that would cost approximately \$5 in a retail store.

Eight types of the participant’s statements to the advanced practice nurse earned points (a) stating the name of the medication prescribed, (b) stating the symptom that the medication addressed, (c) indicating how serious the symptom was, (d) stating the extent to which the medication helped or did not help the symptom, (e) stating the undesirable side effects of the medication, (f) stating how serious the side effects were, (g) stating the

good effects of the medication, and (h) stating how good the effects of the medication were. In order to earn the maximum of 500 points, participants had to provide all eight of the types of statements for each psychotropic medication that was prescribed for them.

Initially, medication compliance behaviors were collected on each participant throughout the study, but there were only five incidents of noncompliance throughout the entire study for all the participants. As a result, that particular variable was dropped from the analysis.

Class Curriculum

Class One included a general overview of the course, the definition of post traumatic stress disorder and the symptoms and causes that were associated with it. The Personal Medication Survey was passed out. Participants were told that they would use their Personal Medication Survey to present information to the advanced practice nurse during the two treatment reviews that followed the last class instruction. Participants were also told that they would be given the Personal Medication Survey that they filled out during the seventh class, that they would take the Personal Medication Survey with them to the treatment review, and they would use this survey to provide information to the advanced practice nurse, either by reading the information on the Personal Medication Survey or by using what was written on the Personal Medication Survey as a prompt. Participants were also told that they could earn points that could be exchanged for items at the Points Canteen. Then each of the participants filled out their Personal Medication Survey. This survey served as the pretest measure of the participants' ability to provide the information asked for in the survey. A copy of the Personal Medication Survey is provided in Appendix B. After the participants completed the Personal Medication Survey, the researcher read the assent form to the participants to ensure that they were still willing to participate in the study (see Appendix C).

Class Two began with a knowledge pre-test (see Appendix D for the test questions) about how post traumatic stress disorder was diagnosed, treated, and what medications might have been prescribed for the diagnosis. Hospital and residential treatment was described. A lecture was given by the researcher about how post traumatic stress disorder was diagnosed, treated, and what medications might have been prescribed for the diagnosis. Hospital and residential treatment was described. The researcher asked if anyone had any questions about the lecture, or if anyone wanted to discuss some aspect of the lecture. When questions and the discussion about the lecture were finished, a post-test about the diagnosis, the treatment, and the medications used to treat post traumatic stress disorder was administered to the participants.

Class Three began with the introduction to the video “Teens and Trauma” and the presentation of the video. At the conclusion of the video, the researcher asked the participants if they had any questions or opinions about the video. The researcher answered the questions and listened to statements about the video by the participants. Each participant filled out an evaluation of the video at the end of the class (see Results Section, Table 4 for a list of questions in the evaluation and the results).

Class Four began with the introduction of a video “Abused Boys, Wounded Men” and the presentation of the video. At the conclusion of the video, the researcher asked the participants if they had any questions or opinions about the video. The researcher answered the questions and listened to statements about the video by the participants. Each participant filled out an evaluation of the video at the end of the class (see Results Section, Table 4 for a list of questions in the evaluation and the results).

Class Five began with a knowledge pre-test (see Appendix D for list of questions in test # 2) about medications used to treat post traumatic stress disorder, what symptoms the medications addressed and what were the possible side effects. A pharmacist then

presented information about medications used to treat post traumatic stress disorder, what symptoms the medications addressed, and the possible side effects of the medications. An exercise followed during which each participant asked the pharmacist at least two questions about their own medication(s) and the symptom(s) that it treated, as well as at least two questions about the possible side effects of the medication(s). A knowledge post-test followed about medications used to treat post traumatic stress disorder, the symptoms the medications addressed, and the possible side effects.

Class Six began with the introduction of a guest speaker who then gave a personal account of the traumatic events that she experienced and how she had lived with the symptoms of post traumatic stress disorder. Participants were encouraged to ask questions and make statements to the speaker in a calm voice and without interrupting the speaker. At the conclusion of the speaker's personal account, the researcher asked if there were any more questions or comments that the participants would like to say. When the participants were done with this part of the activity, the participants were encouraged to talk individually with the therapist who was present at the group if the participant had any upsetting symptoms as a result of the speaker. Each participant filled out an evaluation of the speaker at the end of the class (see Results Section, Table 4 for a list of questions in the evaluation and the results). Participants were also encouraged to talk with their therapist the next day about their responses to the speaker.

Class Seven began with a knowledge pre-test about how suicide, substance abuse and addiction behaviors were related to post traumatic stress disorder. The participants listened to a lecture about how suicide, substance abuse, and addiction behaviors were related to post traumatic stress disorder. Each participant then filled out the Personal Medication Survey. The Personal Medication Survey had places to list each participant's psychotropic medications, the good effects, the symptom(s) the medication was

prescribed for, and the side effects of the medication, as well as to rate the efficacy of the medication, and the severity of the symptoms and side effects (see Appendix B for a copy of the Personal Medication Survey). A rehearsal of these statements followed in which each participant took turns reading his/her Personal Medication Survey to a partner while the partner listened. Then the other participant took their turn rehearsing the statements by reading their Personal Medication Survey. The researcher observed each rehearsal to determine that each participant was able to read their own survey correctly. Next, the group took the knowledge post-test about how suicide, substance abuse and addiction behaviors were related to post traumatic stress disorder.

Class Eight began with the researcher asking the participants to ask questions if they had any about the information presented over the prior seven weeks about post traumatic disorder. The motivational system for participants to take their Personal Medication Survey with them to the next treatment review and to use the survey to provide information to the advanced practice nurse was explained again. A game of Round Robin (question and answer review of knowledge) was played. Each participant took a turn answering a question based on the content presented in the prior six weeks of classes until each participant had answered four questions correctly. Each participant filled out an evaluation of the curriculum at the end of the class (see Results Section, Table 4 for list of questions in evaluation).

As part of a motivational system already used at CCC, points were earned during each class for the following behaviors: (a) complete pre and posttest and sign in sheet, (b) complete group activity, (c) ask a question or make a comment about the focus of the group, (d) use a normal voice tone, (e) make a supportive comment, (f) speak when called on, (g) say please or thank you when appropriate, and (h) wait turns. Points could be taken away for the following behaviors: (a) using a loud voice, (b) making fun of others,

(c) insulting someone, (d) sitting with one's back to the group, (e) not focusing on the topic, (f) calling someone names, (g) throwing things, (h) physical aggression (including but not limited to pretending to or actually having contact with a person while trying to bite, hit, or kick a person). A participant could earn up to eight points but could have points taken away as well. The points earned were added to the total points earned each week by the participants and were used to determine what activities the participants could participate in. For example, a level four meant that the participant could go off the unit for field trips, etc. whereas a level one meant that the participant had to remain on the unit except for attending school and meals.

Finally, an additional motivational system was used to reward participants for completing each class activity. Each week at the end of class, the participants were asked what they would like for a healthy and inexpensive treat for the next class if they were successful in completing the activity during the next class. Two options were chosen so that allergies and preferences for all participants were considered. The two healthy snacks were available the next week for participants who completed the group activity.

Measures

In the weekly classes, the effects of the intervention were evaluated by gathering data on the behavior of participants. In the monthly clinical reviews, the effects of the intervention were evaluated by gathering data on the behaviors of the participants and the advanced practice nurse.

In the weekly classes, two types of information about participant knowledge were collected. The first type of information was the Personal Medication Survey that was collected in the first and the seventh classes. The eight questions on that survey asked for a list of all of the psychotropic medications prescribed for the participant, the good effects of the medication, the symptom that the medication was prescribed to treat, the

side effects of the medication, the efficacy of the medication and the severity of the symptoms and side effects (see Appendix A for a complete copy). The researcher compared this information to the medication chart and had the participant correct any errors. The second set of information was three tests of participant knowledge about the information presented in three classes (tests are contained in Appendix D).

A Participant Program Evaluation Survey about the series of classes was administered to each participant who attended Class Eight for both groups. The survey contained six questions about the significance of the course and the acceptability of the procedures and was rated using a 5 point Likert scale from “Not at all helpful” (1) to “Very helpful” (5). The first question was “How helpful was this course for you?” The second question was, “How helpful to you were the two videos about teens with post traumatic stress disorder?” The third question was “How helpful was the pharmacist who came to talk to you about your medication?” The fourth question was “How helpful was the Daily Symptom Chart that you used?” The fifth question was “How important was the person with a mental illness who came to talk to you about his/her life?” The sixth and final question was “How helpful do you think this course will be to future residents?”

During the monthly treatment reviews, the behaviors of the participants and of the advanced practice nurse were recorded. The participant behaviors that were recorded in the monthly treatment reviews were oral statements or questions by each participant of: (a) naming each of the prescribed psychotropic medications, (b) the symptoms that each of the medication(s) was prescribed for, (c) a rating of the severity of the symptom(s), (d) a rating of the effect of the medication on the symptom, (e) stating the side effects caused by the medication, and (f) a rating of the severity of the side effects of the medication(s), (g) stating the positive effects of the medication, and (h) a rating of the positive effects of the medication. These statements were recorded on observation sheets by the researcher

each time the statements occurred during treatment reviews. The statements from the Personal Medication Survey which: (a) rated how the medication affected the symptom, and (b) rated the side effects of the medication were rated as to whether the statements were: (a) statements of satisfaction and dissatisfaction about medications that were not specific to a drug, the dose, the route of drug administration, or the time of administration as well as statements of satisfaction or dissatisfaction that were specific to a drug, the dose, the route of drug administration, or the time of administration; (b) requests for a change that were not specific to a drug, the dose, the route of drug administration, or the time of administration as well as requests that were specific to a drug, the dose, the route of administration, or the time of administration. In addition, any statements of satisfaction, dissatisfaction or requests for change that were made independent of the use of the Personal Medication Survey or made during treatment reviews before the survey was introduced were recorded as well on the observation sheet and rated as preference statements.

The behaviors of the advanced practice nurse that were recorded for the monthly treatment reviews were responses by the advanced practice nurse to change the medication or not to change the medication such that it was: (a) in agreement with participant preference statements about their psychotropic medication regimens or agreed with the participant but only after the participant agreed to the alternative response of the advanced practice nurse; (b) made in the absence of the participant's preference statements; and, (c) disagreed with the participant's preference statements.

Reliability of Recording Measures

Reliability of the observational data collected during treatment reviews for participant statements made about their medication was evaluated during 24 % of the treatment reviews (19 out of 80). The researcher and the advanced practice nurse independently

recorded whether or not a participant said one of the eight types of participant statements or questions that earned points listed above for each of the psychotropic medications prescribed for the participant. The average agreement between the researcher and the advanced practice nurse was 92%.

A second reliability evaluation was conducted for the scoring of “yes” or “no” for the category of was there a “change to medication regimens. An independent rater (a nurse at CCC) and the researcher independently reviewed 95 medication prescriptions for participants during the entire duration of the study. The independent rater and the researcher scored a “yes” if a change had been made to the participant’s prescription and “no” if there was no change. The raters agreed upon whether or not a change had occurred for 94 of the 95 instances examined (99%). A total of 44 changes in medications prescribed occurred during treatment reviews for the duration of the study.

A third reliability evaluation was conducted to determine if scoring “yes” or “no” for the category of “changes to medication regimens were made in response to participant preference statements or participant agreement to the change”. An independent rater (a nurse at CCC) and the researcher independently reviewed 97 medication prescriptions that were active during the study and scored whether or not the prescriptions were changed or not changed and whether the decisions were consistent with preference statements or agreements to change made by participants during the treatment review. The independent rater and the researcher scored a “yes” if a prescription change had been made in response to a preference statement made by the participant. A “yes” was also scored if the participant agreed to no change or a change to another medication if the participant agreed to the decision after a discussion with the advanced practice nurse. A total of 48 “yes” categories were rated. A “no” was scored if the change was made in the absence of a preference statement by a participant or if a prescription either stayed the

same or was changed and this decision was not consistent with a participant's stated preference. A total of 49 "no" categories were rated. The raters agreed on the scoring of "yes" or "no" in 86 of these conditions. The raters agreed 86 times (N=97, 89%).

Results

Demographics for participants for gender, age, custodial arrangements, racial characteristics, and diagnosis are reported in Table 1. The gender breakdown for all participants who completed the study was eight females and two males. The non-completers were four females. The average age for completers was 15 years, 8 months. The average age for Non-completers was 14 years, 7 months. Custodial arrangements were reported for each participant and 7 of the 10 participants who completed the study were in state custody. Three of the four participants who did not complete were in state custody. The racial characteristics for completers were two African Americans and eight Caucasians. The racial characteristics for the non-completers (n=4) were; two African Americans and two Caucasians.

All participants who participated in the study had been diagnosed with Post Traumatic Stress Disorder. In addition, other diagnoses were reported as well. The following diagnoses were recorded: (a) bipolar disorder (5), (b) attention deficit hyperactivity disorder and bipolar disorder (3), (c) attention deficit hyperactivity disorder (1), and (d) conduct disorder (1). The average number of medications prescribed for each participant in Group One was 2.3 medications and for Group Two was 2.07.

The percent of sessions attended out of the eight sessions offered was: 80% for Group One, 78% for Group Two, and 79% for both groups combined. (see Table 2).

Knowledge pre- and post-test scores are presented in Table 3. Scores for the combined groups for Test One indicated that the average increase in scores was 20%. Scores for the combined groups for Test Two indicated that the average increase in scores was 9%.

Scores for the combined groups for Test Three indicated that the average increase in scores was 8%. The scores indicated that there was not a substantial increase in scores for each test.

Table 1.*Participant Demographics (at Time of Admission to Program)*

Group 1	Gender	Age	Custody	Race	Diagnosis
1	female	14 yrs., 9 mo.	State	Caucasian	PTSD, Bipolar Disorder
2	female	15 yrs., 10 mo.	State	African American	PTSD, Conduct Disorder
3	female	16 yrs., 0 mo.	Parent	Caucasian	PTSD, Bipolar Disorder, ADHD
4	female	16 yrs., 2 mo.	Parent	Caucasian	PTSD, Bipolar Disorder, ADHD
5	male	17 yrs., 8 mo.	State	Caucasian	PTSD, Bipolar Disorder
*12	female	15 yrs., 8 mo.	State	African American	PTSD, Bipolar Disorder
*14	female	14 yrs., 3 mos.	State	Caucasian	PTSD, Conduct Disorder

Group 2	Gender	Age	Custody	Race	Diagnosis
6	female	16 yrs., 5 mo.	State	Caucasian	PTSD, Bipolar Disorder, ADHD
7	female	13 yrs., 10 mo.	Parent	Caucasian	PTSD, Bipolar Disorder
8	female	14 yrs., 4 mo.	State	Caucasian	PTSD, ADHD
9	female	14 yrs., 2 mo.	State	Caucasian	PTSD, Bipolar Disorder
10	male	17 yrs., 1 mo.	State	Caucasian	PTSD, Bipolar Disorder
*11	female	16 yrs., 0 mo.	State	African American	PTSD, Bipolar Disorder
*13	female	12 yrs., 10 mo.	Parent	Caucasian	PTSD, Bipolar Disorder

*Participants who were discharged from the residential program prior to the start of the intervention

Table 2.*Percent of Sessions Attended by Participants*

Group One	Percent Attendance	Group Two	Percent Attendance
Participant 1	75%	Participant 6	63%
Participant 2	75%	Participant 7	100%
Participant 3	75%	Participant 8	75%
Participant 4	100%	Participant 9	88%
Participant 5	75%	Participant 10	63%
Average Attendance	80%		78%
Average Total Attendance for both Groups Combined: 79%			

Table 3.

Pre-, Post- and Difference Scores (Percent) for Knowledge Tests by Participant, by Group and Combined Across all Participants

Group One:			
<u>Pre /Post Difference Scores</u>	<u>Test One</u>	<u>Test Two</u>	<u>Test Three</u>
	Diagnosis Treatments Medications	Medications Symptoms Side effects	Suicide Substance Abuse Addiction
Participant 1	75/75 (0%)	80/60 (-20%)	100/100 (0%)
Participant 2	75/100 (25%)	80/100 (20%)	66/66 (0%)
Participant 3	75/75 (0%)	100/80 (-20%)	66/66 (0%)
Participant 4	50/75 (25%)	80/80 (0%)	66/100 (34%)
Participant 5	75/100 (25%)	40/80 (40%)	100/100 (0%)
Average Percent Increase	70/85 (15%)	76/80 (4%)	80/86 (6%)
Group Two:			
<u>Pre /Post Difference Scores</u>	<u>Test One</u>	<u>Test Two</u>	<u>Test Three</u>
Participant 6	-----	25/100 (75%)	80/100 (20%)
Participant 7	0/50 (50%)	100/66 (-44%)	80/80 (0%)
Participant 8	75/75 (0%)	-----	-----
Participant 9	50/75 (25%)	100/100 (0%)	80/100 (20%)
Participant 10	75/100 (25%)	-----	66/66 (0%)
Average Percent Increase	50/75 (25%)	75/89 (14%)	77/87 (10%)
Combined Across all Participants:			
<u>Pre /Post Difference Scores</u>	<u>Test One</u>	<u>Test Two</u>	<u>Test Three</u>
	60/80 (20%)	76/85 (9%)	79/87 (8%)

Observed Behavior During Treatment Reviews

The participant behaviors that were recorded in the monthly treatment reviews were oral statements or questions by each participant of: (1) naming each of the prescribed psychotropic medication, (2) the symptom that the medication was prescribed to treat, (3) a rating of the severity of the symptom, (4) stating the side effect caused by the medication, (5) a rating of the severity of the side effect, and (6) stating the positive effect of the medication. Scores for each group were calculated in percentages and were reported for each group for each treatment review (see Figure 1). These scores indicated a substantial increase in the number of times that these verbal behaviors were observed from the first treatment review to the final treatment review for both groups.

The total number of preference statements recorded during the treatment reviews throughout the study indicates that there was a substantial increase made from the first treatment review to the final treatment review for Groups One and Two (see Figure 2). An increase in statements of satisfaction was most pronounced especially for Group Two.

The response of the participant to the advanced practice nurse's decision about each medication during the treatment reviews changed in type and frequency for both Group One and Group Two from the first treatment review to the last treatment review (see Figure 3). The number of times that the participant agreed with the response of the advanced practice nurse about each medication decision increased substantially for both groups. The number of responses by the advanced practice nurse that did not agree with preference statements made by the participant changed very little from the first to the final treatment review. The number of responses by the advanced practice nurse in the absence of a participant preference statement changed very little as well.

A total of 14 medication changes were made for Group One during the study. A total of 30 medication changes were made for Group Two during the study (see Figure 4).

Participant Evaluation Survey

In Class Eight a Participant Program Evaluation Survey was given to all of the participants. The survey used a 5 point Likert scale (see Table 4) and no rating fell below the midpoint. However, the lowest ratings occurred for the two videos (3.9) and for the Daily Symptom Tracking Sheet (3.8). The highest rating was for the pharmacist who answered questions (4.9) (see Table 4).

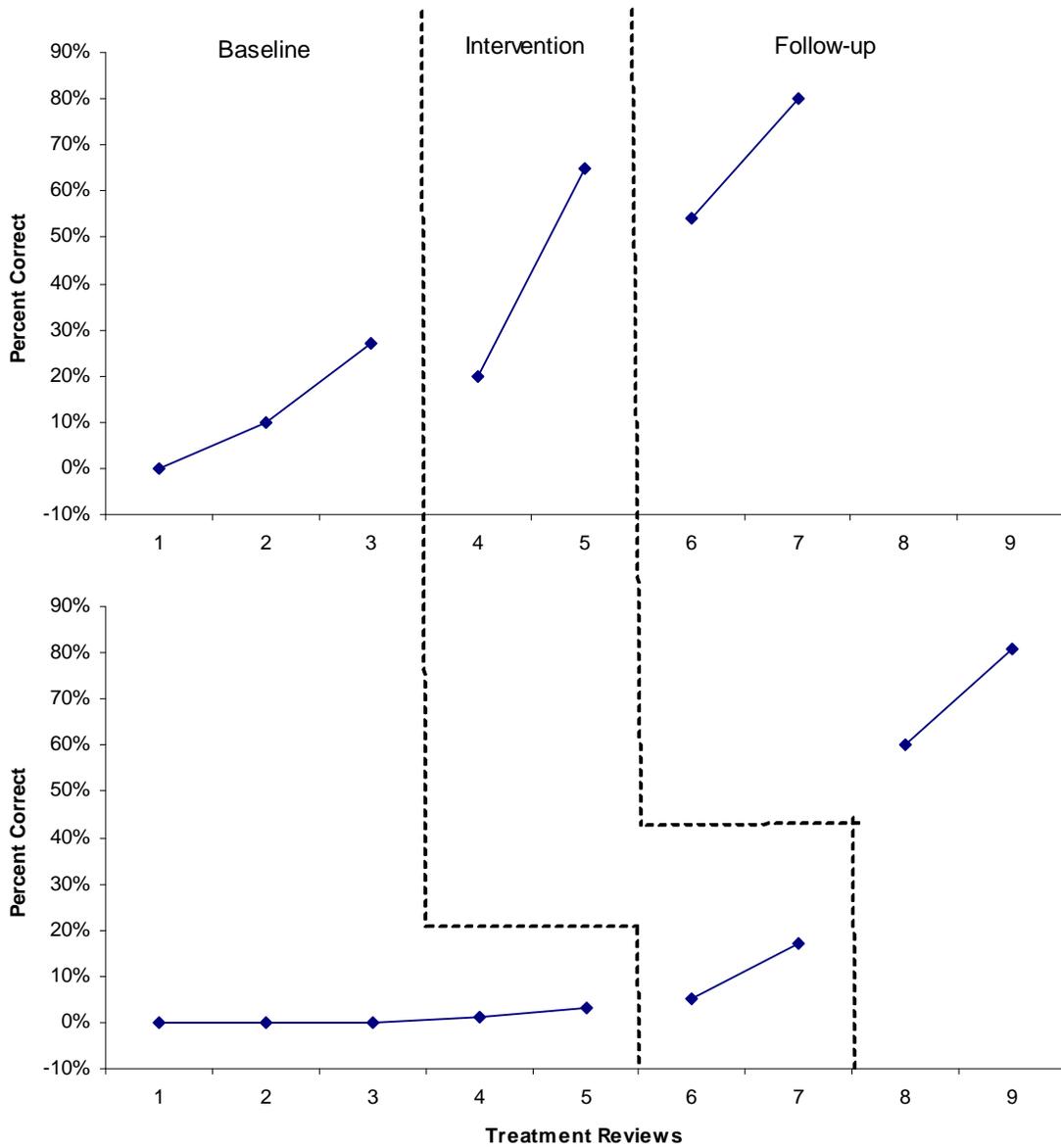


Figure 1. Participant statements to advanced practice nurse during treatment reviews about prescribed medications

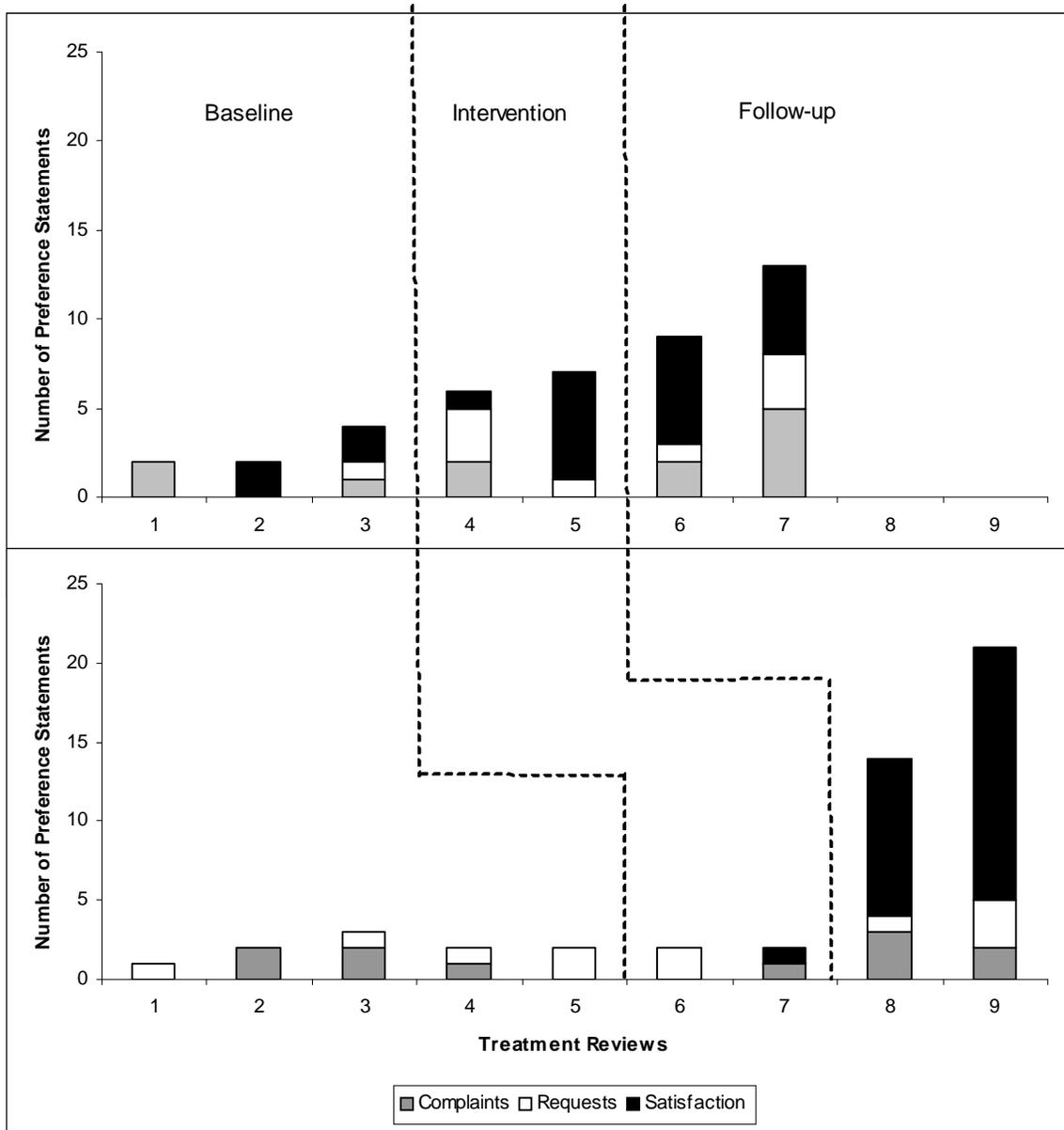


Figure 2. Number and Types of Preference Statements for Each Treatment Review

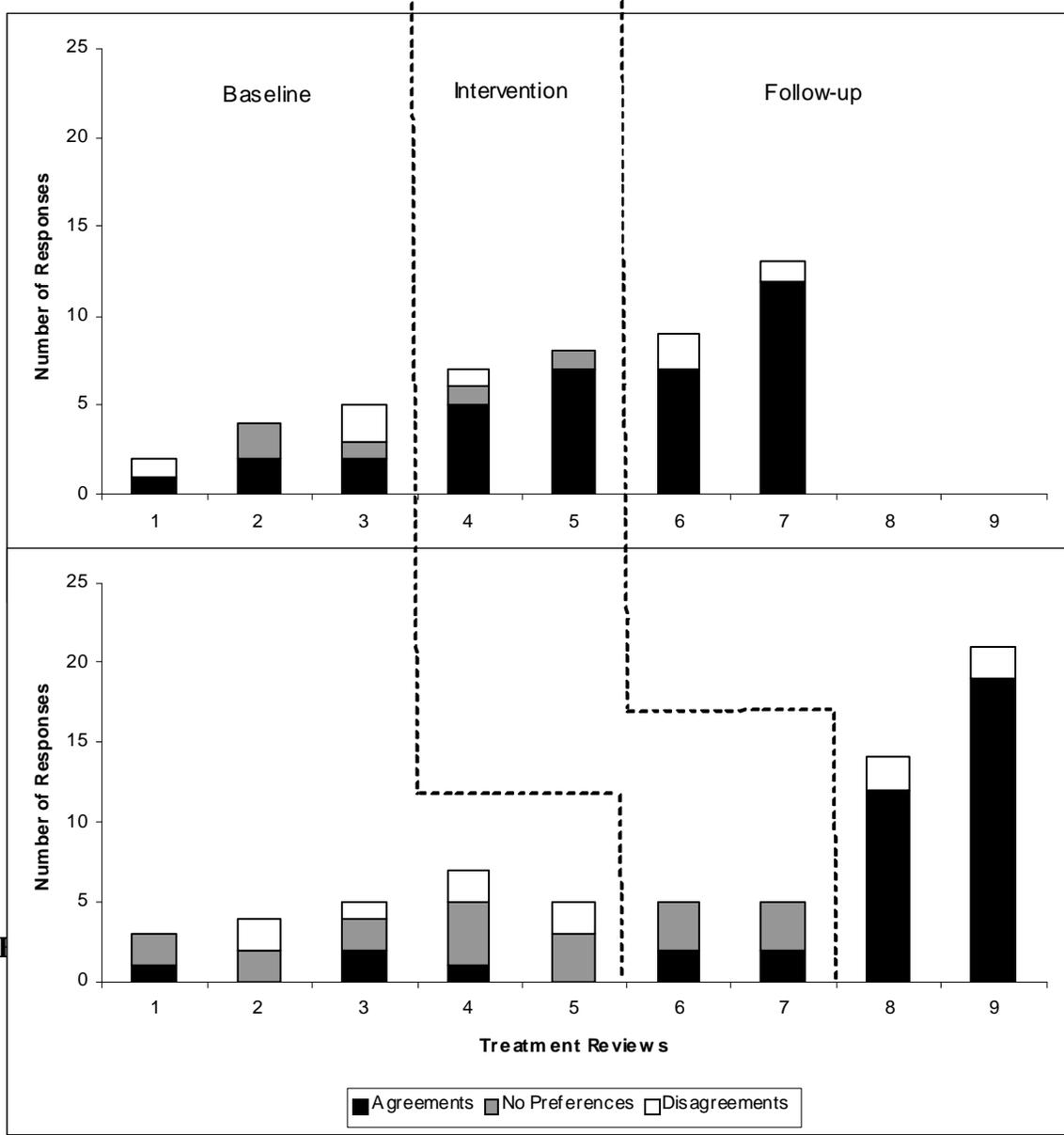


Figure 3. Responses of Advanced Practice Nurse to Statements by the Participants

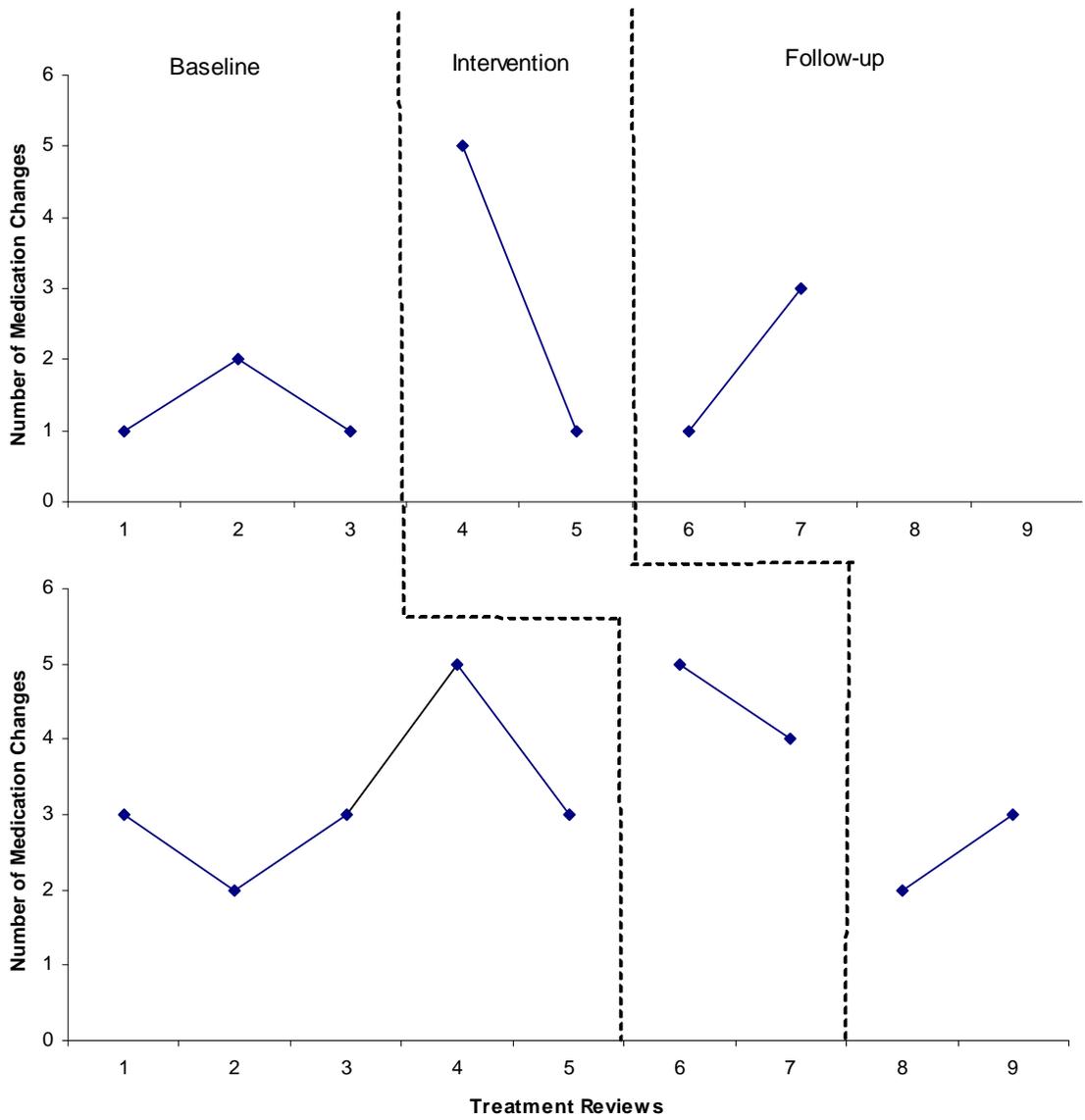


Figure 4. Number of changes made by advanced practice nurse to medications prescribed for participants during each treatment review.

Table 4.
Participant Program Evaluation Survey

TEEN SURVEY	Group One (n=5)	Group Two (n=3)	Combined Rating (N=8)
1. How helpful was this course for you?	4.0	4.4	4.2
2. How helpful to you were the two videos About teens with PTSD?	4.0	3.8	3.9
3. How helpful was the pharmacist who came to talk to you about your medications?	5.0	4.8	4.9
4. How helpful was the Daily Symptom Chart that you used?	4.0	3.6	3.8
5. How important was the person with a mental illness who came to talk to you about his/her life?	4.3	4.75	4.5
6. How helpful do you think this course will be to future residents?	4.3	4.6	4.4

Discussion

The purpose of this study was to teach participants self-management skills with respect to communicating with the advanced practice nurse about medications prescribed for the participants. Part of the self-management skills taught to participants was to present or discuss “factual” information with the advanced practice nurse such as what medications were prescribed for the participant, and what the positive effects of the medication were supposed to be. The majority of the information presented, however, was information that was available only to each participant such as what were the effects and side effects of the medications, how good or bad the medications made a participant feel, and whether a participant wanted to continue with the present medication(s) or switch medication(s). It was this information that only the participants could provide that, presumably, should be part of the decision making process of the advanced practice nurse.

As shown in Figure 1, during the baselines for both groups of participants, the number of statements the participants provided about their medication to the advanced practice nurse was relatively low. The number of these statements from participants in Group 1, however, gradually increased over the first three sets of clinical reviews. Statements from participants in Group 2 also increased during baseline, but only slightly. For both groups of participants, the number of statements made to the advanced practice nurse increased moderately during the two sets of clinical reviews that were held during the time when the class sessions were held (the intervention period labeled on the graphs). During the follow-up period for both groups (just after the final class period when participants practiced how to present information to the advanced nurse with each other and when participants received points for making statements to the advanced practice nurse) the number of participant statements about their medications increased substantially.

Thus, the overall effects of the class sessions, the practice participants had with each other as to how to give information to the advanced practice nurse, and the use of points to reward giving information to the advanced practice nurse produced a substantial amount of information on which the advanced practice nurse could make a more informed decision. Interestingly enough, the greatest increases in statements made by participants from baseline to the follow-up period were statements of satisfaction with their current medications (see Figure 2).

The data shown in Figure 3 indicate an increasing amount of decisions made by the advanced practice nurse that were in agreement with or consistent with the statements of preference by the participants. It could be argued that this was true only because the participants made more preference statements with which the nurse practitioner could agree. If this were true, however, there also should be an increasing amount of decisions made by the advanced practice nurse that were in disagreement with the statements of

preference by the participants. This was not the case. The number of decisions made by the advanced practice nurse that were in disagreement with the statements of preference by the participants remained relatively stable while the decisions made by the advanced practice nurse that were in agreement with the statements of preference by the participants increased substantially over time. This was especially apparent during the follow-up period and, together with the increasing amounts of satisfaction statements by the participants, suggests a developing partnership between the advanced practice nurse and the participants in achieving agreed-upon outcomes of the medication(s) prescribed.

The present study had a number of limitations. First, the sample of participants was drawn from one program site and the majority of participants were female. Thus, the participants in this study may not represent the breadth of diversity of adolescents diagnosed with post traumatic stress disorder. Nevertheless, the present sample of participants responded to the intervention in ways that suggest the exercise of self-management with the prescribing nurse. A second limitation was that only one advanced practice nurse was involved in the study and made the decisions as to what medications to prescribe. Hopefully, other medical personnel who prescribe medications for disorders such as post traumatic stress disorder would also be responsive to medication self-management skills of their adolescent patients. This, of course, requires additional replications of the procedures across an increased number of participants and prescribing agents.

A third limitation was the experimental design used in the study was not a “true” multiple baseline design. In a “true” multiple baseline design, interventions are implemented only after there is no trend in the behaviors being studied or that the trend in the behaviors being studied is in a direction opposite from that expected to be produced by the intervention. Clearly, this was not done in the present study: for both groups the

intervention started during a time when the behaviors of the participants that were being measured were increasing (substantially for Group 1 only slightly for Group 2). Thus, the experimental design used in this study was flawed and this flaw makes it difficult to conclude definitely that the intervention was responsible for the increased behaviors of the participants. Unfortunately, the requirements of a “true” multiple baseline design could not be followed because of the need to complete the study before participants were discharged from CCC.

A fourth limitation of the study was that the intervention was composed of several components and it is difficult to determine which of the components were responsible for the increases in medication self-management skills. We suspect that the practice the participants had with each other about how to provide statements and information to the advanced practice nurse and the point motivational system used during follow-up were particularly useful.

A fifth limitation was that the implementation of the intervention was not measured to ensure that the procedures used in this study were put into place as described. Future researchers might well benefit from having two or more observers measure the essential elements of the intervention to assess whether the class sessions and other parts of the intervention were conducted as described.

Finally, this study does not include any measures of the maintenance of the behaviors that were displayed by the participants. A lack of successful, long-term self-management can have serious implications for chronic disease. Dobbels et al. (2005), for example, found that the survival rates for adolescent transplant recipients were lower than for younger recipients when tracked and compared for five years. The authors asserted that the lower survival rates were associated with lower, long-term self-management of medication regimens for the adolescent patients studied. Because the symptoms of post

traumatic stress disorder can last for many years, the need for effective self-management of medications should be a skill that is maintained for many years. Thus, information about environmental supports that can maintain the self-management behaviors learned during this intervention will be critical for long-term success with the self-management of medications for adolescents with post traumatic stress disorder.

The participants for this study were drawn from a population seldom studied in research on adolescents. Several of the participants were in state custody. The need for this population to be successful in managing their own medication becomes apparent when viewed in light of the number of changes in foster care placements that can occur for this population. The need to train adolescents in foster care about how to manage their medication regimens may be linked to maintaining positive health outcomes.

An additional suggestion for the direction of future research would be to address the social validity of self-management skills for adolescents who have been prescribed psychotropic medications for a psychiatric diagnosis. Social validity was originally defined as a qualitative measure that could be used to determine the: a) significance of goals chosen; b) acceptability of procedures used; and, c) importance of outcomes that were the result of an intervention (Wolf, 1978). Positive results of social validity measures are hypothesized to be directly related to the likelihood that people will be willing to start, complete and maintain interventions. Wysocki et al. (1997) found that higher social validity scores were correlated with better treatment outcomes for children and parents in a diabetes education intervention, although this finding has not been replicated. While the hypothesis that higher social validity scores are related to maintained use of a medical procedure seems reasonable and may have considerable support in the clinical experience of practitioners, there is little empirical evidence to support it as yet.

Despite the current limitations of the study, some conclusions seem to be reasonably justified on the basis of the current data. Adolescents can be taught the skills needed to provide important information about their medications to their health care provider (in this case advanced practice nurse). Teaching adolescents how to present information about their health routines and their responses to medications to the health care provider increases the opportunity for the health care provider to respond to the stated preferences of adolescents. Health care providers can reinforce the role of information provider and can respond positively to preference statements by adolescents in ways that seem to benefit both the adolescent and the health care provider. Hopefully, once adolescents learn effective health self-management skills, they will continue to use those skills well into adulthood.

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Appendix A

Curriculum

Week one: General Overview

1. Sign-in

2. Go over class outline- table of contents.

3. Pre-test.

4. Goal of this class.

The goal of this class is to inform and teach each of you about your diagnosis, post traumatic stress disorder. I want each of you to leave this course knowing what post traumatic stress disorder is, signs and symptoms, treatments (medications & therapy). I will also be bringing in some guest speakers to talk to you about various aspects of the behavioral responses. One person will be a pharmacist to answer your questions about the medications you are taking and the other will be an adult with a history of abuse. There will be time to talk about your responses and I will answer questions if I can. If I don't know the answer at that time, then by the next class I will have the answer for you (if possible). Overall, the goal is for you to have a better understanding of what post traumatic stress disorder is and how this affects you as an individual.

5. What is post traumatic stress disorder?

Post traumatic stress disorder can occur following an event that happens to you or that you witness happening to someone around you. The event is life- threatening and you or the person you see is very frightened. If you do not get help about this event then it can continue to cause problematic responses for a long time. Post traumatic stress disorder has been around since ancient times. During the Civil War there were documented cases but it had a different name. There was more written about it after World One and the Holocaust. Then after the Viet Nam War the government began studying post traumatic stress disorder very closely. Thirty percent of the veterans that returned from that war suffered from post traumatic stress disorder. We know that children and adolescents can experience post traumatic stress disorder after a catastrophic event.

6. What Are Some Possible Causes of post traumatic stress disorder?

Youth may be diagnosed with post traumatic stress disorder if they have experienced at least one traumatic event in their life. Those events can include disasters such as floods, violent crimes such as kidnapping, rape or murder of a parent, sniper fire, school shootings, motor vehicle accidents, plane crashes, severe burns, sexual and physical abuse and war.

7. How many children and adolescents develop post traumatic stress disorder?

Rates of post traumatic stress disorder are much higher in children who have experienced at least one traumatic event. Studies indicate that 15 to 43% of girls and 14 to 43% of boys have experienced at least one traumatic event in their lifetime. Of those children 3 to 15% of girls and 1 to 6% of boys will be diagnosed with post traumatic stress disorder. 100% of children who witnessed a parent being killed developed post traumatic stress disorder. Ninety percent of those youth who were sexually assaulted developed post traumatic stress disorder. Seventy-seven percent who witnessed a school shooting and thirty-five percent who were exposed to community violence developed post traumatic stress disorder.

8. What are some facts and myths?

Facts:

- Anyone can be diagnosed with post traumatic stress disorder. Race, sex, age play no part in the selection.
- Post traumatic stress disorder can be treated at this time.
- Post traumatic stress disorder affects adolescents who have been exposed to a violent or frightening event.

Myths.

- You are crazy, a bad person, a psycho or nuts. Incorrect, you have a behavior that can be modified.
- You choose to be upset. Nobody who has post traumatic stress disorder chooses to be traumatized.
- You can't lead a "normal life". Incorrect, many people diagnosed with post traumatic stress disorder are active, functioning people. There are interventions which can reduce your fear behaviors. Those problem behaviors can be modified.
- It's contagious – FALSE

9. What are the symptoms of post traumatic stress disorder in children?

Responses to post traumatic stress disorder in adolescents are more like adult responses than the responses of children. Their responses involve the spontaneous recovery of an event that scared you. Adolescents may act as if they are in danger as a result. They may be impulsive or aggressive. Fear is a normal response to dangerous situations. But with post traumatic stress disorder the fear lasts long after the situation has passed. Triggers or cues may cause the fear. Some of those triggers can include places, times of the day, certain smells or noises or any situation that reminds you of the event. If you can pay more attention to the times that you act afraid then you may be able to modify your behavior. (Introduce the Symptom Chart). People may re-experience the event in the form of flashbacks. Nightmares are common. A person may feel jumpy, jittery or easily startled or may have trouble sleeping or concentrating. Avoidance is another way of dealing with the event. The person may want to avoid situations that remind them of the event and if that doesn't work the person may have trouble remembering the event altogether. The person may be angry or irritable. They may blame themselves for the attack or others might try to blame them. This is never true but people may begin to think it is. The person may not want to spend time with other people or may show fear behavior when alone. Other problems that youth may have that relate to post traumatic stress disorder are changes in sleep patterns, changes in eating patterns and substance abuse.

Symptoms *may* include:

- fear behavior
- spontaneous recovery of the event
- flashbacks
- nightmares
- increased arousal
- irritability
- avoidance of the situation where the trauma happened
- flat affect or numbness
- anger
- guilt
- shame
- helplessness
- depression
- grief
- fear of people
- increase in use of alcohol or other drugs

Loss of trust: I felt like I could never trust anyone ever again. At first I couldn't think about having sex and then I began to numb myself like I wasn't even there when I was having sex.

Flashbacks: I couldn't stand the smell of burning rubber because it reminded me of the smell of the accident. I would start to re-live the accident again just like it was still happening.

9. Symptom tracking sheet – handout. Participants will be instructed on how to fill the document out and are asked to begin that night and fill in for the next 24 days.

10. Personal Medication Survey filled out by each participant

11. Post-test.

12. Consent administered

13. The assignment for the fifth class will be discussed. Participants will be expected to think of and ask the pharmacist two questions about their medication and their symptoms and two questions about their side effects of their medicine during the question/answer part of the class.

Week Two– Diagnosis and Treatment

1. Sign-in

2. Knowledge Pre-test

3. How is post traumatic stress disorder diagnosed?

There are six major criteria for diagnosing post traumatic stress disorder:

- The first criterion is the presence of a catastrophic event.
- The second criterion is fear about the event which may remain for a lifetime and can evoke nightmares, flashbacks or trouble focusing during the day.
- The third criterion is avoidant or numbing symptoms such as avoiding any trauma related stimuli (includes dissociation and a form of amnesia).
- The fourth criterion is hyper-vigilance or startle reflex
- The fifth criterion is that the symptoms must last at least a month and may last a lifetime if untreated.
- The final criterion is that the distress experienced was significant.

These six criteria are described in the *Diagnostic and Statistical Manual for Mental Disorders, fourth edition (DSM-IV)*.

4. Different types of treatment

A good treatment plan includes medication, close monitoring of symptoms, education about the illness, behavioral therapy for the individual, support for the family, relaxation techniques such as biofeedback instruction, good nutrition, regular sleep and exercise, and participation in a network of support.

- Medication may be one tool used to help
- Behavioral therapy helps to change the fear response.
- Treatment facilities and hospitalizations – Crittenton is an example of residential treatment. There is also short term hospitalization for short term high risk patients.

5. Medications

Medications for post traumatic stress disorder are prescribed by psychiatrists— medical doctors (osteopaths or allopaths) with expertise in the diagnosis and treatment of mental disorders. While primary care physicians who do not specialize in psychiatry also may prescribe these medications, it is recommended that people with post traumatic stress disorder see a psychiatrist for medication and check with their pharmacist whenever medications are prescribed.

- Medications known as selective serotonin reuptake inhibitors (SSRI) usually are prescribed to help treat symptoms of post traumatic stress disorder. Two different medications have recently been approved for the treatment of post traumatic stress disorder. They are Paxil (Paroxetine) and Zoloft (Sertraline)
- Changes to the treatment plan may be needed at various times during the course of post traumatic stress disorder to manage the diagnosis most effectively. Symptoms are different for every person so a variety of medications may be used. A psychiatrist will change types or doses of medication.
- Be sure to tell the psychiatrist about all other prescription drugs, over-the-counter medications, or natural supplements you may be taking. This is important because certain medications and supplements taken together may cause adverse reactions.
- To reduce the chance of symptoms returning it is important to stick to the treatment plan. Talk to your doctor and your pharmacist if you have any concerns about the medications.

6. Treatments

As an addition to medication, behavioral therapy can be very effective in reducing the fear behavior associated with post traumatic stress disorder. Support, education, and guidance can also be helpful to people with post traumatic stress disorder and their families. Studies have shown that behavioral interventions can lead to better health outcomes. A licensed Applied Behavior Analyst, psychologist, social worker, or counselor typically provides these therapies and often works together with the

psychiatrist to monitor a patient's progress. The number, frequency, and type of sessions should be based on the treatment needs of each person.

Behavioral therapies used for post traumatic stress disorder usually target the fear responses that are typical of post traumatic stress disorder and desensitize the patient to the stimuli that create the fear response. Behavioral therapy, education, medication and family therapy all help to increase the positive behaviors associated with improvement. Psycho education involves teaching people with post traumatic stress disorder about the diagnosis and its treatment, and how to recognize symptoms so that early intervention can be sought before long term problems occur. Psycho education also may be helpful for family members.

- Family therapy uses strategies to reduce the level of distress within the family.
- The treatment plan should be individualized because each patient's response to their traumatic event will be different. Many factors contribute to the severity of the fear response and often talk therapies will concentrate on those factors. Behavioral interventions will focus on the fear behaviors that occur in response to the negative stimuli associated with the traumatic event. Ex. Smells may trigger spontaneous recovery of the fear response. It is important to remember that the collaboration between patient and treatment provider should create a treatment plan that is individualized for each patient. One way of determining the stimuli for problem behaviors may be by performing a functional assessment.

7. Treatment Facilities and Hospitalization

Residential

Residential treatment programs are designed for adolescents who need a structured, safe, and secure environment. The program helps adolescents develop new problem solving skills such as anger management, problem resolution, and coping skills. They also can increase social skills. Residential patients may have long-standing problems that often have resisted management in other programs or the resident may lack the support system needed for treatment. Adolescents in this program participate in school sessions, individual, group, and therapeutic recreational activities. Psychiatrists manage medication for psychiatric disorders.

Hospital

Each patient is under the care of a psychiatrist, who works with a multidisciplinary team of behavioral health professionals. It is usually used for short-term crisis intervention. If a person is suicidal or doing other risky behaviors, a hospital stay may be used to keep the patient safe, adjust medications if needed, provide therapy, and help the patient get through the crisis period. The team helps youth understand their behavior and learn how to manage it.

Help can also be found with:

- Behavioral psychologists
- School programs – school nurse
- Hospital departments of psychiatry
- Private psychiatric offices and clinics
- Offices of family physicians, internists, and pediatricians
- Public community mental health centers

People with post traumatic stress disorder may need help:

- People with post traumatic stress disorder may not link their problems to their fear responses.
- A person with post traumatic stress disorder may need much positive reinforcement from family and friends to seek treatment. Family physicians can play an important role in providing referral to a mental health professional.
- Sometimes a family member or friend may need to take the person with post traumatic stress disorder for a mental health evaluation and treatment.
- A person who is in the midst of a reaction may need to be hospitalized for his or her own safety and for much-needed treatment. There may be times when the person will be hospitalized against his or her wishes if that person does things to hurt themselves or others.

8. Knowledge Post-test.

Week Three – Video and Discussion

1. Sign-in

2. Watch video “Teens and Trauma”

3. Discuss video.

4. Discuss Symptom Tracking sheet: ask if anyone has found out anything from tracking their symptoms.

5. Participant evaluation measure given to each participant.

Week Four – Video and Discussion

1. Sign-in

- 2. Watch video “Abused Boys, Wounded Men”** (Before viewing please warn participants that some of the people in the video may make them uncomfortable or may talk about upsetting things. Instruct them that if this happens they may ask to speak privately with the therapist who is there during the session)
- 3. Discuss video.** Remind participants to bring in questions for the pharmacist.
- 4. Participant evaluation measure given to each participant.**

Week Five– Guest Speaker (Pharmacist) on Medication

- 1. Sign-in**
- 2. Pre-test.**
- 3. Pharmacist will lecture on medications used to treat post traumatic stress disorder.** The pharmacist will discuss medications commonly used to treat post traumatic stress disorder, what happens if you combine those medications with other medications or over-the-counter drugs and with natural supplements. The pharmacist will also talk about combining medications, side effects of medications and compliance issues.
- 4. The pharmacist will take questions during and after the presentation** (each participant must ask two questions about their medications and two questions about the side effects to get all eight points for this class).
- 5. Post-test.**

Week Six – Living with Post Traumatic Stress Disorder

- 1. Sign-in**
- 2. Guest speaker (adult) will give history of abuse and describe symptoms experienced.** After speaking the participants can ask questions and make statements on the topic for this group.
- 3. Participant evaluation measure given to each participant.**

Week Seven – Self-injurious behavior and substance abuse

- 1. Sign-in**
- 2. Pre Knowledge Test.**
- 3. Self-injurious behavior.**
Some people with post traumatic stress disorder may try to hurt themselves. Anyone who is thinking about committing suicide needs immediate attention, preferably from a mental health professional or a physician. Anyone who talks about suicide should be taken seriously. Signs that may accompany self-injurious behavior may include:

- talking about wanting to die
- verbalizations about nothing ever changing, nothing one does makes any difference or being a burden to family and friends
- abusing alcohol or drugs
- putting affairs in order (e.g., organizing finances or giving away possessions to prepare for one's death)
- writing a suicide note
- putting oneself in harm's way, or in situations where there is a danger of being killed

While some suicide attempts are carefully planned over time, others are acts with no plan. It is important to understand that suicidal behavior can be changed with help.

4. Are substance abuse and addiction related to post traumatic stress disorder ?

Teens with untreated post traumatic stress disorder may use alcohol and drugs. Any child or adolescent who abuses substances should be evaluated. Adolescents who had a normal routine and seemed normal until a traumatic event and then experience a comparatively sudden onset of new behaviors should be observed. Increased use of drugs or alcohol could happen. If addiction develops, it is essential to treat both the post traumatic stress disorder and the substance abuse at the same time.

5. Rehearsal of behaviors listed by Personal Medication Survey that will earn points for participant during treatment reviews

6. Post-test.

Week Eight – Discussion and Review

1. Sign-in

2. Discussion and participant questions about post traumatic stress disorder curriculum.

3. Review and complete Personal Medication Survey (explain reward system for treatment reviews again).

4. Round Robin question and answer review: participants sit in a circle and each participant is asked a question based on the curriculum until each participant has answered four questions correctly.

5. Class Evaluation given to each participant to rate procedures and importance of the course.

6. Party.

Appendix B

Personal Medication Survey

Date _____

First Name and Last Initial _____

What is the information that you have learned about your symptoms from your symptom tracking sheet? _____

Medication # 1	Medication # 2	Medication # 3
Name:	Name:	Name:
Symptoms you take it for:	Symptoms you take it for:	Symptoms you take it for:
How bad is this symptom: 5 4 3 2 1 Really Bad Not Have Don't Bad Good or But Have Bad Don't Any Bother Me	How bad is this symptom: 5 4 3 2 1 Really Bad Not Have Don't Bad Good or But Have Bad Don't Any Bother Me	How bad is this symptom: 5 4 3 2 1 Really Bad Not Have Don't Bad Good or But Have Bad Don't Any Bother Me
The medication makes this symptom: 5 4 3 2 1 Whole Worse No A A Lot Worse Little Lot Worse Better Better	The medication makes this symptom: 5 4 3 2 1 Whole Worse No A A Lot Worse Little Lot Worse Better Better	The medication makes this symptom: 5 4 3 2 1 Whole Worse No A A Lot Worse Little Lot Worse Better Better
The bad side effects of this medication for me are:	The bad side effects of this medication for me are:	The bad side effects of this medication for me are:

<p>The bad side effects are:</p> <p>5 4 3 2 1 Really Bad Not Have Don't Bad Good Them Have Or Bad But Any Don't Bother Me</p>	<p>The bad side effects are:</p> <p>5 4 3 2 1 Really Bad Not Have Don't Bad Good Them Have Or Bad But Any Don't Bother Me</p>	<p>The bad side effects are:</p> <p>5 4 3 2 1 Really Bad Not Have Don't Bad Good Them Have Or Bad But Any Don't Bother Me</p>
<p>The good effects of this medication are:</p>	<p>The good effects of this medication are:</p>	<p>The good effects of this medication are:</p>
<p>The good effects of this medication are:</p> <p>5 4 3 2 1 Fantastic Really Good Slightly Not Good Or Bad</p>	<p>The good effects of this medication are:</p> <p>5 4 3 2 1 Fantastic Really Good Slightly Not Good Good Good Or Bad</p>	<p>The good effects of this medication are:</p> <p>5 4 3 2 1 Fantastic Really Good Slightly Not Good Good Good Or Bad</p>

Appendix C

Consent and Assent

Consent for Participation in Evaluation Study

This is a research study, which is being done to determine if a series of educational groups about Post Traumatic Stress Disorder will improve your child's behavior and medication compliance. You and your child will be asked to participate in the study upon admission to Crittenton Children's Center. If you both agree, there will be a professional counselor who will assist your child in filling out a behavior rating scale (University of California at Los Angeles Post-traumatic Stress Disorder Index) about your child's behavior. Your child will attend an eight-session medication education class that will help him/her learn how to understand his/her diagnosis, symptoms and any medications that may be given to him/her. The purpose of this class is to assist your child in managing the issues and problems associated with his/her diagnosis and to become an equal partner in managing his/her life by acquiring the life skills necessary to do so.

Procedures

If you choose to have your child be part of this study while receiving treatment at Crittenton Children's Center, he/she will receive a psycho-educational intervention known as medication compliance education. Each of these eight educational sessions will be held with other residents present. These groups will require that the patients view educational videos, participate in group discussions, listen to lectures from pharmacists and staff members, meet and ask questions of a young adult who has a mental illness and join with other patients in other educational group activities. All of these groups are based on research, which has established the effectiveness of each individual educational tool used. The effectiveness of the entire curriculum has been piloted in a previous study, but changes have been made to the curriculum, which reflect the results of the analyses of that curriculum.

Before the beginning of each group, the participants will be given a knowledge pre-test and at the end of the class a knowledge post-test. Also, before the start of the first class, each participant will be given an attitudes survey, and at the end of the eighth session each participant will be given an attitude survey. These surveys are administered for the purpose of measuring the effects of the different parts of the curriculum on the participants. Participants will be asked to evaluate the usefulness of the speakers who present and the video tapes used during classes. Data will be recorded about how many questions were asked of the pharmacist about medication and side effects. The number of questions asked will be recorded but not the content of those questions. Finally, nurses will also record each incidence of medication noncompliance and the rationale for the behavior given by the participant. This data will be collected by the nurses at Crittenton Children's Center for regulatory purposes and would be collected whether or not the study was conducted.

Rev. Date: 9/25/06



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Participant Assent Form

Assent of Minor to participate in a Study: Does the medication compliance group help you do better after you get out of Crittenton?

You are being asked to take part in a group called PTSD/Post Traumatic Stress Disorder at Crittenton Children's Center (CCC). This group will help you learn about the symptoms of Post Traumatic Stress Disorder and how you get it. When you first talk about joining this group with your guardian and then with the researcher you will be asked to fill out this assent form. You do not have to take part in this group. You may stop taking part at any time by telling Jan Talley or by calling her at 816-767-4242. If you choose to not take part in the group, you will not get in any trouble, and you will continue to receive care at CCC.

This group may help you better understand your symptoms and medication for Post Traumatic Stress Disorder. These are some of the things that you will do in group: watch movies about Post Traumatic Stress Disorder, listen to speakers, fill out forms about medication, discuss topics about Post Traumatic Stress Disorder and have healthy snacks at the end of group. Some questions during group might be uncomfortable and you do not have to answer these. You will write answers to questions before and after each Post Traumatic Stress Disorder group about things you learned that day in group. If you choose to attend this group and participate, you will be given eight points at the end of each week.

There will be eight groups that last about one hour and fifteen minutes each and will be on eight week nights. There are two homework assignments. The first one is to fill out a medication list and the second one is to fill out a symptom tracking sheet. These two assignments will be for you to keep. The two homework assignments will be your property and will be kept by you on your person. All other data which include: 1) your pre and post tests, 2) your opinion measures about the course, 3) the behavior rating scale. 4) the number of questions that you ask the pharmacist, as well as 5) any incidents of medication non-compliance, will be stored in a locked cabinet in a locked office. The study investigator and study manager will be the only persons having access to the locked cabinet. Questions about medication, daily routines, diagnoses and symptoms will be discussed. The number of questions that you ask the pharmacist about your medications and your side effects will be recorded but not what your questions are about.

Confidentiality

The researchers will keep your records related to the study private unless disclosure 1) is required by law (including court orders, court ordered warrants, subpoenas),

- 2) is needed to identify or locate a person who is a suspect, fugitive, material witness or missing person,
- 3) is needed to get information about a victim or suspected victim of a crime,
- 4) is needed to alert law enforcement of a person's death if related to criminal activity,
- 5) is needed if health information is evidence of a crime that occurred on its premises,
- 6) is needed in a medical emergency not occurring at CCC but necessary to police a crime, the location of the crime or crime victims and who did the crime.

By signing this form, you give permission for your information from the study to be reviewed by the Saint Luke's Institutional Review Board to protect you. If Crittenton Children's Center decides to publish study data, they will not identify you. If you want to take back your permission to release your health records, you may do so by writing to Jan Talley at Crittenton Children's Center at 10918 Elm Street, Kansas City, Missouri, 64134. You may also call Jan Talley at 816-767-4242 and ask to be withdrawn from the study. This will be done immediately, and your study data will be shredded in a secure and confidential manner.

If you choose to enroll in this study, you can do so by signing this assent form. Your name will be entered into a log and will be assigned a number. All records of your pre and post tests and the opinion measures, the behavior rating scale score and the number of questions you ask of the pharmacist, as well as any incidents of medication non-compliance, will be identified by that number once it is entered into the study records. The list containing your name will be kept in a locked cabinet in a separate locked room, and the key to that cabinet will only be used by the study investigator and study manager. The data will be stored in a locked cabinet in a locked room separate from the log book with subject names. The data will be stored in a secure and confidential place for seven years. This assent is good for one year after date you sign it, but the data may be used for seven years and will be stored for seven years in a confidential place as long as neither your assent nor the consent of your parent or guardian is revoked.

If you agree to be in the group sign your name below.

Signature of patient

Date

In my opinion, the nature of the study and its risks and benefits have been adequately explained to the minor subject, and he/she has voluntarily agreed to participate.

Signature of child advocate

Date

Appendix D

Knowledge Tests

NAME _____

DATE _____

BIRTH DATE _____

Pre-Test Class # 2

1. How is Post Traumatic Stress Disorder diagnosed?

2. Name three different types of treatment for PTSD.

a) _____

b) _____

c) _____

3. Name two medications used to treat PTSD.

a) _____

b) _____

4. People who have PTSD can get control of their symptoms and live a good life.

True

False

DATE_____

FIRST NAME, LAST INITIAL_____

DATE OF BIRTH_____

MEDICATION CLASS # 5 PRE-TEST

1. Name one medication that you are taking for Post Traumatic Stress Disorder:

2. Name the symptom that medication is used to treat.

3. Medications can interact with each other. Circle the correct answer.

True False

4. Name one side effect that you can have from your medication.

5. Medication can take weeks to become effective. During that time you should continue to take your medication. Circle the correct answer.

True False

DATE _____

**FIRST NAME, LAST
INITIAL** _____

**DATE OF
BIRTH** _____

MEDICATION CLASS # 7 PRE-TEST

1. Do some people with post traumatic stress disorder want to commit suicide? Please explain what they should do.

2. How is addiction related to post traumatic stress disorder?

3. Could substance abuse be a response to a traumatic event? Please explain.

Appendix E

DAILY SYMPTOM CHART

Name: _____

Day: _____

Date: _____

Symptoms Scale

My symptoms

Were: 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24

Unbearable																							
Very Bad																							
Bad																							
A Little Bad																							
Almost None																							
None																							

Appetite

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24

Eating Too Much																							
Eating Normal																							
Not Eating Enough																							

Sleep Pattern

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24

What hour did you go to sleep																							
What hour did you wake up																							
Nightmare or Bad Dreams																							
Bedwetting																							
Slept during daytime hours																							
Startle Response While Awake																							
Flashbacks																							

