

Telephone Intervention for Schizophrenia Spectrum Disorders (TIPS) Manual

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Foreword

This manual was designed for use in training mental health nurses to provide Telephone Intervention – Problem Solving (TIPS) to outpatients with schizophrenia spectrum disorders (SSDs) residing in the community. TIPS is designed to support problem solving in response to a variety of everyday problems. The use of the problem solving process compensates for a variety of cognitive deficits often present in SSDs that interfere with effective daily coping. TIPS is designed to foster problem solving, offer coping alternatives, suggest reminders so patients remember to use these alternatives, and assess the effectiveness of these coping efforts. Effective use of problem solving to identify ways to cope with everyday problems may reduce stress, reduce symptoms and improve community survival for persons with SSDs. Data from prior studies indicate that persons receiving weekly telephone nursing intervention experienced (a) lower rates of rehospitalization, (b) fewer and shorter readmissions, (c) longer community survival (d) significantly greater medication adherence as measured by pill count and (e) significantly greater numbers of persons with serum medication levels in therapeutic range than those who did not over periods ranging from 3 to 6 months of follow up (Beebe, 2001, 2002, 2003, 2005,; Beebe & Tian, 2004;Beebe et al.,2008, Beebe , Smith & Phillips, 2017). TIPS was developed with the goal of providing effective, economical community support to persons with SSDs.

Didactic training with this manual will be followed by supervised “role-play” training with the developer of TIPS who is experienced in its use. The manual consists of 3 sections. Section 1 provides background information on the symptoms of SSDs and specific cognitive deficits and how these deficits impact problem solving and community functioning. In section 2 common problems in daily living and the problem solving process are discussed. In section 3 we discuss how to provide TIPS to the persons with SSDs, and how to respond to the person presenting specific daily life problems.

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Section 1: The schizophrenia spectrum disorders (SSDs)

Learning objectives

After completing Section 1 of the TIPS manual participants will:

- a. describe the 3 groups of of symptoms present in SSDs
- b. describe how cognitive deficits contribute to difficulty with problem solving in everyday life

Introduction:

Schizophrenia spectrum disorders (SSDs) include schizophrenia, schizoaffective disorder and schizophreniform disorder. The diagnostic overlap between the three is well known; all include positive symptoms such as hallucinations and delusions (American Psychiatric Association, 2013). Further, research indicates that persons with these disorders do not differ significantly on symptom categories as identified by the Brief Psychiatric Rating Scale (Kopelowicz, Ventura, Liberman & Mintz, 2008), nor on basic cognitive measures such as executive functioning (Premkumar et al, 2008) and associative learning (Sacchetti, Galluzzo, Panariello, Parrinello & Cappa, 2008).

SSDs are chronic and severe brain diseases that have three main classes of symptoms. These include positive symptoms, negative symptoms and cognitive symptoms. Positive symptoms include hallucinations and delusions. Hallucinations refer to sensory experiences when external stimuli are absent. For example, someone may hear voices talking about him or her. Delusions are false fixed beliefs. For example, someone may believe she is a famous actress, or that aliens are pursuing him. When positive symptoms are severe, they may interfere with daily life activities such as shopping or conversing with other people. Often health care workers and others are not aware of the extent of the positive symptoms, as some patients have learned not to discuss these events. It is therefore helpful to ask about the frequency and severity of voices, the last time voices were heard, and the degree to which false beliefs are held.

Negative symptoms refer to observable behaviors such as a flat affect, decreased motor activity and motivation, and social withdrawal. Patients with a flat affect use few gestures, maintain the same facial expression throughout conversation, and often speak in a monotone. Those with decreased motor activity may move and speak slowly, or spend a lot of time sitting or lying down. Problems in motivation are

evident in persons who lack goals or plans, even for performing everyday activities like showering or taking out the trash. Patients who have social withdrawal generally keep to themselves even when others are in the same room. It is easy to see how negative symptoms interfere with daily functioning. Many tasks may be undone or partially done if the person is inactive much of the time. These negative symptoms are often mistaken for laziness or lack of cooperation by families, health workers or even the patients themselves. However, negative symptoms are not laziness; rather they are a group of behaviors resulting from problems in brain function. These problems in motivation, movement, speech and socialization are often the symptoms that concern families the most.

Cognitive symptoms are also present in persons with SSDs. Patients with these illnesses often have trouble paying attention to an activity when distractions are present. For example, they may have trouble conversing when other people are talking nearby. Another common problem is the inability to pay attention for a long time. Attention may wander after a few minutes. Memory difficulties are also present in person with SSDs. Remembering lists of words is often more difficult for persons with SSDs than for those who do not have those diseases.

Finally, people with SSDs often have impairments in executive functioning. Executive functioning refers to the ability to make plans, start a project, carry out the steps of a task, or complete a task when distractions are present. These cognitive difficulties are the root of many problems in community functioning experienced by persons with SSDs. It is also possible that cognitive deficits have a part in producing the positive and negative symptoms discussed above. Research has shown that cognitive deficits negatively impact community functioning in many areas. Some of the areas that are affected negatively include basic self-care, socializing and job performance.

Cognitive functioning may change at different points in SSDs. Some cognitive problems are worse during an acute psychotic episode. Some cognitive deficits are present before the positive symptoms of the illness and some remain after the hallucinations and delusions are controlled with medication.

While medications have had some success in reducing the positive symptoms in many persons, they do less to treat the negative or cognitive symptoms. These lingering cognitive symptoms can lead to difficulty in problem solving. Problem solving refers to the ability to clearly state the difficulty, generate

possible solutions, choose a reasonable solution, try out the solution and evaluate how the solution worked. These impairments in problem solving make it hard for person with SSDs to respond to daily stress.

The treatment described in this manual is Telephone Intervention for SSDs (TIPS). TIPS is based upon the idea that we can assist persons with SSDs to apply the problem solving process to daily problems. By helping the person problem solve in response to daily stress, it may be possible for persons with SSDs to function better.

In the next section of this manual, we will describe the most common problems in daily living identified by community-dwelling persons with SSDs in previous studies. We also will provide a detailed review of the problem solving process.

Section 2: Problems in community living identified by persons with SSDs and the problem solving process

Learning objective: After completing section 2 of the TIPS manual participants will:

- a. describe 3 problems identified by persons with SSDs residing in the community
- b. describe the problem solving process as one way to assist a person with these life difficulties

Introduction: As we learned in the previous section, people with SSDs have cognitive deficits that lead to difficulty responding to problems in everyday life. In this section we focus on three specific areas of problems identified by community dwelling persons with SSDs and on the problem solving process as a way to improve their efforts to cope with these difficulties. The three problems presented in this chapter were chosen because they were identified as problem areas by a majority of persons in prior studies, because they apply to a wide range of persons with SSDs and because the problem solving process can be applied to each of them.

Problem 1: Treatment difficulties (Appointments and medications)

Over half of the patients in prior studies had problems with their medications or appointments. Studies show that, like many people with chronic physical illnesses, more than half of persons with SSDs do not take their medication as prescribed. One major reason for nonadherence is that people may just forget to take their medication. Many patients also fail to appear for appointments due to forgetting or having transportation problems. Failure to take medicine or appear for follow up appointments may result in worsening of psychotic symptoms or rehospitalization. Guiding the person

with SSDs through the problem solving process can help them come up with ways to remember their medications or appointments, and generate back up plans if transportation is a problem.

Problem 2: Psychiatric symptoms

About one third of patients in prior studies complained of psychiatric symptoms even when they said they were taking their medication regularly. The most common symptoms were anxiety, insomnia and hallucinations. Many people with SSDs who are taking medication regularly experience some symptoms. Guiding the person with a SSD through the problem solving process may help them identify helpful things to do to cope with symptoms that are not completely controlled by medication. In addition, many people with chronic diseases, such as SSDs do not take their medications as they are prescribed. It is very important to check for missed doses and encourage medication adherence during each call. Specific interventions are discussed in Section 3.

Problem 3: Interpersonal Stress

About one third of patients in prior studies reported that conflict with family or those they lived with was causing them stress. Patients with SSDs have been found to have more poorly developed social skills than those who do not have the disease. Social skills training is a complex process that involves a series of group sessions, role-play and sometimes videotaping. Such a program is beyond the scope of TIPS; however some basic problems with others can be avoided through the use of the problem solving process. For example, different ways of communicating or handling disagreements can be discussed during TIPS.

The problem solving process:

Stressors are life events (such as interpersonal conflict) or internal processes (such as hallucinations) that are perceived as stressful by the person experiencing them. Coping is a response to perceived stress that involves behavioral and cognitive processes. Examples of behavioral processes include exercising, moving to a less stimulating location or listening to music. Examples of cognitive processes include thought stopping techniques, reading or talking to a support person. The ability of persons with SSDs to use specific cognitive or behavioral strategies to manage stressful events is limited by impairments in problem solving ability. Improving the problem solving ability of persons with SSDs has been shown to be related to successful community functioning and reduced time in the hospital.

Researchers believe that regular use of problem solving can enhance social functioning and protect against relapse in persons with SSDs. The provision of TIPS involves nurses helping patients respond to everyday problems by guiding them through the steps of the problem-solving process, as follows:

- Identify the problem
- Generate solutions
- Discuss solutions
- Select a solution
- Plan to implement the solution.

Section 3: How to provide TIPS to the patient

Learning Objectives:

After completing Section 3 of the TIPS manual participants will:

- a. describe the procedure for providing TIPS to the patient
- b. describe how to address identified problems using TIPS

The initial TIPS session is used to tell the patient about the treatment and how problem solving may be helpful to them. The session is held in the hospital, or for outpatients is held either at the time of their outpatient appointment in the community mental health center, or covered at the beginning of their first TIPS call. Each step in the problem solving process is presented to the patient along with a brief explanation.

Key principles: Discuss how reduced memory and concentration make it hard to cope with everyday problems. Explain how the problem solving process can help everyone. Describe each step in the problem solving process. Answer questions.

TIPS provider- Everyone sometimes has trouble knowing what to do when problems come up. This can be even harder for some people because of their illness. Sometimes people with schizophrenia and similar diseases forget to take medicine, or go to a doctor's appointment, or don't know what to do when they feel nervous. Problem solving helps you think of what might help when difficulties arise. We will be going through problem solving steps together each week when I call you.

You will need to listen to what the patient has to say before you move on. If they have any questions you will need to answer them.

Using the TIPS protocol to respond to identified problems.

TIPS provider: Hello this is (name) from the telephone study. This is your weekly telephone call to see how you are doing.

Protocol Item # 1

Are you taking your medication (list each medication by name) as it is prescribed?

Have you missed any doses at all?

If not say, that's good. It is very important to staying well that you take your medication as it is prescribed, and let your doctor know if you have any problems with it.

If yes, say It is very important to staying well that you take your medicine as it is prescribed.

Let's talk about some things that might help.

Identify the problem

Say, What seems to be the trouble that you are missing doses of medication?

The three most common reasons for missed medication doses in prior studies were forgetting, troublesome side effects or not having money to buy the medicine. Each of these common scenarios is presented in the table below:

Example interaction for:

Forgetting

Side effects

Financial problems

<u>Generate solutions</u> -What are some things that might help you remember to take your medication?	<u>Generate solutions</u> -What side effects are bothering you the most?	<u>Generate solutions</u> - How could you be sure to have the money you need for your medicine?
Solutions include making a reminder sign, having family remind them or tying medication to some other routine like brushing one's teeth	Common side effects of antipsychotic medications include weight gain, feeling like one can't sit still, and drowsiness. Discuss things that might help each side	Solutions include budgeting money for prescriptions, asking family members to help, or asking case manager to explore options for financial aid.

	effect	
<u>Choose solution</u> -Which one of these things are you willing to try this week?	<u>Choose solution</u> -Which of these things are you willing to try this week?	<u>Choose solution</u> -Which of these things are you willing to try this week?
<u>Plan</u> - What would be a good way to remember to do _____?	<u>Plan</u> - What would be a good way to remember to do _____?	<u>Plan</u> - What would be a good way to remember to do _____?
<u>Follow up</u> - OK so you are going to do _____to help you remember to take your medicine and when we talk next week I will ask how it has worked for you.	<u>Follow up</u> - OK so you are going to do _____to help this side effect and when we talk next week I will ask how it has worked for you	<u>Follow up</u> - OK so you are going to _____to get money for your prescriptions and when we talk next week I will ask how it has worked for you

Protocol Item #2

Do you know when your next appointment is scheduled? Ask about appointments with physician and/or case manager.

If yes, verify date time and location. Say, that’s good, it is very important to staying well that you keep your appointments.

If no say it is very important to staying well that you keep all your appointments. Give patient information on follow up from record review. Let’s talk about how you can remember these appointments

<u>Generate solutions</u> -What would be a good way to remember this appointment?
Solutions may include writing self a note, asking family to remind patient or arranging a reminder phone call from provider.
<u>Choose solution</u> -Which of these things are you willing to try this week?

<p><u>Plan</u>-What would be a good way to remember to do _____? If reminder note, have patient write note while you wait on the phone, using notebook and markers given. Work with patient on placement of note in a prominent location.</p>
<p><u>Follow up</u>-OK so you are going to _____ to remember our appointment and when we talk next week I will ask how this has worked for you.</p>

If patient had an appointment since last call, ask how it went. Persons may have concerns about medication changes or need reinforcement of teaching that took place during their appointment.

Protocol Item # 3.

Ask about symptoms that often precede hospitalization such as anxiety, insomnia, or positive symptoms. Ask, Have you had any (symptom) since we last talked?

If no, say that’s good. It is important to let your caregivers know if any symptoms are troubling you.

If yes say, what seems to be the trouble?

The most common symptoms reported in our study were anxiety, insomnia and hallucinations.

Each of these common scenarios is presented in the table below. Example interaction for:

Anxiety	Insomnia	Hallucinations
<u>Generate solutions</u> -Let’s talk about things that might help.	<u>Generate solutions</u> -Let’s talk about things that might help.	<u>Generate solutions</u> -Let’s talk about things that might help.
Solutions include deep breathing, reading or listening to relaxing music	Solutions include reducing caffeine, not napping, and developing a bedtime routine.	Solutions include watching TV, listening to music, taking a walk
<u>Choose solution</u> -Which one of these things are you willing to try this week?	<u>Choose solution</u> -Which one of these things are you willing to try this week?	<u>Choose solution</u> -Which one of these things are you willing to try this week?

<u>Plan-</u> What would be a good way to remember to do _____?	<u>Plan-</u> What would be a good way to remember to do _____?	<u>Plan-</u> What would be a good way to remember to do _____?
<u>Follow up-</u> Ok so you are going to _____ when you feel anxious and next week I will ask how this worked for you	<u>Follow up-</u> OK so you are going to _____ when you can't sleep and next week I will ask how it worked for you.	<u>Follow up-</u> OK so you are going to _____ when your voices bother you and next week I will ask how this worked for you

Protocol Item # 4.

Have you had cravings for alcohol or other drugs this week that you've found uncomfortable?

If no, that's good.

If yes, ask what happened? In prior studies feeling lonely or having conflict with others often preceded cravings.

<u>Generate solutions-</u> Let's talk about some things that might help when you have cravings
Solutions include talking with a support person, distracting oneself with another activity like exercise, or taking a break to "cool down" if they are having conflict with others. You may also ask if they are connected with an alcoholics or narcotics anonymous group, or if they would like a referral.
<u>Choose solution-</u> Which one of these things are you willing to try the next time you have cravings?
<u>Plan-</u> What would be a good way to remember to _____?
<u>Follow-up-</u> OK, so you are going to _____ if you have cravings, and next week when we talk I will ask how that worked for you.

Protocol Item # 5

How have you been getting along with others this week?

If ok, that's good.

If problems, ask what seems to be the trouble? In our study a number of patients experienced conflict with family members or others in the home.

<u>Generate solutions</u> -Let's talk about some things you could do to get along better.
Solutions include calling friends or support people, helping out at home, or having the person they are in conflict with talk to care provider with them.
<u>Choose solution</u> --Which one of these things are you willing to try this week?
<u>Plan</u> -What would be a good way to remember to _____?
<u>Follow-up</u> -OK so you are going to _____--when you have trouble getting along with others and next week when we talk I will ask how that worked for you.

Protocol Item # 6

Ask, do you have any questions about anything this week?

If no that is good.

If yes, respond with requested information. In prior studies the most common questions had to do with medication side effects, whether they were usual or unusual and what to do about them. See the table under protocol Item # 1 for suggestions.

Protocol Item # 7

Is there anything else you would like to talk about today?

Cell Phone Feasibility Assessment:

Say, Thank you for your time. I will call you again next week at (day) and (time).

Follow-Up Calls

Each week after the first telephone contact it will be important to follow up on solutions for coping that you discussed the previous week.

Step 1: Review problems and strategies from previous week. You will need to find out

1-if the persons tried the solution

2-if not, why not

3-if so, was it effective.

If the solution was not tried because of forgetting go back to the planning step and choose another reminder strategy. If not tried because they didn't think it would work encourage them to try it. Tell them these strategies do work for many people. If tried and solution did not work, get details. Was the strategy done correctly or for long enough? You may need to clarify exactly what is to be done, for example "take a walk" means go outside and walk around your neighborhood for at least 10 minutes, or you may need to choose an alternate strategy.

Step 2: Address remaining protocol items (i.e. items NOT identified as problematic the previous week).

Common Problems

The most common difficulties in prior studies involved making telephone contact with participants. Difficulty connecting with patients usually involved failing to catch the person at home, or the person's having lost their phone service or moving. Subjects in previous studies required an average of 3 calls before contact was made. You may need to try calling at different times of day, perhaps very early or very late. Try to establish a set day and time for the call each week. You should try for three times a day for 3 consecutive days each week and if contact is not made, wait until the following week and try again. Loss of telephone service will be minimal in this study because we are providing patients who need them with telephones for study use.

Rare Problems

Less than 2% of patients refused to talk in prior studies. Should this occur, politely ask if the person would care to say why they do not wish to talk. It may just be a bad time. Remain friendly, explain that the person does not have to talk if they do not wish, and reinforce the study contract by saying you will call back next week. Depending on the reason for not wishing to talk, (i.e. paranoia or anger) you may need to alert their case manager or PI to arrange for a face-to-face assessment.

During prior studies we have provided over 2400 telephone interventions to hundreds of persons with SSDs. At no time did any person verbalize thoughts of harming themselves or others. Nevertheless, due to the seriousness of this safety issue, the slim chance of suicidal or homicidal thoughts must be considered and a response prepared. If at any time during TIPS the person expresses thoughts of harming themselves or others, assess whether they are alone. If someone is with them, ask to speak to that person. Explain the situation and ask that person if they are willing and able to immediately transport the patient for

emergency evaluation. If they are unwilling or unable to do so, OR if the patient is alone, use another telephone line to immediately dispatch emergency personnel to the scene by calling 911. Explain the situation. 911 personnel will then evaluate and provide appropriate disposition. Remain on the telephone with the patient until help arrives.

Call Vignette

Provider: Hello, this is (name) for the telephone study. This is your weekly telephone call to see how you are doing.

Patient: I'm OK.

Provider: Are you taking your Risperdal 2 mg three times a day as it was prescribed?

Patient: I guess so.

Provider: Have you missed any doses at all?

Patient: maybe a few.

Provider: It is very important to staying well that you take your medicine as it is prescribed. What seems to be the trouble?

Patient: Well, I stay up late at night. Then I sleep in and when I get up I have missed the morning dose.

Provider: Let's talk about some things you could do to be sure you get all 3 doses each day. What are some things that might help?

Patient: I don't know.

Provider: How could you fit in 3 doses of medicine on the days you sleep in?

Patient: Why can't I just take all 3 pills at once?

Provider: the medicine needs to be spread out through the day to work best. But you could still take 3 doses. For instance you could take one at lunch, one at dinner and one when you go to bed. That way you wouldn't miss any doses. What else might work?

Patient: I don't know.

Provider: Do you have an alarm clock?

Patient: Yes.

Provider: You could set your alarm for your morning dose, then go back to bed if you were still tired.

Patient: Or I could ask my mom to wake me.

Provider: Yes that's a good idea. Which of these things would you like to try this week?

Patient: I'll ask my mom to wake me up for my morning pill. But can I still go back to bed if I want?

Provider: Yes, you can. What would be a good way to remember to ask your mom to wake you for your morning medicine?

Patient: I'll ask her when we hang up.

Provider: Is she home now?

Patient: Yes.

Provider: OK . So you are going to ask your mom to wake you for your morning medicine, that way you won't miss it. When we talk next week I will ask you how it has worked for you.

Patient: OK.

Provider: Do you know when your next appointment is scheduled with your doctor and case manager?

Patient: I have an appointment on the 12th.

Provider: Who will you be seeing that day?

Patient: My case manager.

Provider: That's good. It is very important to staying well that you keep your appointments. Have you had any (symptom) since we last talked?

Patient: I still have voices once in awhile.

Provider: What seems to be the trouble?

Patient: Nothing, I just hear mumbling sometimes.

Provider: Let's talk about things that might help. What things seem to work for you?

Patient: Sometimes watching TV helps.

Provider: That's good. Watching TV is a good way to cope with bothersome voices. Can you think of other things that help?

Patient: Not really.

Provider: Listening to music or taking a walk outside helps some people. Which of these things are you willing to try this week?

Patient: Watching TV, because it helped before.

Provider: Write yourself a note so you'll remember to do this when your voices bother you. I'll wait while you get paper and a pencil. (pause). Write "When voices bother me I can watch TV, take a walk or listen to music". Now when you are bothered by voices you can look in your notebook for ideas that may help, and next week I will ask how this worked for you. If the voices get louder or more often be sure to tell your doctor or case manager.

Patient: OK.

Provider: How have you been getting along with others this week?

Patient: OK.

Provider: Have you had any problems at all with anybody?

Patient: Not really.

Provider: Do you have any questions about anything this week?

Patient: No.

Provider: Is there anything else you'd like to talk about today?

Patient: No.

Provider: OK. Thank you for your time. I will call you again next week at (day) and (time).

Follow-Up Vignette

Provider: Hello, this is (name) for the telephone study. This is your weekly telephone call to see how you are doing.

Patient: I'm OK.

Step 1: Follow up on problems from previous week.

Provider: Last week we made a plan for you to ask your mom to wake you for your morning dose of Risperdal. How did that work?

Patient: Not too good.

Provider: What happened?

Patient: I got mad at my mom for waking me up and she wouldn't do it anymore.

Provider: Let's choose something else to try. We had talked about setting an alarm or about taking your medicine at lunch, dinner and bedtime. Which of these things do you want to try this week?

Patient: Let's try the second one.

Provider: OK let's get this written down so you will remember. Can you go get paper and pencil now?
(pause). Write: "Take Risperdal at lunchtime, dinnertime and bedtime". Where can you put this note so you'll be sure to see it?

Patient: I'll put it on the dresser where I keep my pill bottle.

Provider: Good idea. So this week you're going to try a new Risperdal schedule and when we talk next week I will ask how it has worked for you.

Patient: OK.

Provider: Last week you also said you heard mumbling voices sometimes. We talked about things you could do that might help. How did that work this week?

Patient: I haven't had any problems with voices this week.

Provider: That's good. You can keep the note you wrote to look at if this bothers you again.

Step 2: Address remaining protocol items.

Provider: Do you know when your next appointment is scheduled with your doctor and case manager?

Patient: I have an appointment on the 12th.

Provider: Who will you be seeing that day?

Patient: My case manager.

Provider: That's good. It is very important to staying well that you keep your appointments.

Provider: How have you been getting along with others this week?

Patient: OK.

Provider: Have you had any problems at all with anybody?

Patient: Not really.

Provider: Do you have any questions about anything this week?

Patient: No.

Provider: Is there anything else you'd like to talk about today?

Patient: No.

Provider: OK. Thank you for your time. I will call you again next week at (day) and (time).

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