Supportive Therapy Training Manual

Study Title: Confronting Unequal Eye Care in Pennsylvania

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Supportive Therapy Training Manual

Introduction..................................................................................................................................1
Administering ST..............................................................................................................................3
Establishing Rapport........................................................................................................................3
Introduce ST to the Participant.........................................................................................................5
Guidelines for Administering ST.....................................................................................................6
Important Limitations.......................................................................................................................7
Structure for ST Sessions.................................................................................................................8
  Introduction .................................................................................................................................8
  Explaining the Structure of Study ..............................................................................................9
  Providing Rationale for ST .........................................................................................................9
  Using Supportive Therapy Techniques ......................................................................................10
  Answer Questions ......................................................................................................................11
  Schedule the Next Visit ............................................................................................................12
Appendix A: Example Transcript of a ST Session .................................................................13
Appendix B: Possible Topics in Supportive Therapy ..........................................................16
Appendix C: Handling Emergencies ............................................................................................17
Supportive Therapy (ST) is a standardized psychological treatment that encourages patients to express and evaluate their life situation. Living with a chronic disease, such as diabetes, can significantly impact all major domains of life (e.g., social, financial, occupational, leisure), and this can leave patients feeling frustrated, helpless, dependent, or depressed. The major premise underlying ST is that offering patients an opportunity to articulate how their lives are affected by illness may lead to a greater understanding and acceptance of their circumstances.

One of the goals of this study is to determine whether ST has any beneficial effects on how well patients manage their diabetes. We will be looking to ST patients to determine whether the process of expressing emotions about diabetes, in general, can impact self-care behaviors such as eating healthy and checking blood glucose levels regularly. Keep in mind that there are many different therapeutic and educational approaches to help people manage chronic disease.

Despite the many therapeutic and educational approaches, your goal in this study is to determine how emotional expression may help patients.

To maintain this goal, we will be instructing you to refrain from:

- Giving specific advice to subjects
- Giving recommendations regarding diabetes to subjects
- Providing suggestions to managee one’s health
- Discussing the relationship between diabetes and eye disease
We recognize that you may encounter situations in which patients may need immediate medical advice, and this manual will review what those situations are and how to handle them. The safety of our patients is our most important priority, and the study protocol is designed to insure that medical emergencies and inquiries about diabetes management are handled in a responsive and timely fashion (See Appendix C).

This training manual describes the protocol for administering the ST intervention to participants in the CURE project. In this clinical trial half of the approximately 200 subjects will be randomly selected (determined by chance) to receive ST. Each ST subject will have 4 in-home ST sessions over the course of 2-3 months. The first session will take place approximately 2 weeks after the baseline assessment, and the full treatment course (i.e., completion of 4 sessions) should be completed 4 months from the baseline assessment. When scheduling subject sessions, you should try to schedule each session approximately two weeks apart. Each session should last about 45 to 60 minutes and will take place in subjects’ homes. If the subject prefers, the sessions may take place at TJU, WEI, or Temple. All subjects will have signed an informed consent form (to be administered by the study assessor) prior to randomization. All sessions should be recorded (if the subject consented to this).
Administering Supportive Therapy

1. General Considerations

The goal of ST is to promote emotional expression. It provides a space for participants to release their feelings and share their thoughts. We have found that patients respond positively to this type of support, similar to the way that people tend to feel after “crying on the shoulder” of a good friend. The ST interventionist’s role is to provide a warm, safe, non-judgmental environment where participants can feel free to express their feelings and life situations. In a sense, the interventionist takes on the role of a trusted friend who provides unconditional positive support. This type of therapy is different from other commonly used modalities, such as cognitive behavior therapy or problem solving therapy, in that it doesn’t directly aim to change behavior, modify thought patterns, or solve specific problems.

It is essential that the interventionist refrain from giving advice or recommendations regarding participant’s problems in general or their diabetes in particular. If the participant has general, non-emergent, questions regarding their health, they should be advised to call their primary care physician (PCP). The appendix of this manual describes situations that warrant immediate attention, as well guidelines for handling medical and other emergencies.

2. Establishing Rapport

Establishing a good relationship with the participant is an important component of this intervention. Much has been written on strategies to
develop a working and collaborative therapeutic relationship. These writings all stress that the most important elements in creating a trusting relationship are to be warm, empathic, and genuine while also promoting an image of self-assurance and knowledge about supportive therapy and how diabetes can affect the aging process. Developing a trusting empathic relationship, however, may be challenging because of the brief appointment times, limited number of sessions, and the need to remain faithful to supportive therapy’s techniques. Given the limited amount of time, interventionists must be ready to develop as much trust and engagement as possible within the first session. Thus, careful attention must be paid to the first visit so that the participant does not leave the session confused or unconvinced about the efficacy of the intervention.

To facilitate a collaborative attitude with the participant, the interventionist should take care to express herself in a manner that communicates a common interactive approach rather than an authoritarian or paternal relationship. Frequent use of phrases such as “We will work together to…”, or “As a team we will try to…” will help to communicate this message. The interventionist should avoid statements that communicate a one-sided view of the relationship, such as, “You are seeing me so that I can help you feel better,” “If you do what I teach you, you will get better,” or “I can only help you if you cooperate with this therapy.”

Likewise, in order to efficiently join the participant in the collaborative treatment process the interventionist should always strive to match their vocabulary to the educational level and manner of the participant’s vocabulary. This includes adopting terms that the participant commonly uses and refraining from using terms that are obviously overly technical or
intellectually advanced. A good rule of thumb is to limit word use to two syllables and sentence length to 10 words until a clear sense of the participant’s intellectual/educational level is achieved. The interventionist should always endeavor to find alternative expressions for technical medical or psychological terms.

3. Introduce ST to the Participant

Once a participant is randomized to ST, the ST interventionist will call the participant to inform them of their treatment group assignment (BA vs. ST), and to set up the first appointment. (See below for example script).

“Hello. My name is Shayla, and I am calling about the CURE project that you are participating in. Just like Bianca/Deiana, the young lady you met with a couple of weeks ago, I am a community health educator on this project, and I am calling to tell you that you were selected to be in the Supportive Therapy group. Supportive Therapy involves talking about how diabetes is affecting your life, particularly how it makes you feel. One of the reasons we are conducting this study is to learn whether Supportive Therapy is an effective way to help people cope with diabetes. I would like to meet with you 4 times over the next 4-5 months in your home. If you prefer, we can make arrangements to meet at Jefferson instead (WEI or Temple). Each of these visits will be about 45 minutes to an hour, and I will schedule them at your convenience. Please feel free to invite a family member or friend to attend our sessions. In about 6 months, Bianca/Deiana will visit you again to have another question and answer session. Just like last week, you will be paid $25 for this 6-month visit. When would be a good time for me to come? Let me also confirm your address. I will mail
you a letter/postcard confirming our date and time and I will also call you the day before to confirm. Is this the best number to reach you at or do you have a cell phone? I look forward to meeting you. Thank you.”

4. Guidelines for Administering ST
This section provides the guidelines for conducting supportive therapy. The procedures to be followed for supportive therapy are the same in every session; thus, session-by-session procedural guidelines are not necessary and therefore are not provided below.

During the rationale portion of the first session, participants are told that treatment will allow time for exploration of important life experiences, particularly as they relate to aging. The goals are to facilitate and deepen knowledge about the participant’s life situation and its relationship to growing older and all of the issues associated with aging such as illness, disability, retirement, social isolation, and loss. This portion of therapy is presented as an exploration process that might be helpful for increasing self-confidence. The interventionist’s role will be one of providing for self-reflection in a safe environment.

Your role as interventionist is to provide an accepting, non-judgmental, and empathic environment in which the participant can talk and think about themselves and their lives by using supportive statements, and reflective listening. It is important to remember, and if necessary, communicate to the subject that ST is not performed under the assumption that they are depressed. Chronic illnesses often create many different stressors and ST
can provide a mechanism to process thoughts and feelings associated with that stress.

If you and the participant clearly focus on the goal of this therapy portion as support and self-awareness within a warm, empathic relationship, you will have little trouble carrying out this element of the session within the limits proscribed procedurally for this treatment trial. These limitations are:

- Never make direct suggestions or interpretations, avoid cognitive restructuring via your questions, and refrain from assisting with problem-solving and giving specific advice regarding how to manage health or memory problems.
- Never imply that the participants’ suggestions are good or bad. Give equal, judgmentally neutral support to suggestions, observations, or decisions that the participant mentions.
- Never inquire about feelings, with the exception of asking about changes in feeling states. You cannot deepen their accessing or experiencing of emotion via any other techniques, nor can you use questions or reflections to directly or deliberately facilitate cognitive or behavioral changes, nor can you attempt to direct the participant toward more primary affective experiences.
Interventionists responses encouraged during ST include:

- Reflective listening
- Empathic communications
- Supportive statements
- Very general questions whose exclusive goal is to help the participant to continue talking about his/her life situation and that allow the interventionist to genuinely improve their understanding of the participant’s situation.

The responses to avoid during supportive counseling include:

- Advice
- Suggestions of any kind
- Problem Solving
- Logical analysis
- Evidence and/or probabilities
- Alternative thought
- Belief generation
- Specific memory-enhancing strategies
- Relaxation suggestions
- Exposure Suggestions
- Coping method suggestions
- Worry program
- Decatastrophizing
- Errors in thinking
- Interpretations
- Inferential reflections
- Use of imagery
- Any techniques from behavioral, cognitive, psychodynamic, experiential, or other therapy traditions

If absolutely necessary to prompt discussion, the interventionist may ask about areas of the participant’s life that he/she thinks are contributing to their emotional state. The intent of this action is to broaden the scope of the conversation rather than to find solutions to these areas. You will encounter subjects who are obstinate or reluctant to actively participate in
It is important that you are very patient with these subjects, as you will have to try many different approaches in order to engage them (see Appendix B for a list of example questions and topics).

It is also permissible to ask questions of the subject to clarify facts regarding their personal history or current circumstances. This should only be done to allow the interventionist to understand the person’s situation and thereby accurately communicate this understanding and appropriate empathic statement. Again, the interventionist should never state or imply that they believe that any one piece of information is any more important in relation to the subject’s emotional life than other areas.
Structure for Sessions:

1. **Introduction** *(first session only)*
   The first goal is to *establish rapport* with the subject and create trust. This is the most important goal in the first session. Establishing a trusting and friendly relationship with the subject will make the subject more likely to discuss their feelings about aging in future sessions. Begin by asking if any family members would like to join the session. There are many ways that you can break the ice. Here are some suggestions:
   - Tell me about yourself and your family?
   - What are the names of your children?
   - How many grandchildren do you have?
   - Do you have any hobbies?
   - What do you like to do during the day?

   Be genuine when building rapport. Instead of going through the list of suggested questions, begin with one and listen to what the subject says and use that information to guide the rest of the conversation.

   *Explain the structure of the study* *(first session only)*: There will be 4 in-home sessions over the course of 10 weeks, and each session will be about 1 hour long. Sessions will be scheduled at the subject’s convenience. Then, inform subjects that they may invite a family member/friend to attend the sessions. Explain that all sessions will be
audio taped (if the subject is agreeable to this as per the consent form), and that these tapes will only be used for [your] supervision purposes.

*Provide rationale for supportive therapy (every session)*: Our time together will be different than the visit you had with Bianca/Deiana last week. While Bianca/Deiana spent a lot of time asking you questions about your health and life circumstances, I will be asking you to talk about issues that *you* would like to discuss and things that are on your mind that you may want some help thinking through. During each of our meetings I will be asking about what your life is like and how your health and growing older affect you, but feel free to talk about anything you like. I’ll be here to help you clarify your thoughts. You are the expert on your own situation and my role in this process is to help you think about your situation so that if you want to, you can better understand your life as it is now.

At the first session, briefly remind the participant that there will be 4 visits over the next few months.

2. Using Supportive Listening Techniques

Supportive listening entails being empathetic, respectful, and genuine, and conveying a sense of unconditional positive regard (a sincere concern for the participant’s well being). The following techniques will help establish a supportive environment.

A. Non-verbal communication

1) Display an open posture, especially with arms (i.e., don’t sit with crossed arms)
2) Maintain eye contact
3) Appear calm and relaxed
4) Try to sit directly across from the participant

B. Reflective listening

1) Pay attention to body language and verbal signs of a participant’s feelings towards any given topic
2) Do not rehearse your answers while the other person is talking—make sure the participant has your undivided attention
3) Do not interrupt, especially to correct mistakes or make points
4) Do not judge
5) Use clarifying questions or statements to check your perception (such as “I’m hearing you say that XXXXX, is that right?”)
6) Avoid expressions of approval or disapproval, but affirm that you understand
7) Do not insist on having the last word
8) Ask open-ended questions that encourage reflection and discussion

C. Supportive responding

1) Respond in a way that lets the participant know that what they’ve said is important (i.e., “That’s important to know; I would like to know more about that.”)
2) Validate the participant’s feelings (i.e., “It sounds like being diagnosed with diabetes was very scary for you. It sounds like managing your sugar can be frustrating at times. How do you deal with your frustrations?”)
3) Paraphrase back to the participant (i.e., “So you feel guilty when you ask your daughter to help you do things; you are worried about how you are going to continue to pay for your medications.”)

3. **Answer Questions** that the participant may have about the study, or make a note to have the appropriate person contact them to answer their questions.

4. **Schedule the day and time for your next visit.** The following is an example script of how to close each session. “We talked about a lot of issues today relating to your life and aging. I hope that these sessions will help you process how diabetes is affecting your life. Let’s schedule our next visit.”
Appendix A: Example Transcript

The following transcript is an example of a supportive counseling session. This participant is a 75-year old woman who lives alone in a subsidized senior housing complex. The participant’s daughter is actively involved with her mother’s life, calling her every day and driving her to church every Sunday. Until the past year or so, the participant was regularly involved in many activities including singing in the choir, volunteering at church, and attending various social events at the Senior Center. More recently, she will only attend church activities when prompted by her daughter, and she is no longer interested in the choir. As the transcript begins, she is discussing that she is often bored and does not know how to fill her time. She considers herself to be highly extraverted, yet she is socially isolated as she has lost most of her social network. She goes on to describe her feelings of being burdensome to her daughter and her frustration over spending so much time alone.

HOW HAVE YOU BEEN FEELING?

OK I guess, not too much going on.

THAT DOESN’T SOUND LIKE MUCH FUN.

No it’s not. I’m bored and there is not much to do. I go with my daughter to church once in awhile, but I don’t do as much as I used to. It’s hard when you are older.

SO YOU ARE NOT GETTING OUT MUCH. WHY IS THAT?

Well, it’s hard when you can’t drive. And I don’t want to bother anyone. I used to have neighbors---they were like my best friends. We did everything together. We raised our kids together and hung out, but now they’ve either moved away or died. I see one or two of them around sometimes.

I SEE, SO YOU FEEL LIKE YOU DON’T HAVE MANY FRIENDS AROUND ANYMORE. THAT MUST BE TOUGH.

It sure is. I am a people person. I loved being part of the choir and doing my work at the church. I feel like that part of my life is gone.

UH HUH.
I feel lonely. I look forward to talking to my daughter every day, hearing about her life and her kids. But I feel left out. I miss all the activity. Like I’m not a participant in life.

UH-HUH. RIGHT. SO NOW THINGS FEEL SLOWED DOWN?

Oh yeah. Sometimes my house is so quiet I can’t stand it. I don’t like living alone. I feel better when I have people to take care of. My grandkids are teenagers now, so they don’t come around as much.

UH HUH. AND NOW YOUR DAUGHTER DOES THINGS FOR YOU INSTEAD OF THE OTHER WAY AROUND.

Well yeah. If it weren’t for her, I would never get to church or even to the doctor.

REALLY.

Yes. If I didn’t have my daughter to take me places, I would be in big trouble.

AND THIS CAUSES YOU TO FRET AND FEEL DOWN.

Oh, it CAUSES ME! Oh brother does it ever. Especially since I’ve always been a strong and independent person. I’m not used to this helplessness.

UH HUH. RIGHT. SO YOU’RE FEELING KIND OF HELPLESS?

Oh, very helpless. Yeah. I feel like a child. I don’t feel like a grown-up, like I don’t have my own life anymore. I’m just passing the time.

I SEE. AND THAT’S BECAUSE YOU HAVE TO ASK YOUR DAUGHTER FOR HELP AND BECAUSE YOU DON’T HAVE A LOT OF FRIENDS AROUND?

Yes, I feel helpless and lonely.

WHEN DO YOU FEEL MOST LONELY?

Mostly at dinner time, when I know that everyone else is getting dinner ready for their families, and I am making a sandwich or soup for just me. It isn’t much work, but I miss the fuss and all the noise.
AND IT UPSETS YOU TO EAT DINNER ALONE MOST NIGHTS?

Right. I’m used to being around people—I am a people person. I liked making the big meals and making a fuss at the Holidays. I liked organizing the Church dinners and keeping busy. I need to be needed.

YEAH. SO YOU WERE ALWAYS THE CENTER OF ACTIVITY AND NOW THINGS ARE QUIET AND LONELY.

Yeah, that’s right. I miss being all the excitement and activity.

SO YOU SPEND A LOT OF TIME ALONE.

That’s right. I don’t want to bother people.

SO YOU HATE HAVING TO BE ALONE YET YOU FEEL LIKE A BURDEN WHEN YOU ASK PEOPLE TO SPEND TIME WITH YOU.

Right, right.

AND THAT UPSETS YOU.

It sure does. I don’t feel needed anymore.

I SEE. AT OUR NEXT SESSION WE’LL TALK MORE ABOUT WHAT IT’S LIKE TO NOT FEEL NEEDED.
Appendix B: Possible Topics for Therapy

Often times the participant will have difficulty in coming up with topics to discuss. Any topic that is relevant to aging or health is appropriate content for ST. Below are some possible topics (and questions for discussion) that you can pose to the participant.

- It must be difficult to live with diabetes. How is your life different since you’ve been diagnosed?
- As we get older it is harder and harder to visit with people due to illness or transportation problems. Have you had this experience? Have you had to give up driving? It’s tough when you can’t get out as much as you want to.
- Many of us have more trouble remembering things as we get older and this can be a scary feeling. Has this happened to you? How do you feel about it? How has this changed your life?
- How do you feel about being retired? How do you feel about the way that you are spending your time? Would you rather be working? Or are you enjoying the free time?
- A lot of people say they have less energy as they get older. Do you find this to be a problem? How have you changed your life to accommodate this?
- With times being the way they are, it can be tough to make ends meet when you are older. Do you ever think about this? Are you worried about your future?
- Diabetes can be challenging to manage. How has it been for you? How do you feel about the dietary restrictions? What is it like to always think about what you are eating?
## Appendix C: Handling Emergencies

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<th>Alert</th>
<th>Action to Take</th>
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| Medical emergency:                                                  | The staff person will call 911 immediately, and stay with subject, until help arrives. Project Coordinator and PI are informed within 24 hours of the event. Project Coordinator then contacts subject as a follow-up within two days.  
- Chest pains  
- Excessive bleeding  
- Fall and can not get up  
- Difficulty breathing                                                                                                                                 |
| Suicidal ideation, threats to hurt self, major clinical depression that is not responding to the intervention | If a research staff person encounters a situation in which the subject threatens to hurt self immediately, Dr. Rovner, Co-PI will be notified, who will then contact the subject with a plan of action (e.g., recommendation of ER visit).  
If subject is not an immediate threat to self, then staff person will call Co-PI, a geriatric psychiatrist, who will administer crisis intervention.  
Staff person fills out Alert form and gives it to Project Coordinator.                                                                                                                                 |
| Evidence of abuse                                                  | Evidence of physical abuse or neglect is as follows:  
- Subject states to staff that abuse occurs  
- Staff observes physical evidence (black eye, black and blue marks on CR arms/legs)  
Staff informs subject that a senior member of the research team will be contacting him/her later that day. Staff informs PM immediately upon completion of interview. Project Coordinator (or designate) contacts subject to obtain further information about situation. Based on this phone call and consultation with PI, the Philadelphia Corporation for Aging Protective Services Department at 215-765-9040  
Project Coordinator (or designate) completes Alert form.                                                                                                                                 |
| Environmental Hazards                                             | Staff notifies Project Coordinator within 24 hours. Project Coordinator contacts subject and refers subject to local Area Agency on Aging (AAA).  
Project Coordinator (or designate) completes Alert form.                                                                                                                                                  |