Telephone-Based, Clinician-Guided Self-Help Cognitive Behavioral Therapy for Depression in Parkinson's Disease (dPD): The Responder Cases of "Alice" and "Carl," and the Nonresponder Cases of "Ethan" and "Gary"

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## **ABSTRACT**

Roseanne Dobkin and her colleagues (e.g., Dobkin, Interian, Durland, Gara, & Menza, 2018) have developed a 10-session, individual cognitive-behavioral treatment (CBT) program for treating depression in individuals with Parkinson's disease (dPD). The program has been found to yield statistically and clinically significant success in both uncontrolled group trial designs and randomized clinical trials—originally in a face-to-face version, and then in a telehealth version, using telephone therapy sessions and guided self-help materials for patients. This latter version is herein called "Teleheath Guided Self-Help for dPD," or "TH-GSH-dPD," for short. Applying Fishman, Messer, Edwards, and Dattilio's (2017) "case studies within psychotherapy trials" methodological model, the present research was designed to complement the group research findings by my conducting systematic, pragmatic case studies (Fishman, 2013) with four patients representative of those in the telehealth studies, given the names of "Alice" (and her caregiver husband "Bob"); "Carl" (and his caregiver wife "Doris"); "Ethan" (and his caregiver wife, "Fay"); and "Gary" (and his caregiver mother, not named). Specifically, Alice and Carl were representative of those patients in the group studies with positive, responsive outcomes; and Ethan and Gary were representative of those patients in the group studies with *negative*, nonresponsive outcomes. Each case combines (a) quantitative data, comprised of demographic information, psychiatric diagnostic data, neurocognitive data, caregiver distress, and treatment outcome measures; and (b) qualitative data, consisting of recordings of the telephone therapy sessions, my treatment notes, my observations as the therapist, and systematic, post-treatment "Exit Interviews" I conducted with each of the patients and their caregivers about their therapy experience. Each of the four case studies aims (a) to provide a detailed, thickly described portrait of the TH-GSH-dPD treatment process; and (b) to explore the presence and influence of barriers and facilitators of treatment in an idiographic context. Regarding point (b), the following variables that cut across the case studies are explored as appearing to be particularly impactful: patients' worldviews, patients' cognitive functioning, caregiver involvement, and homework adherence.

*Key words*: Parkinson's disease (PD); depression in Parkinson's disease (dPD); telehealth; cognitive behavioral therapy (CBT); manualized therapy; case studies; clinical case studies

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<sup>&</sup>lt;sup>c</sup> Note: This article is a reformatted and edited version of my dissertation (Durland, 2017).

## 1. CASE CONTEXT AND METHOD

## Psychiatric Features of Parkinson Disease (PD)

Parkinson's disease (PD) is a common and highly debilitating degenerative neurological disorder. It is estimated that more than 10 million individuals currently suffer from PD worldwide, and recent estimates suggest that there are roughly 60,000 new cases of PD each year in the US alone (Parkinson's Disease Foundation, 2017). Motor symptoms are the hallmark of PD, and include tremors, rigidity and bradykinesia (slowed movement). In addition to motor symptoms, many PD patients suffer from psychiatric and cognitive symptoms, including anxiety, depression, psychosis, sleep disorders, and deterioration of executive function and memory.

Evidence suggests that these psychiatric and neurocognitive features of PD may lead to greater functional impairment and distress than the motor symptoms of the disease (Forsaa et al., 2008; Cummings, 1992). Depression is hypothesized to onset earlier than many motor symptoms of PD (Ishihara & Brayne, 2006; Shulman, Taback, Rabinstein & Weiner, 2002), and is one of the most common non-motor complications of the disease, affecting as much as 50% of PD patients (Reijnders et al., 2008). This prevalence rate is nearly twice that found in the general population, and higher than that found in patients with many other chronic medical conditions (Kessler et al., 2005; Tandberg, 1996).

Overall, the psychiatric complications of PD, particularly depression in PD (dPD), are associated with a host of functional impairments in patients and their caregivers, which cause profound distress and loss of quality of life without appropriate treatment. In addition, the neurocognitive, physical, and psychiatric complications associated with the PD population have important implications for the development of effective psychological treatments, a topic that is focused on in the section below about the therapy program for dPD developed by Roseanne Dobkin and her colleagues, and employed in the present case studies. (More background about the research on the psychiatric complications of PD can be found in Durland [2017]).

# Roseanne Dobkin and Colleagues's Program of Group Research

Roseanne Dobkin and her colleagues have developed a program of research to adapt cognitive behavior therapy (CBT) to treat depression in individuals with Parkinson's disease (dPD), using four research studies. This project began with Study 1, a randomized clinical trial showing that a face-to-face version of CBT is effective in treating dPD (Dobkin, Menza, Allen, et al., 2011a), which the authors describe the treatment as follows:

Participants received 10 weekly individual sessions (60–75 minutes) of manualized CBT. Treatment incorporated exercise, behavioral activation, thought monitoring and restructuring, relaxation training, worry control, and sleep hygiene and was augmented with four separate individual caregiver educational sessions (30–45 minutes) that were intended to provide caregivers with the skills needed to facilitate participants' home-based practice of CBT techniques. For example, caregivers were taught to help participants identify negative thoughts and replace them with more balanced alternatives and were given tools to assist them in completing therapy goals (i.e., exercise, socializing). The primary focus was not to address the caregivers' own personal concerns (p. 1067).

In order to make the program more logistically accessible, Dobkin's group then developed a telehealth, guided self-help version of the CBT treatment, hereafter labelled the

"Tele-Health, Guided Self-Help for Depression in PD Program," or "TH-GSH-dPD," for short. TH-GSH-dPD involves 10 weekly self-help manual modules for patients and caregivers, together with a weekly therapist meeting by phone organized around the modules. The Dobkin group (Dobkin, Menza, Allen, et al., 2011b) then pilot-tested this telehealth version in Study 2 with 21 individuals, with positive results similar to those from the face-to-face RCT.

With 34 additional individuals, Study 3 (Dobkin, Interian, Durland, Gara, & Menza, 2018) then tested an updated version of the TH-GSH-dPD protocol used in Study 2, with an expanded and more detailed self-help manual for the patients, also with successful results. (This manual was the one employed with the four patients in this article, and the manual is described below in the Guiding Conception section, and listed in Table 1.

Finally, with the manual from Study 3, an RCT test of the TH-GSH-dPD program was conducted in Study 4 (Dobkin et al., 2020), also with similar results as the pilot groups and the face-to-face version.

The Four Present Case Studies Drawn from Dobkin et al.'s Group Research Projects: The Responder Cases of "Alice" and "Carl," and the Nonresponder Cases of "Ethan" and "Gary"

## The Research Design for the Case Studies

Applying Fishman, Messer, Edwards, and Dattilio's (2017) "case studies within psychotherapy trials" methodological model, the present research was designed to complement the group research findings by my selecting systematic, pragmatic case studies (Fishman, 2013) with four patients representative of those in the telehealth studies, for all of which I had been the therapist. Specifically, the Fishman et al. (2017) model calls for comparing, within the same therapy group study of a particular type of patient, (i) representative patients who have successful, responsive outcomes, with (ii) representative patients who have unsuccessful, nonresponsive outcomes. Since all the patients are in the same study with the same theoretical and procedural model and the same therapist (as in the instance of the present study), this design identifies differences between patient outcomes that are associated with differences in: (a) a patient's psychological characteristics and present life circumstances; and/or (b) how a particular patient interacts with a particular therapist and/or the particular theoretical and procedural model. Finding differences in (a) and (b) is in line with one of the goals of the present case study design: to generate hypotheses regarding individualized facilitators of and barriers to treatment success in the Dobkin et al.'s TH-GSH-dPD treatment program used in their Studies 3 and 4.

In line with the above, in the present study I included two patients who were responders—"Alice<sup>1</sup>" (and her caregiver husband "Bob"), and "Carl" (and his caregiver wife "Doris"). And I included two nonresponders: "Ethan" (and his caregiver wife, "Fay"); and "Gary" (and his caregiver mother, not named).

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<sup>&</sup>lt;sup>1</sup> Names listed for the patients are pseudonyms to protect confidentiality.

## Inclusion and Exclusion Criteria in the Group Studies

The four patients selected for the case studies were drawn from Dobkin et al.'s group Study 3 (2018) and group Study 4 (Dobkin et al., 2020) described above. To be included in these studies, a participant was required (1) to have been given a diagnosis of Parkinson's disease by a general neurologist or Movement Disorders Specialist; (2) to be 35-85 years of age, (3) to meet criteria for Major Depression, Dysthymia, or Depression Not Otherwise Specified based on the Structured Clinical Interview for DSM-IV (SCID-I) (Spitzer, Gibbon & Williams, 1998); (4) show at least a mild to moderate degree of depression as indicated by a score of "Slightly Ill" or "Moderately Ill" on the Clinical Global Impressions-Severity Scale (Busner & Targum, 2007; see description of this measure below); (5) have had a stable medication regimen for six or more weeks prior to initiation of the program; and (6) have had no change in mental health treatment in the past two months.

A participant was excluded from the study if he or she: (1) endorsed suicidal plans or intent; (2) displayed insufficient cognitive faculties, as indicated by a score below 26 on the Mini-Mental State Examination (Folstein, Holstein & McHugh, 1975); (3) reported significant motor symptom fluctuations (i.e., motor symptoms poorly controlled for 50% of the day or more); (4) reported other unstable medical conditions; (5) met criteria for Bipolar Disorder, Psychotic Spectrum Disorders, or Substance Abuse Disorders; (6) were already receiving CBT treatment; or (7) had already participated in Dobkin et al.'s Study 1 or Study 2.

Caregivers were required: (1) to be 25-85 years of age; and (2) to have regular contact with study participant. Caregivers were excluded if they: (a) reported suicidal ideation, plans or intent; (b) reported an unstable medical or psychiatric condition; or (c) showed signs, based on clinical history and presentation at intake interview, of significant cognitive impairment.

Procedures for Choosing, from the Group Studies, the Responder Cases of "Alice" and "Carl," and the Nonresponder Cases of "Ethan" and "Gary"

Patients in the Dobkin et al.'s research Study 3 and research Study 4 were defined as therapy "responders" or therapy "nonresponders" in terms of the change in clinical status from baseline (T1 in the study) to the end of therapy (T3 in the study) or at follow-up (T4 in the study). Specifically, they were defined as responders if they showed:

- either a 50%+ reduction in depressive symptoms, with depressive symptoms assessed on the "HAM-D" and "BDI" measures, described below in the section on Quantitative Measures; or
- a score of at least "much improved" or "very much improved" on the Clinical Global Impressions-Improvement (CGI-I) scale (described below).

For the specific results on these various quantitative measures for the four cases in this study, see Table 2.

In choosing the four patients for the case studies, several factors were considered. First, participants who completed the TH-GSH-dPD program more recently were preferred candidates, since it was assumed that this would aid in the accuracy and quantity of qualitative data produced by participant, caregiver, and therapist in the Exit Interview given at follow-up.

Second, candidates were preferred if they were particularly relevant for the case study project's goal of exploring clinical decision-making in treatment scenarios with putative applicability for clinicians using similar protocols or working with similar populations. Specifically, of the patients I had conducted therapy with in Studies 3 and 4, I preferred those who, in my view, had the potential to highlight unique or significant aspects of the treatment protocol, the dPD population, or some combination of the two. (For more details on choosing the four patients in the case studies, see Durland, 2017).

As mentioned above, to control for the therapist and Exit Interviewer variable, I conducted all the four therapies and the in-depth Exit Interviews about the case study participants' clinical experiences. The Exit Interview structure involved a set of standard questions asked of each participant and their caregiver, with follow-up questions asked at the discretion of the interviewer. Exit interview question content is described below in "Qualitative Data."

## Administering Quantitative Assessment Measures at Timepoints T1-T5

A variety of quantitative measures were administered at five time points: at the in-person intake meeting (T1); at the midpoint of the treatment program (approximately 6 weeks after intake (T2); immediately after completion of the program (approximately 11 weeks after intake) (T3); at a follow-up timepoints approximately 15 weeks after intake (T4); and at follow-up timepoint approximately 35 weeks after intake (T5).

The following measures were included in the quantitative assessments:

- The clinician-administered *Hamilton Depression Rating Scale (HAM-D*; Hamilton, 1960);
- the clinician-administered *Hamilton Anxiety Rating Scale* (*HAM-A*; Hamilton, 1959);
- the self-report *Beck Depression Inventory (BDI*; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961);
- the clinician-administered *Clinical Global Impressions (CGI) Scale, which assessed* the patient's overall functioning (for more on this measure, see below); and
- the self-report Caregiving Distress Scale (CDS; Cousins, Davies, Turnball & Playfer, 2002).

## The Clinical Global Impressions (CGI) Scale

The CGI (Busner & Targum, 2007) is a global clinical rating based on a variety of clinical data, including the CGI was developed for use in NIMH-sponsored clinical trials to provide a brief, stand-alone assessment of the clinician's view of the patient's global functioning prior to and after initiating a study medication or psychosocial treatment. The CGI provides an

overall clinician-determined summary measure that takes into account all available information, including a knowledge of the patient's history, psychosocial circumstances, symptoms, behavior, and the impact of the symptoms on the patient's ability to function.

The CGI consists of two subscales. The CGI-Severity Scale (CGI-S) rates the patient on a point scale, from 1="normal" to 7="extremely ill." The CGI-Improvement Scale (CGI-I) rates the patient on a 7-point scale in terms of improvement from initial baseline assessment, from 1=very much improved" to 7="very much worse."

In Dobkin et al.'s Study 3 and Study 4, for each time point, the assigned CBT therapist, in consultation with the principal research investigator, Dr. Dobkin, reviewed data from the HAM-D and BDI, along with the evaluator's clinical impressions to determine a CGI rating of the participant's functioning.

## Measures of Patient Cognitive Functioning at Intake

Two measures were administered at intake to assess the patient's baseline cognitive functioning: the *Mini-Mental State Examination (MMSE*; Folstein, Holstein & McHugh, 1975); and the *Montreal Cognitive Assessment (MoCA*; Nasreddine et al., 2005).

## Qualitative Data, Including an Exit Interview

The qualitative data employed in the case studies consisted of the recorded telephone sessions with the patients, my written clinical case notes and clinical impressions, and the transcript of my Exit Interview at follow-up between T4 and T5. Clinical case note material included initial case conceptualization; module session plans; records of each treatment session (e.g., approximate length of call, module material that was emphasized or deemphasized, a patient's report on her or his mood, and homework assignments devised for the coming week based on program material); and the documented content of regular supervision sessions in which case process was discussed with Dr. Dobkin, who clinically supervised me on the four cases.

In addition, as mentioned above, the qualitative dataset included material from the Exit Interview, which I administered at follow-up between T4 and T5. Exit interview questions focused on the experiences of the patient and his or her caregiver in the treatment program, their perspectives on important barriers to and facilitators of treatment outcome, their functioning since the end of the program, and the extent to which they had employed concepts and skills from the intervention since completing the program. The standard set of questions used as initial prompts during each of these Exit Interviews is listed in Table 3.

## 2. THE PATIENTS

A summary of each of the patients is quoted from the extended case descriptions below describing their identifying information.

## "Alice," A Responder, and Her Caretaker Husband "Bob"

"Alice, a 70-year old, married, domiciled, retired, Caucasian woman living in Central New Jersey who had been diagnosed with PD 9 years prior to intake (2006), ... [was living with] her husband and caretaker, Bob, a 69-year old, Caucasian, retired male. ... Alice and Bob had known each other for 45 years and reported no significant marital discord. Alice and Bob had one daughter who was married and living in Hawaii. Alice and Bob reported a very close relationship with their daughter throughout their lives, and Alice stated that she spoke with her daughter over the phone on a daily basis."

# "Carl," A Responder, and His Caretaker Wife, "Doris"

"Carl presented for treatment as a 67-year old, married, domiciled, retired, Caucasian, Latino man living in Central New Jersey who had been diagnosed with PD 11 years prior to intake (2004). ... Carl had completed a 4-year undergraduate degree, and worked as a federal investigator for much of his career. ... Carl's caregiver for the study, his wife Doris, was a 68-year old, Korean, retired female domiciled with Carl. Doris had been diagnosed with bipolar II disorder, which she described as 'stable.' ... Carl and Doris had known each for other for 45 years, and reported that their relationship had been tumultuous in the past."

## "Ethan," a Nonresponder, and His Caretaker Wife, "Fay"

"Ethan presented for treatment as a 73-year old, married, domiciled, retired, Chinese-American man living in Western New York who had been diagnosed with PD 6 years prior to intake (2010). .... Ethan had worked as an engineer for about 30 years, but had retired several years ago. ... Ethan's caregiver for the study, his wife Fay, was a 73-year old, Asian-American, retired female living with Ethan. ... Ethan and Fay had known each other for 48 years, and reported no significant marital discord. Ethan and Jay had one daughter who was married and lived in the Northeastern United States with her husband. Ethan and Jay reported a close relationship with their daughter, but stated that it had been harder for them to see her since she moved away from Western New York."

## "Gary," a Nonresponder

"Gary presented for treatment as a 42-year old, divorced, employed, Caucasian man living in Central New Jersey who had been diagnosed with PD 6 months prior to intake (2014). ... At the time of intake, Gary was employed as a sales representative, and Gary reported that he had worked in this capacity for most of his professional career. Gary reported intermittent contact with his mother [who was officially his caretaker], and stated that he did not have close relationships with the rest of his family of origin. Gary had a 12-year old son with his recent exwife. His ex-wife had primary custody of the child and lived within driving distance."

## 3. GUIDING CONCEPTION

## Barriers to dPD Treatment and the Advantages of Telehealth Treatment Delivery

As summarized earlier and in Durland (2017) and Dobkin et al. (2018), there is a well-documented contribution of depression to distress and functional impairment in PD patients, and a growing evidence base for the efficacy of psychotherapeutic interventions like CBT to address this problem. However, patients are faced with a number of barriers to effective treatment, especially involving the logistics, for movement-impaired individuals, of traveling to therapists' offices (Dobkin et al., 2013; Dobkin et al., 2018; Durland, 2017). Telehealth delivery of services—that is, electronic delivery of health services by telephone, video-conference, or another digital technology—is a response to this problem. In support of this idea, in a survey of 769 PD patients, Dobkin et al. (2013) found that 84% of the respondents reported that they would be more motivated to receive psychotherapy if they could do so from their own home, with a majority of respondents reporting that they had access to technology required to facilitate telehealth treatment. Moreover, a great majority reported feeling comfortable interacting with healthcare providers via these forms of technology.

Telehealth is an increasingly popular means of overcoming geographical, physical, and other access barriers for patients with a variety of chronic medical and mental health conditions (Glueckauf & Ketterson, 2004; Guler & Ubeyli, 2002; Liss, Glueckauf & Ecklund-Johnson, 2002). Telehealth has been shown to be cost- effective (Cryer, Shannon, Van Amsterdam & Leff, 2012; Wennberg, Marr, Lang, O'Malley & Bennett, 2010) and has been used to deliver education, promote coping skills, and offer support for patients suffering from diabetes, hypertension and multiple sclerosis (Guler & Ubeyli, 2002). A videoconference-based telehealth program was recently used to deliver specialty medical care to PD patients living in remote areas with promising results (Dorsey et al., 2010). Telehealth interventions have also proven effective in delivering mental health treatment for depression (Andersson & Cuijpers, 2009; Mohr et al., 2005), particularly in chronic medically ill populations (Dorstyn, Matthias & Denson, 2011). Telephone-based CBT protocols have shown particular promise in treating depression in chronic medically ill patients and their caregivers (Glueckauf et al., 2012; Himelhoch et al., 2011; Mohr et al., 2000; Mohr, Hart & Vella, 2007).

## Guided Self-Help (GSH) Treatment for Depression in Parkinson's Disease

The Dobkin et al. telehealth program of depression services to PD patients falls into the category of a "Guided self-help (GSH)" mental health treatment. GSH treatments typically involve less contact between patient and therapist than other telehealth interventions, and GSH supplement this contact with written or recorded treatment materials provided in hard copy or in digital form. The therapist's role in GSH is to assist the patient to make sense of treatment materials and to apply the concepts or skills provided in these materials to their particular context. GSH treatment is often delivered using telehealth technology (e.g., telephone, e-mail, videoconference, web resources) and often consists of CBT or other structured, empirically-supported treatment modalities (Cuijpers, Donker, van Straten, Li & Andersson, 2010).

Like telehealth, GSH has been gaining favor in recent years due to its ability to provide low-cost, effective treatment to patients who may otherwise have difficulty accessing care (Newman, Szkodny, Llera & Przeworski, 2011), and some evidence shows that it can significantly reduce therapists' time investment without sacrificing treatment efficacy (Wright et al., 2014), an enormous benefit given the growing evidence of a vast worldwide shortage of mental health care resources (Kessler et al., 2009).

GSH has an expanding evidence base demonstrating its effectiveness in treating a number of mental health disorders. One meta-analysis of 21 studies in which GSH interventions were compared to similar face-to-face studies for anxiety and depression demonstrated a slight advantage in treatment outcome effect size for GSH treatments and no differences in drop-out rates between the two treatment types, and GSH treatments targeting mild to moderate depression were demonstrated to be effective (Cuijpers, Donker, van Straten, Li & Andersson, 2010). In addition, GSH approaches have been shown to be effective in treating medically ill populations (Voerman et al., 2015) and older adults (McKendree-Smith, Floyd & Scogin, 2003).

A parallel to the present case design has been published in this journal, conducted by Thomas Berger and his colleagues in Europe. Using Fishman et al.'s (2017) "case studies within psychotherapy trials" methodological model, the Berger group conducted two randomized clinical trials involving telehealth-based, guided self-help CBT treatment of panic disorder and social anxiety disorder. For each randomized clinical trial they then conducted systematic case studies of a positive-outcome client and a negative-outcome client (see Ciuca, Berger, & Miclea (2017) and Schulz, Vincent, & Berger, 2017, respectively). Within each study, a comparison of the contrasting outcome cases revealed process variables associated with the different outcomes

In addition to the general advantages of GSH described above, adding a GSH component to Dobkin's telehealth CBT protocol seemed particularly appropriate for the dPD population because the provision of written materials in GSH is a plausible means of mitigating the negative impact of PD patients' executive dysfunction on treatment outcome, particularly if caregivers were involved in review of written materials.

# Dobkin et al.'s Teleheath, Guided Self-Help for Depression in Parkinson's Disease (TH-GSH—dPD) Protocol—Theoretical, Cognitive-Behavioral Principles

The TH-GSH-dPD treatment protocol is based on the theoretical principles of cognitive behavioral therapy, originally developed by Aaron T. Beck (Beck, 1967) and later elaborated and refined by many others (Hollon & Beck, 1994; Kendall & Kriss, 1983; Linehan, 1993). This theoretical perspective holds that emotions, thoughts and feelings are interrelated, and that depression arises and is maintained in large part through the influence of an individual's thoughts and behaviors. Beck's model of depression emphasizes the important role of negative thoughts in depression, and proposes that depressive thinking can be understood as a layered structure: at

<sup>&</sup>lt;sup>2</sup> In the write-up of this research, an earlier version of Fishman et al.'s model was used, labeled the "Individual—Case-Comparison" (ICC) method.

the most global, fundamental level are "core beliefs," (e.g. "I cannot cope," "I am unlovable," "The world is dangerous"), which underlie "intermediate beliefs" and "conditional assumptions" about the world (e.g. "If I try to engage with others, I will be embarrassed," "Other people will always let me down"), and at the most surface level, "negative automatic thoughts." Negative automatic thoughts are conceived as specific manifestations of the deeper cognitive structures that occur spontaneously during the course of daily life, and are available to consciousness.

Negative automatic thoughts are frequently based on "cognitive distortions," i.e., overly negative interpretations of situations, such as are seen as a consequence of the depressive condition.

Categories of negative thoughts have been identified based on the type of bias or distortion. Patients' behavior is also seen as contributing to the origin and maintenance of depressive symptoms. Lewinsohn's model of depressive etiology (Lewinsohn & Graf, 1973) suggests that frequently a depressive episode is precipitated by a change in life circumstance that prevents an individual's participation in rewarding activities. This individual then begins to develop negative cognitions (see the discussion of Beck's cognitive theory above) that maintain the individual's disengagement from rewarding activities (e.g. "If I try to play baseball again, my Parkinson's disease symptoms will prevent me from enjoying myself"), which maintains low mood.

Mowrer's two factor model (Mowrer, 1951) explains the relationship between anxiety and depressive symptoms, and between thoughts and behaviors: it posits that when negative expectations are created in a certain situation (e.g., when a PD patient first experiences tremors in public, and feels embarrassed), anxiety may be present in situations that resemble the original unpleasant experience (e.g., other social settings) through the process of classical conditioning, and that avoidance of these situations (i.e., not attending social events at all) will be negatively reinforced as per the principles of operant conditioning. Many PD patients experience anxiety in a variety of situations as a result of their physical symptoms of PD and then avoid potentially rewarding experiences, which promotes depressive symptoms through the process described by Lewinsohn's model.

Dobson et al.'s TH-GSH-dPD program strives to teach patients to be more aware of negative automatic thoughts, catch them when they occur, and where possible, replace them with more accurate or more productive thoughts, a process called cognitive restructuring. Cognitive behavioral theory holds that as patients improve their ability to recognize and replace their automatic negative thoughts, these thoughts cease to maintain depressive symptoms, and their mood improves. In addition, the program seeks to improve patient's mood and reduce anxiety by increasing patients' engagement in meaningful and enjoyable activities, and by encouraging patients to face their fears by putting negative predictions to the test where possible, either through cognitive restructuring or behavioral experiments.

The cognitive and behavioral techniques described above form the core of the TH-GSH-dPD program, and are central to cognitive behavioral therapy for depression. The protocol was adapted to address the needs of the PD population in two main ways. First, due to the high rates

of anxiety in the PD population (Dobkin et al., 2011), supplementary skills designed to help patients manage anxiety and worry were included. These skills include various relaxation strategies designed to make use of the five senses, and a variety of cognitive and behavioral worry control techniques. In addition, the protocol emphasizes educating caregivers about program concepts and skills as a means of mitigating the impact of PD patients' executive functioning deficits on their skill acquisition. Program skills and concepts are presented in the modules using examples designed to relate to the specific experience of PD patients (e.g., negative automatic thoughts that involve catastrophic predictions about future functional capacity).

An outline of the principal topics covered in each treatment module of the TH-GSH-dPD program is presented in Table 2.

# 4A. ALICE'S ASSESSMENT: PRESENTING PROBLEMS, GOALS, STRENGTHS, AND HISTORY<sup>3</sup>

# **Identifying Information**

As described earlier, Alice presented for treatment as a 70-year old, married, domiciled, retired, Caucasian woman living in Central New Jersey who had been diagnosed with PD 9 years prior to intake (2006), and she reported increasing struggles with depression and anxiety during the preceding year and a half. Alice worked as an office administrator for about 30 years. Alice stated that for most of her life, she had always been a "happy, energetic person" and kept a full social calendar, particularly focused on involvement at her church. However, since her PD diagnosis, she had noticed significant reduction in her comfort and interest in socializing with people besides her husband.

Alice's caregiver for the study, her husband Bob, was a 69-year old, Caucasian, retired male living with Alice. Bob reported no prior psychiatric history, and stated that his medical history included well-controlled high blood pressure and high cholesterol.

Alice and Bob had known each for other for 45 years and reported no significant marital discord. Alice and Bob had one daughter who was married and living in Hawaii. Alice and Bob reported a very close relationship with their daughter throughout their lives, and Alice stated that she spoke with her daughter over the phone on a daily basis.

## Presenting Problem, Psychiatric History and Assessment.

During the year and a half prior to intake, Alice reported feeling "sad a lot" and "spending a lot of time in bed, crying", and stated that she had felt "very sensitive" to setbacks

<sup>&</sup>lt;sup>3</sup> The next 12 sections are numbered 4A-6A, 4B-6B, and 4C-6C, and 4D-6D, respectively, to indicate their parallel to sections 4-6 of a typical pragmatic case study (Fishman, 2013)—specifically: 4) Assessment of the Client's Problems, Goals, Strengths, and History; 5) Formulation and Treatment Plan; and 6) Course of Therapy. Chapters 4A-6A describe Alice's therapy; Chapters 4B-6B, Carl's, therapy; and Chapters 4C-6C, Ethan's therapy; and 4D-6D, Gary's therapy.

and disappointments. The patient reported very little engagement with activities or other people aside from her husband, and stated that during the preceding year and a half, there were several periods lasting weeks in which she rarely left the house, depending on her husband to run errands and do much of the housework. Alice's depressive symptoms included depressed mood most of the day more days than not, persistent anhedonia, poor sleep, difficulty concentrating, poor appetite, and loss of weight. Alice reported being highly focused on and distressed by her PD symptoms (e.g. poor balance, slow and halting speech, and cognitive difficulties), particularly when she spent time in public. At baseline, her HAM-D score was a 19, her BDI was a 23, her HAM-A was a 19, and her CGI was a 4 (Moderately III).

Alice did not report having been diagnosed with any psychiatric illnesses prior to intake aside from depression, but during the intake she reported having experienced 10-15 panic attacks in the past. Most of these attacks occurred roughly 4 years prior to intake (having already been diagnosed with PD), while the most recent attack occurred several months prior to intake. She described the "first few" panic attacks as coming 'out of the blue', and stated that all attacks lasted about 5-10 minutes. Her symptoms included racing heart, profuse sweating, difficulty concentrating, and "tunnel vision." Largely as a result of these panic attacks, Alice and Bob decided that she would not drive about 4 years ago, and at the time of intake, Alice had only recently resumed driving after three years hiatus. Alice also stated that her first panic attack occurred at a crowded PD event, and that following the onset of panic attacks, she began to avoid crowds, and went through periods in which she did not leave the house. Alice also met DSM-IV-TR criteria for Generalized Anxiety Disorder: she stated that she spent roughly 30% of her waking hours worrying about her daughter's health and safety, her husband's health and her own health. Alice reported that these worries caused significant distress (e.g. frequent crying spells) and impairment (e.g. difficulty focusing on other activities). Alice did not meet criteria for other current or past psychiatric disorders.

## **Diagnoses**

Axis I: Major Depression, Moderate, Single Episode (296.32); Panic Disorder w/ Agoraphobia (300.21); Generalized Anxiety Disorder (300.02)

Axis II: None

Axis III: Parkinson's Disease (ICD-9 Code 332) Axis IV: GAF Score: 55

## **5A. ALICE'S CASE FORMULATION**

Based on the intake information and the guiding conception of this treatment, I conceptualized Alice's depression as originating from the stress and functional impairment of her Parkinson's symptoms, which lead to disengagement with rewarding activities (e.g. exercise, socializing, church involvement). I saw Alice's depression as maintained by a self-reinforcing cycle of negative interpretation of her experiences and further withdrawal from rewarding activities. Alice endorsed automatic negative thoughts like "It will be embarrassing for my friends to see my in the state I am in," and "I can't handle the challenges of being involved at church like I used to," intermediate beliefs like "engaging in activities that I used to enjoy will

put me in physical danger or risk embarrassment due to my PD symptoms," and the core belief "I am fundamentally flawed." These thoughts contributed to Alice's depressive symptoms by lowering her sense of self-efficacy and reducing her engagement in activities that might have improved her mood.

At intake, Alice's behavioral avoidance and anxiety about activity engagement were significant: Alice reported a recent period of several months during which she had rarely left her house. Prior to this period, Alice had been heavily involved in church activities and other social engagements because she "had trouble saying no," and became overwhelmed by the cognitive and physical demands of these activities. Alice's period of extreme disengagement is conceptualized as an overgeneralized response to negative experiences.

In addition, Alice's husband, Bob, played a significant role in reinforcing Alice's worries about activity engagement and facilitating her avoidance by compensating for Alice's lack of activity or otherwise minimizing Alice's anxiety through participation in 'safety behaviors' (e.g. accompanying Alice outside the home, speaking for Alice in social settings), and by rewarding Alice for her behavioral avoidance (e.g. comforting Alice and justifying her avoidance of social engagement when she became anxious at the prospect of interaction).

## **6A. ALICE'S COURSE OF TREATMENT**

# Module 1<sup>4</sup>

At the outset of Module 1<sup>4</sup>, Alice reported a mood rating of 3/10 (10=best) over the last week, stating that she had been crying frequently, feeling overwhelmed, and spending a great deal of time in bed. She reported significant concerns about her own health and the health and safety of her daughter, who was married and living in HI with her husband.

Module 1 is the longest module in the protocol, and offers significant psycho-education regarding the etiology of depression, the CBT model (relationship between thoughts, behaviors and feelings), and the basic principles of behavioral activation.

Based on my conceptualization of Alice, increasing her engagement in meaningful activities seemed a logical starting point for her treatment, and activity scheduling happens to be a major focus of the first two sessions of the TH-GSH-dPD protocol. The first half of the first session was spent explaining the CBT model to Alice and Bob, and the rest of the session focused on assessing how Alice had been spending her time over the last week, which of these activities she found enjoyable or meaningful and which she did not, what activities she had interest in pursuing but had not engaged in recently, and what activities had been important to her historically. During the last week, Alice said she had done a few chores around the house and had gone for a brief walk around the block accompanied by Bob, but had spent most of her waking hours watching TV or resting in bed. Alice stated that she had enjoyed the walk, and to a lesser extent the TV shows she watched, but that most of the time she had felt listless and

<sup>&</sup>lt;sup>4</sup> For a list of the 10 Modules, see Table 1.

hemmed in. The writer explained the Pleasure Predicting Worksheet found in Module 1, which is designed to compare expected enjoyment and actual enjoyment, and for homework, asked Alice to engage in two activities that had been enjoyable to her in the past, but had not engaged in for some time: going to an exercise class at a local gym, and having lunch with several friends. Alice expressed significant trepidation about both activities, particularly the lunch date with her friends, stating that she imagined she would feel ashamed for her friends to see how her PD symptoms had progressed, and worried that she would not be able to communicate effectively. However, Alice ultimately agreed to give these activities a try, and to rate her predicted and actual enjoyment for each activity for us to discuss at session 2.

## Module 2

In our second session, Alice reported a mood rating of 4/10 (10=best) for the previous week, and endorsed persistent depression and anxiety throughout the week, for several hours each day. She stated that she had not gone to the gym because she had been too tired on the day the class was held, but had scheduled a lunch date with friends, and had been surprised at how much she enjoyed their company, and that while she experienced some with sufficient volume and following conversation, these issues had been much less significant than she had expected. She rated her Expected Pleasure as a 30 and her Actual Enjoyment as a 70. I validated Alice's courage and effort, and asked Alice to consider whether the discrepancy between her expectations and her actual experience in this instance might also be true of other activities she had eliminated from her schedule.

We spent significant time discussing the idea of "Acting In Accordance With Goals And Not Feelings," a Module 1 concept which proposes that when someone feels depressed, if they wait to do Activity X until they "feel like" doing it, they may never do Activity X, and that overcoming emotional barriers to activity engagement by just "getting started" in spite of them may be the best way to change their mood, since it allows their feelings to be guided by the activity, rather than the other way around. Alice and I, with Bob's help, spent significant time identifying past instances in which this dynamic may have been at work for Alice, focusing particularly on her two homework assignments from the previous week: she had not "felt like" going to the exercise class or to meet her friends, but in the latter case, she felt obliged not to disappoint them, pushed herself to "get out the door," and ended up feeling much more comfortable than she expected to after 15-20 minutes of conversation. We discussed this experience as an example of Alice's feelings "following" the activity. We speculated on whether she might have been similarly pleasantly surprised by the experience of exercising had she pushed herself to get to the gym, and decided to include a trip to the gym as well as attendance at her church's women's group to her weekly activity schedule for the coming week, with these activities framed as 'experiments' to test the "Acting In Accordance..." idea.

At the end of Module 2, we revisited the cognitive model and discussed the role that thoughts/interpretations play in guiding feelings, and went through several examples described in Module 2. Alice and Bob seemed to get caught up in the details of the examples and assessing whether they matched Alice's literal experience. In an effort to find a more relatable example, I presented a hypothetical comparison between Alice's actual mood preceding her lunch date with

friends, and what Alice's mood would have been if she knew she was going to enjoy her lunch with her friends as much as she eventually did. This seemed to aid Alice's understanding, and paved the way for a discussion of the Thought Log as a tool for recording thoughts that are associated with negative mood and behavioral avoidance. Alice was asked to compile, with Bob's help, a list of thoughts that were associated with negative mood over the coming week for homework, in addition to the exercise session and attendance at the women's group.

#### Module 3

At the outset of Module 3, Alice reported a mood rating of 5/10 (10=best) for the previous week, and stated that she had felt "a little bit" more energetic, although she continued to have crying spells and bouts of intense anxiety and sadness at times.

In reviewing the homework from the previous week, it became clear that Alice had gone above and beyond her activity scheduling assignment: she had exercised twice (rather than once, as assigned), attended the women's group at church, had arranged another lunch meeting with friends, and made plans to attend a play the following week. Both Alice and Bob expressed growing confidence in Alice's autonomy and her ability to navigate social situations. In particular, Alice had decided to use her walker while attending her weekly activities, and although she had been fearful about "looking frail" in front of friends and acquaintances, several people had congratulated her on how well she looked, and having the walker had significantly allayed her fears of falling while out of the house without Bob.

Alice and Bob reported having difficulty relating to many of the distortions listed in Module 3, and during our in-session review of cognitive distortions, I struggled to help Alice generalize from the specifics of the provided examples to the concepts the distortions were meant to capture (e.g. catastrophizing = focusing on the worst possible outcome), and Alice expressed feeling overwhelmed by the number and complexity of the distortions. When Alice and I went over her Thought Log homework, Alice had made a number of entries that were associated with sad and anxious feelings over the last week, but in session, she had difficulty putting her thoughts into useful forms (i.e. evaluable statements about the world, future or self). I provided examples of revisions of Alice's thoughts that were better suited to assessing their degree of distortion, but despite my best efforts, it was clear that Alice and Bob did not understand the rationale behind the revision, and Alice and Bob struggled to apply cognitive distortion categories to these revised thoughts. I worried that Alice might feel invalidated or criticized, and decided to shift emphasis from general principles to specifics. Since many of Alice's thoughts seemed to be negative predictions about the future, I decided to focus on several Thought Log examples of 'catastrophizing' in an effort to solidify Alice's understanding of this particular thinking pattern.

Alice seemed to feel more relaxed focusing on a single distortion, and was able to recognize 'catastrophizing' in her anxieties around activity scheduling in earlier weeks.

Since our discussion of cognitive distortions had bogged down, and I got the sense that Alice and Bob might have been feeling somewhat alienated by the abstraction of the discussion, I sought to compensate by asking Alice whether there was anything she wanted to discuss. Alice

reported that a great deal of her distress over the last week, and in general, involved worry and sadness over her daughter's life circumstances. Alice's daughter had married a veteran whose spending and drinking habits made Alice very worried. In addition, her daughter's husband suffered from infertility and also carried genetic risk for a rare but debilitating congenital disease, and Alice was very concerned that her daughter might not be able to conceive, or that her child would be unhealthy. In addition, Alice felt that the number of homeless individuals living in her daughter's neighborhood put her daughter's safety at risk. Alice stated that she talked to her daughter twice a day, and that when her daughter did not call when she expected her to, she became deeply concerned that something terrible had happened to her (e.g. she had been attacked). Socratic questioning suggested that Alice might be overestimating the likelihood of some of the feared outcomes she imagined, and I saw an opportunity to revisit the idea of distorted thinking.

One of the thoughts Alice had written in her Thought Log was: "She [Alice's daughter] walks on the beach where homeless people live." In analyzing the implicit message in this thought, Alice and I came up with two related thoughts: "If I'm not on the phone with my daughter, something bad might happen to her and no one would know or be able to get help," and, "If I my daughter doesn't call, it is likely that something bad has happened to her." Given the fact that daughter was not on the phone with her for most of the day and nothing terrible had happened to Alice's daughter yet, Alice agreed that it seemed like a stretch to suggest that her daughter was in danger as a result of not being on the phone with Alice. During this discussion, Alice frequently Alice reframed her thought to, "It is unlikely that anything terrible will happen to my daughter if we are not on the phone."

As of session 3, Alice had been talking to her daughter an average of twice per day. Bob felt that Alice was "too attached," and suggested that Alice might feel less anxious if she had somewhat less contact with her daughter. Alice expressed concern that reduced contact would put her daughter in danger. I suggested, that based on our analysis of Alice's negative thoughts about the connection between her daughter's safety and their level of telephone contact, there seemed to be little evidence that less phone contact would be dangerous, and Alice ultimately agreed to an experimental trial test her negative predictions in which she would speak with her daughter 1x/day until our next session. I suggested that Bob be present for the calls if possible, since Bob had expressed feeling "out of the loop" of communication with her daughter, and I also sensed that Bob might be able to help remind Alice of evidence against her fears if they were roused by statements their daughter made. In addition to this homework assignment, Alice and I agreed that she would exercise twice and schedule two social events.

## Module 4

At the outset of Module 4, Alice reported a mood rating of 7/10 (10=best) for the previous week, and stated that she was "feeling a good deal better" than she had at the beginning of treatment. When I asked how she explained the change in mood over the first few weeks of treatment, Alice cited how much she was enjoying engaging with friends, the church community, and regular exercise, and how relieved she felt that some of her feared predictions about how she

would be received in these communities (e.g. that she would be regarded with pity, or be unable to communicate effectively) had not been confirmed.

In reviewing Alice's activity scheduling for the previous week, it became clear that she had surpassed the assignment we had discussed: she had exercised twice, gone to a play with friends, started attending a yoga class, taken in a concert at church, and attended two church meetings designed to prepare church members to begin volunteer work with other parishioners in hospice care. She had rated each of these activities on the Pleasure Predicting Worksheet as more pleasurable than she had expected, and several by wide margins.

Alice and Bob felt that prior to the program, Alice had taken on too much responsibility at church because she had "trouble saying no", but Alice stated that reconnecting with her friends at church and identifying a way to "give back" in a way that was commensurate with her capacities (i.e. through the church's hospice volunteer program) was deeply gratifying to her. In reviewing Alice's homework assignment to reduce her contact with her daughter, Alice initially focused on how difficult it was for her to relinquish contact, and that Bob's presence on the calls had helped her cope with this distress. I tried to validate Alice's experience, and then focused attention on the question of whether there was any evidence that the reduction in contact between Alice and her daughter had put her daughter in greater danger. Alice allowed that there had been nothing that her daughter had said that had suggested an increase in danger, but still felt that she would feel less worried if she had more contact with her daughter. Based on Bob's participation in the conversation, he suggested that their daughter might find her mother's worrying during their calls upsetting, and suggested that their daughter frequently said things that cued Alice's anxiety during their calls, which Alice would often ruminate about after the calls were finished. I suggested that if this were true, more calls might actually increase Alice's anxiety. The Session ended before we were able to finish this inquiry. Alice was asked to maintain her current level of activity, add activities if warranted, read Module 5, and record at least three thoughts on the Thought Log to be discussed at our upcoming session.

## Module 5 & Module 6.

At the beginning of sessions 5 and 6, Alice rated her mood over the previous week as a 7/10 (10=best). Over this two-week period, she continued to engage in exercise (2x/week), the women's group and hospice volunteering through church, and socialized with friends. In addition, at Alice's midpoint assessment, her HAM-D score was a 12, and her BDI score was a 14, and her HAM-A score was a 15, suggesting a moderate improvement in her symptoms.

Because the discussion of Alice's homework assignment involving her phone calls with her daughter had taken up a great deal of time during session 4, I decided focus on the cognitive restructuring strategies described in Modules 4-6 in sessions 5 and 6. Alice was able to grasp the idea that examining the accuracy of thoughts associated with negative mood might be useful in improving mood, but getting the thoughts on her Thought Log into a form that could be evaluated continued to be a challenge. For example, Alice's negative thoughts were often written as descriptions of her mental state (e.g. "I was worrying about my daughter's safety"), rather than first-person statements capturing the distressing thoughts she was having in the moment. I

worked to try to help Alice convert these phrases into evaluable statements corresponding to her original experience (e.g. "My daughter will get hurt if she walks around in her neighborhood"), but Alice frequently expressed uncertainty about whether these thoughts did in fact capture her experience, and had trouble generating evaluable negative thoughts on her own. In addition, when we turned to sample negative thoughts taken from Modules 4 and 5 with which to practice generating the "evidence for and against" restructuring technique, the hypothetical nature of the thoughts seemed to be an obstacle for Alice, as she often provided evidence consistent with her actual experience, rather than the imagined situation we were discussing.

Because Alice's improvement in mood seemed clearly tied to her increase in behavioral activation, and because it seemed that Alice had actually been able to disconfirm negative thoughts through activity scheduling (e.g. through socializing with her friends, she recognized that her fear that her PD symptoms would make her friends uncomfortable was unfounded), I decided not to belabor the cognitive restructuring aspect of the program in a formal way. Instead, I opted to emphasize the way in which Alice's activity scheduling had served as "behavioral experiments" that tested her fears, and focused on the "cost/benefit analysis" approach to evaluating negative thoughts.

Alice's assigned homework was to read Module 7, continue her activity scheduling, and monitor her negative thoughts using the Thought Log.

#### Module 7

At session 7, Alice reported her mood rating over the previous week as an 8/10 (10=best).

She stated that aside from brief periods of sadness and worry related to two calls with her daughter, her mood had been consistently "excellent" since our last session. Again, Alice related her good mood to engagement in rewarding activities, particularly her volunteer work with members of her church community under hospice care.

Alice was able to apply "cost/benefit analysis" to her worries about her daughter, as per her homework assignment, with a great deal of help from Bob.

After a call in which her daughter described the inconclusive results of a medical test designed to assess her ability to conceive a child, Alice experienced intense anxiety associated with worries about her daughter's ability to conceive, and was able to recognize that her worries had no bearing on whether her daughter would in fact be able to conceive, and had the potential to negatively impact her mood. As an alternative to her worrying thoughts, she decided to focus instead on an engrossing activity with Bob.

Alice and I spent much of session 7 discussing which relaxation techniques she might add to her set of coping skills. Alice stated that she was concerned about using the guided imagery recordings, since she felt that she would have too much trouble operating the audio technology. Although I had my doubts that this was truly the case, it seemed important to let Alice assert her preference in treatment after our difficulty with cognitive restructuring, so Alice and I agreed to focus on Progressive Muscle Relaxation and Complete Natural Breathing for the following

week's homework. Since anxiety had primarily been an issue in the context of Alice's relationship with her daughter, and since Alice had some questions about what to do once she had applied "cost/benefit analysis" to worrying thoughts during our discussion of this technique in the previous session, I framed relaxation exercises as ways to divert Alice's attention away from worrying thoughts that she had identified as counterproductive through "cost/benefit analysis."

I asked Alice to practice one session of Complete Natural Breathing and Progressive Muscle Relaxation each day during the coming week, in addition to reading Module 8.

#### Module 8

At the outset of session 9, Alice's mood rated as 9/10 (10=best), and continued to report increased activity and reduced worry as the foundation of her positive mood. In reviewing her homework, Alice stated that she had not remembered to Progressive Muscle Relaxation and Complete Natural Breathing every day, but she reported that Complete Natural Breathing had been useful in one instance when the cat and dog had gotten in a fight, which had caused Alice much distress. Seeing her distraught and crying, Bob had suggested that a relaxation skill from the previous week might be helpful, Alice had chosen to use Complete Natural Breathing, and found herself much calmer after 5 minutes of breathing practice. Alice seemed worried that I might be disappointed that she had not practiced relaxation exercises daily as I had suggested. I assured her that she had shown great diligence in reading, processing and implementing the skills and concepts in the program thus far, and that the purpose of the homework was not just to complete it for the sake of completion or my appeasement, but to figure out what skills worked for her and which did not, which I thought she had done successfully in using Complete Natural Breathing during an anxious moment. This discussion seemed to reassure Alice to some extent, although she continued to lament not having followed through on her homework.

Module 8 emphasizes worry control and sleep hygiene, and we decided to bypass the latter topic since Alice reported regular and restful sleep (roughly 8 uninterrupted hours per night). Thus, most of session time was spent focusing on supplementing Alice's relaxation techniques with worry control techniques. Alice struggled with many of the worry control suggestions, particularly Scheduling Worry Time, in which the patient attempts to restrict worrying to a short designated period of the day, and asking 'What's The Worst That Could Happen?', which asks the patient to examine their thinking to determine whether they might be overestimating the likelihood of negative outcomes. However, Alice was interested in the idea of writing her worries down, as she had kept a journal as a young person, and felt that putting her thoughts to paper had helped her manage difficult times during adolescence.

#### Module 9

At the outset of session 9, Alice rated her mood over the previous week as a 9/10 (10=best), stating that, as in recent weeks, her mood was supported by her involvement in activities.

In session 9, I focused on helping Alice shift her thinking from a negative thought to a reframe thought without rehashing the, starting with the thoughts that we had most recently worked on relating to her daughter, and moving on to negative thoughts she had mentioned earlier in treatment. Alice stated that she was not having many of these thoughts (e.g. worries that her friends would be distressed by her physical and cognitive limitations) anymore, so I presented our work on these thoughts as preparation for the possibility that similar thoughts might return in the future. Perhaps against my better judgment, I wanted to give Alice and Bob another chance to take the lead role in discussing the session material, but the discussion of the nuts and bolts of cognitive restructuring (e.g. formulating the reframe thought as a direct response to the negative thought). I decided that it was better for them to have some examples of Alice's typical negative thoughts and well-formulated reframe thoughts rather than to spend time trying to help Alice and Bob improve their grasp of cognitive restructuring or take charge of the session, so I went through my session notes, identified the negative thoughts that had been most central to the treatment as well as their reframes, and compiled them in a document for Alice and Bob to keep. Alice and Bob thought this was a good idea, and decided to put the list in a prominent location in their house to help Alice catch her negative thoughts.

Alice was asked to read Module 10 and continue with her activity scheduling before our next session.

#### Module 10

At the outset of session 10, Alice rated her mood over the previous week as a 9/10 (10=best). She continued to report positive mood related to her weekly activities, which included her church group, a tai-chi group, three exercise sessions, volunteer hospice work, and several dinner outings. Alice also reported feeling more capable of managing anxiety related to her daughter's situation, and stated that Complete Natural Breathing and the relaxation recordings from Module 7 had been helpful in this regard.

Module 10 focused on reviewing Alice's progress during the program, and discussing how Alice might use skills she developed in the program to deal with future challenges. In reading through Module 10, which reviews the major emphases of each module, Alice and Bob noticed the degree to which cognitive restructuring skills had been de-emphasized in our sessions, and expressed some regret that they had not developed as much proficiency with this skill. I tried to emphasize the significant and consistent improvement in mood that Alice had achieved without heavily relying on cognitive restructuring skills, emphasized that these skills are not useful for everyone, but also suggested that regardless of whether the formal cognitive restructuring process described in the modules was helpful to Alice, she had challenged and revised her negative expectations about engaging in certain activities by experience. In addition, I helped Alice reflect on her successful use of 'Cost/Benefit Analysis' in reframing her worries about her daughter. Alice continued to express concern that she had not "done the program the way [I] wanted," and I tried to reassure her by saying that the writer's job was to help Alice improve her mood in whatever way possible, that this goal had certainly been achieved, and reminded Alice and Bob that the program is intended to be a 'buffet' of skills from which patients can choose those that work best for them.

Alice and I emphasized the important role that the "Acting In Accordance With Goals And Not Feelings" and behavioral experiment concepts had played in her behavioral activation, and reviewed ways in which Alice could access this concept in the future, focusing on Bob's role in helping Alice recognize instances in which the concept might be helpful, and reminding Alice of its usefulness during the program.

I reviewed the Thought Log as a way to identify negative thoughts that might be appropriate for evaluation through behavioral experiments or restructuring through 'Cost/Benefit Analysis.' We discussed Bob's role in helping Alice add relevant thoughts to the Thought Log and determining which skill to use in a given situation. I proposed several hypothetical scenarios (e.g. Alice's daughter mentions a health concern in a phone call that cues Alice's anxiety), and asked Bob and Alice to chose and implemented skills appropriate to these scenarios with minimal input from I. Alice struggled with this task on her own, but with Bob's help, was able to come up with at least one useful solution in each scenario.

Lastly, writer and Alice reviewed relaxation exercises. Alice expressed particular interest in Complete Natural Breathing, stating that she found it provided an effect similar to that of her tai- chi class. I encouraged Alice to try to incorporate these Complete Natural Breathing into her daily routine, suggesting that regular practice would deepen the impact of the exercise, and make her more likely to remember to use the strategy in a moment of distress.

# Discussion of Alice and Bob's Case

From the first intake call with Alice and Bob, it was evident that they had a close relationship, and were interested in participating in the treatment together. Both Alice and Bob answered the phone at our first session, and both expressed interest in Bob being present for all phone sessions. Bob explained that he was very interested in learning about what Alice was going through, and wanted to be present in case Alice "got tired" or "needed help explaining." Alice concurred that she did need help expressing herself at times, and thought it would be helpful for Bob to be available to provide his input on how she had been doing.

Alice and Bob said they had spent several hours during the previous week reading and discussing Module 1 together, and as they discussed this experience, I was struck by the thoroughness with which Alice and Bob had reviewed the material, and the interest they seemed to take in it, particularly Bob. He asked specific questions about the meanings of certain terms, and seemed interested in learning the concepts covered in the program.

During our discussion of Alice's activities over the previous week, Bob did much of the talking, and presented Alice's inactivity as an unfortunate but necessary consequence of her current condition. For example, he reported that he and Alice felt he needed to escort her outside the home because she "became overwhelmed" easily, was very worried about "running into someone she knew" because she worried she would be embarrassed to exhibit her PD symptoms, and ran the risk of falling due to her weakness and balance difficulties. Alice spoke relatively little, and I was unsure whether this was because she agreed with Bob and felt there was nothing more to say, or disagreed to some extent, but did not want to contradict her husband. Initially, I felt hesitant to ask Alice for her own thoughts for fear of seeming dismissive of Bob's role as

spokesperson, but it seemed necessary to assess the correspondence between Alice's and Bob's views on the matter if possible, and based on my perception that Bob was an open, accepting, supportive spouse, it seemed unlikely that he would take offense to such questions. I expressed interest in gathering as much information as possible from each of them regarding Alice's current situation, and asked Alice to weigh in if she felt she had anything to add.

Alice stated that she generally agreed with Bob's assessment of her physical, cognitive and emotional abilities, but also mentioned that she felt quite limited by them, as she had formerly been a very active member of the community, particular in their church congregation, and had taken great pleasure in her independence.

As our conversation continued, it became clear that these assessments about Alice's abilities had not been tested in quite some time, if ever. Based on my conceptualization, helping Alice engage in rewarding activities was essential, and to do so, it seemed important to test whether Alice and Bob's beliefs about her ability (or lack thereof) to function independently were accurate. However, it was clear that Bob had been playing a close supervisory role for some time, and I became conscious of two concerns regarding Bob's role in Alice's treatment: a) that Bob would feel that testing the limits of Alice's abilities would put her in undue danger, and b) that Bob would feel a sense of loss at having his role diminished.

In Module 2, Alice and I worked on scheduling pleasurable and meaningful activities for the following week. In focusing on this agenda, I worked hard to present a clear rationale for pursuing these activities that I hoped would justify any risks that Alice or Bob perceived to be involved. I focused on the pleasure Alice reported deriving from these activities in the past (attending church groups, volunteering in the community), the idea that her ability to manage these situations had not been tested in some time, and that she might be more capable than she or Bob thought. In addition, I tried present a method for minimizing risk, emphasizing that the three of us would collaborate to choose the activities assigned for homework, and that we could start with activities that seemed at the outer limits of Alice's perceived abilities, and use Alice's experience in these activities to guide the "degree of difficulty" of future activity scheduling.

Although Alice and Bob initially voiced some concern about Alice being "pushed too hard" in certain areas (particularly activities that taxed her mobility and balance, like exercise classes), as we discussed the incremental and collaborative nature the activity scheduling would take, they warmed to the idea. As the precedent for soliciting Alice's opinion had been set in the last session, I mentioned that one initial "test" we could perform would be to see how Alice handled taking on more of the speaking role in our sessions. I stated that I did not want Alice to be uncomfortable, and would check in with her to see if the extra talking was making her tired, but that I felt it was important for her to push herself in order for us to determine where her limits really were. In addition, I emphasized to Bob that asking Alice to participate more did not mean that I was not interested in his perspective, and asked that he speak up when he saw fit. I made an effort to solicit her opinions more and more often in Module 2, and by the end of the session, she was speaking nearly as much as Bob. In addition, I praised Bob when I saw him restraining himself from 'coming to Alice's rescue' when she seemed to be having a bit more trouble than

usual formulating a thought, and also praised him when I felt he offered support or his own perspective at the right time.

At times, I struggled to understand Alice's speech, partly due to chronic telephone connection issues, but also due to a tremulous, halting quality in her voice that made it difficult to discern. Based on our discussions at intake and session 1, I knew that Alice was self-conscious about her speech, but I tried to be honest when I had trouble understanding her, and to ask her to try again rather than turning to Bob, as long as her fatigue was not too extreme, expressing to them that a) vocal exercise might improve the strength of her voice, and b) it was very important for me to hear about Alice's experience in her own words when possible. She did report being tired towards the end of session 2, but also that she enjoyed the opportunity to share more of her experience.

During session 2, Bob made several remarks to the effect that he was surprised and interested by Alice's description of her experiences (e.g. her feeling of shame around her perceived difficulty in communicating and emotional sensitivity). Given the strong bond between Bob and Alice, I was surprised by Bob's surprise, and began to wonder about the interpersonal dynamics that might have limited his awareness of Alice's thoughts and feelings. Based on Alice's reported vulnerability to emotional overload and "embarrassment" over her sensitivity, I hypothesized that the intensity of her distress might make it difficult for Alice and Bob to talk about what was going on when she was upset (Alice stated that prior to the program, she spent a lot of time crying), and that when Alice was feeling better, her sense of shame about her reactions to stress might discourage conversation about her experience in high-stress moments, making it difficult for Bob to get a clear picture of Alice's internal experience.

My perspective on the dynamic between Alice and Bob at the outset of treatment was further clarified by my exit interview conversation with them. Bob stated that "Before program, it was very hard for me to get anything out of her...she would be up in bed in the fetal position...now she is willing to talk to me...and we're able to talk [these issues] through." In addition, during the exit interview, Bob stated that his approach to dealing with Alice's intense distress was to try to "fix it," and that he would often become frustrated with Alice when there was not a clear and immediate solution to be found. For her part, Alice mentioned that she tended to get frustrated with Bob when he took the 'fix it' approach, because she really just wanted to be "listened to." Based on this information, one imagines a dynamic in which Alice is punished for sharing her experience (since she experiences Bob's typical response as unhelpful), and Bob is punished for engaging with Alice about her distress, since his attempts are rejected and seem unsuccessful. Although I did not fully realize this during the treatment, in hindsight it seems that my efforts to elicit more of Alice's perspective as a means of testing her limits may have inadvertently changed Bob's perspective on Alice's illness by giving him a chance to hear what it was like for her when she felt upset. In addition, because my therapeutic style emphasized information gathering and empathic reflection in addition to problem solving, I may have been able to model a different way of relating to Alice's distress for Bob.

In sessions 3 and 4, as Alice increased her activity level, Alice, Bob and I took a look at how these changes were impacting Alice and their relationship. Luckily, Alice's experience in

pursuing Daily and Weekly goals had been overwhelmingly positive: although she had mentioned negative predictions regarding what it would be like to exhibit PD symptoms in front of friends and acquaintances, and had doubts about how her memory and conversational ability would affect her social functioning, she received very positive feedback from her social network (e.g. she reported that most people focused on how glad they were to see her and how much her presence brought them joy), and clearly derived a great deal of pleasure from her reinvigorated social life.

Structural family systems theory (Minuchin, 1974) suggests that significant change in the attitudes and behavior of one member of a couple or family system may destabilize the system, and may provoke reactions on the part of other members of the system that are designed to restore the system's previous equilibrium, regardless of the level of dysfunction in the prior equilibrium. Since Alice was now spending significantly more time separate from Bob, I was concerned that Bob might feel bereft of companionship or a sense of gratification in tending to Alice's needs, and tried to be attuned to behavior on the part of Bob that might function to restore the status quo (e.g. expressing concern for Alice's physical safety in these new environments, and suggesting that she reduce her involvement in these activities or that he accompany her). On the other hand, although Bob never complained about his role in supporting Alice, and presented his efforts in this area as a labor of love, I also tried to be sensitive to any indication that a reduction in caregiver burden was occurring as a result of Alice's increase in autonomy and activity level.

On the whole, I observed little to none of the former and plenty of the latter. In addition to being pleased at the improvement in Alice's mood that seemed tied to her increased activity level, Bob seemed genuinely surprised at the sense of freedom he experienced as he and Alice developed confidence in her ability to operate more autonomously, and in a caregiver session following our 5<sup>th</sup> session, remarked that our discussion of the importance of meaningful and rewarding activities to Alice's mental health had led him to consider adding new activities to his own schedule, and that with Alice's increasing activity level and reduced dependence on him, he felt he had the time and energy to follow through with some of these plans, which included spending time participating in a vintage car club, exercising more regularly, and spending more time with friends. Bob's score on the Caregiving Distress Scale was a 22 at baseline, and showed mild to moderate distress across a range of areas (e.g. impairment). His scores at subsequent time points were 11 (5 weeks), 8 (endpoint - 10 weeks), and 5 (follow-up - 15 weeks). This pattern suggests a significant reduction in caregiving-related distress, and, given Bob's increased engagement in non-caretaking activities during this time, supports the hypothesis that behavioral activation on Alice's part freed up Bob to engage in his own behavioral activation, leading to improvement in mood for both of them.

In parallel to the shifts in autonomy and responsibility that Bob and Alice were exhibiting outside of session, the in-session dynamics during our calls began to reflect Alice's growing confidence, and Bob's growing awareness of the benefits of encouraging Alice's independence within reasonable limits. In Module 7, there was a moment epitomizing this shift in which Alice had been asked whether Progressive Muscle Relaxation would be of interest to her, had not answered immediately, and Bob began to speak for her, but caught himself. Alice eventually was

able to answer the question, and her answer caught Bob by surprise: he had assumed that she would not feel comfortable with the rigors of the PMR, and was about to express this, when in fact Alice said that based on her experience in exercise and tai-chi classes, she felt comfortable giving PMR a try as a homework assignment. Bob reflected on the violation of his expectations with good humor, and said "I sure learn a lot when I keep my mouth shut." I offered Alice and Bob my perspective on the shift in their relationship and the positive consequences of this shift, which they appreciated.

The situation in which a caregiver has taken on a great deal, and potentially an unhelpful degree, of responsibility in their caregiving role, is anecdotally a common one in treatments of medically ill patients, and presents an interesting set of clinical challenges and opportunities.

Often, such a dynamic has arisen as a natural strategy for coping with loss of functional abilities on the part of the patient, but overcompensation on the part of the caregiver can be a barrier to the patient's improvement if it prevents the patient from participating in meaningful and rewarding activities that they are capable of, or undermines their sense of self-efficacy and confidence.

If the patient seems likely to benefit from behavioral activation, but the patient and caregiver's understanding of the patient's capacities seems to limit behavioral activation options, one question to consider is: 'To what extent has the caregiver overcompensated for the deficits of the patient?" In the case of Bob and Alice, I had an early inkling that Alice might be capable of more autonomy than she was showing because much of her disengagement seemed rooted in negative predictions that had not been put to the test, and were not supported by evidence (e.g. believing that she would feel too overwhelmed and be incapable of communicating effectively in social situations without Bob's help).

This is not always an easy question to answer, and answering it may involve some risk to (a) clinician-patient rapport (e.g. if patient resists taking on more responsibility), (b) cliniciancaregiver rapport (e.g. if caregiver sees the clinician's request that the patient try taking on more responsibility/autonomy as unnecessary, dangerous to the patient, or threatening to the caregiver's role), c) the caregiver-patient relationship (e.g. if the shift in responsibility leaves the caregiver feeling bereft of a sense of purpose, which they then take out on the patient, or if the patient takes out the added stress of being asked to "push their limits" on the caregiver), or to d) the patient's physical safety (e.g. if the area chosen to test the patient's need for the caregiver's support actually poses some risk to the patient, like driving). In general, a clinician may be able to mitigate these dangers in several ways: threats to clinician-patient and clinician-caregiver rapport can be managed by being open and honest with patients about the rationale for testing the patient's capacity to take on new activities and responsibilities, attempting to anticipate some of the clients' concerns (e.g. safety issues for patient, a lost sense of purpose for caregiver), and encouraging clients to provide feedback to the clinician about their experience of these experiments. In addition, threats to the patient's safety and related rapport issues may be addressed by gathering collateral information about the patient's capabilities, like asking the patient's neurologist or primary care provider whether they feel like the patient is physically fit to drive a car, or has the balance to manage a crowded subway car safely. This can help the

clinician feel more secure that activity scheduling will not jeopardize patient safety, and also serve as a way to validate the patient and caregiver's safety concerns.

# 4B. CARL'S ASSESSMENT: PRESENTING PROBLEMS, GOALS, STRENGTHS, AND HISTORY

## **Identifying Information**

Carl presented for treatment as a 67-year old, married, domiciled, retired, Caucasian, Latino man living in Central New Jersey who had been diagnosed with PD 11 years prior to intake (2004), and reported increasing struggles with depression and anxiety during the preceding two months. Carl had completed a 4-year undergraduate degree, and worked as a federal investigator for much of his career. Carl described himself as an energetic, outgoing person who enjoyed philosophy, history and other intellectual pursuits. Carl did not endorse significant past or current medical conditions aside from PD.

Carl's caregiver for the study, his wife Doris, was a 68-year old, Korean, retired female domiciled with Carl. Doris had been diagnosed with bipolar II disorder, which she described as "stable." Doris also suffered from diabetes, which she described as "under control," and did not report other significant medical conditions.

Carl and Doris had known each for other for 45 years, and reported that their relationship had been tumultuous in the past. They were separated for 10 months in 1976 in the context Carl experiencing a depressive episode. Carl and Doris had one son, who was married with a young daughter, and lived close to them. They reported being very involved in their son's life, but stated that his financial decision-making was an area of concern that at times caused conflict in their relationship with their son, and their own relationship.

## Presenting Problem, Psychiatric History, and Assessment

Carl stated that two months prior to intake, he had begun experiencing daily low mood, helplessness, hopelessness, poor sleep, and "paralyzing" anxiety. During this time, Carl described himself as "consumed" with worries about coping with PD, and said he had begun to "question the meaning of life." Carl stated that fear of "losing control" due to an interaction between his anxiety and PD symptoms had severely limited his engagement in daily activities (e.g. driving, walking outside the house), and he had begun to feel "claustrophobic" at home. Carl also reported significant short-term and long-term memory problems, although my interactions with him, and reports from his wife Doris, suggested that his perception of the severity of these symptoms was exaggerated.

Carl did not report having been diagnosed with any psychiatric illnesses aside from depression prior to intake. Carl reported a history of recurrent depressive episodes. He stated that he had been depressed for several periods in his teenage years after his parents' divorce, had had another depressive episode in 1976 in the context of marital problems with Doris, and had a "nervous breakdown" which led to psychiatric hospitalization in the late 1990's when, he

believes, he first began to experience PD symptoms. Carl reported feeling depressed "intermittently" since the late 1990's, but noticed a significant increase in symptoms in the two months prior to intake. At intake, Carl was taking 50 mg/day of nortriptyline for depression, 1 mg/night of clonazepam for sleep, and was prescribed 0.5 mg/PRN of lorazepam for his anxiety. He described each of these medications as helpful, particularly the clonazepam, which he felt he depended on to fall asleep.

At baseline, Carl scored a 28 on the HAM-D, a 28 on the BDI, and a 27 on the HAM-A, indicating moderate symptoms of depression and anxiety. Correspondingly, Carl received a CGI score of 5 indicating a "Markedly III" psychiatric status. Doris's baseline score on the CDS was a 49, indicating a very high degree of caregiver burden. Carl scored a 24 on the MoCA at intake, indicating mild cognitive impairment.

## **Diagnoses**

Axis I: Major Depression, Moderate, Recurrent (296.32) Axis II: None

Axis II: None

Axis III: Parkinson's Disease (ICD-9 Code 332) Axis IV: GAF Score: 56

## **5B. CARL'S CASE FORMULATION**

Based on the intake information and the guiding conception of this treatment approach, I conceptualized Carl's depressive symptoms and anxiety as developing due to the stress and functional impairment of his Parkinson's symptoms, and being maintained through behavioral avoidance and negatively biased interpretation of his experience. In particular, Carl expressed significant fear of losing control of his body or his mind since being diagnosed with PD, and viewed himself as weak, helpless and burdensome, endorsing negative automatic thoughts like "If I drive too far from home, my anxiety will cause my tremors to get so bad that I will lose control of the car," "I am rapidly deteriorating," and "I cannot cope without my wife." Due to his anxiety about his ability to engage in a range of daily activities, at the outset of treatment, Carl had been spending much of his time in the house watching TV, which made him feel "trapped" and "depressed." I conceive of Carl's negative automatic thoughts described above as derived from the conditional assumptions and intermediate beliefs "If I engage in this activity, something terrible will happen" and "I can't cope with PD," and the core belief "I am fundamentally flawed." Carl's belief that he is fundamentally flawed was also reinforced by his adherence to the 'just world belief,' (i.e. that good things happen to good people and bad things happen to bad people), which he attributed to his staunchly Catholic upbringing.

In addition I conceive of Carl's wife, Doris, as playing a role in reinforcing Carl's belief in his helplessness and burdensome by voicing these beliefs herself, and also by negatively reinforcing Carl's anxious avoidance by taking over a variety of tasks and chores (e.g. driving, doing yard work, being responsible for feeding the dog). This undermined Carl's self-esteem, and deepened his belief that he was incapable of coping with PD and effectively engaging with

life, which led to further behavioral avoidance, and prompted further criticism and reinforcement of avoidance from Doris.

# **6B. CARL'S COURSE OF TREATMENT**

#### Module 1

Carl and his wife Doris were both present for our first session, and had both read through Module 1. In describing his depression, Carl identified disengagement with activities, helplessness, hopelessness, low mood, and guilt about being a burden to his loved ones. Carl also endorsed significant anxiety about engagement in a variety of activities (e.g. driving, walking by himself), and his primary fear was that he would lose control.

Carl rated his mood over the previous week as 6/10 (10 = best). Carl said he had been surprised when his PT therapist had recently told him he had improved in almost every PD symptom domain. Carl said he believed he had not been making progress, and that his outlook on life improved, albeit slightly, as a result of this feedback. I framed this scenario as illustrating an important principle of the CBT model: the interpretation of a situation, rather than the situation itself, determines its emotional impact. I also suggested that depression tends to promote negative interpretations, and that an important part of the program involved gathering information, as Carl had from his PT therapist, to help rebalance interpretations that were found to be overly negative or unhelpful, and thereby improve mood.

Carl, Doris and I discussed the influence of behaviors on mood through an example Carl provided in which he was pleasantly surprised by his ability to walk on sand without falling during a recent trip to the beach. In light of this instance, we discussed the importance of activity scheduling, and it became clear that Carl's activity level was extremely limited. Carl reported feeling worried about leaving his house, and spent much of his time watching TV. One of Carl's primary fears about going outside involved his belief that if he was in a situation he was not sure he could physically handle, his anxiety would cause his tremors to get worse, and he would eventually lose control (e.g. crash his car, fall down on the sidewalk, get lost). I suggested that if we could help Carl find a way to reduce his anxiety by testing his assumption that he would lose control, he might feel more comfortable engaging in activities.

Next, we reviewed some of the guidelines for setting activity goals outlined in Module 1. Carl stated that he would like to set a goal of walking outside more often, and we discussed how he might safely challenge his fear of falling. Carl stated that he had fallen in the past, but not for at least a year, and Doris opined that he likely had the physical capacity to go for short walks outside, and that fear itself might be his biggest obstacle. In light of this thought, we discussed the concept of 'Acting In Accordance With Goals And Not Feelings.' Carl was less sure of his physical capacity than Doris, so we examined his daily routine to see what amount of walking he had done recently, and in what circumstances, and recognized that he had recently walked steadily for about 10 minutes over level, familiar terrain in the course of helping Doris with chores. We discussed the importance of titrating activity engagement to strike the balance between pushing himself and staying within safe limits. As an initial experiment in utilizing this

concept, Carl agreed to take a walk of 10 minutes each day on level ground with Doris over the next week.

Carl expressed a great deal of interest in discussing the unconscious with me, which he saw as the source of his fearful thoughts, and wondered how these fears were generated. I emphasized that while one might conceive of his thoughts and feelings as having unconscious sources, the TH-CBT treatment program focused on improving mood and anxiety by working with conscious aspects of experience.

In addition to Carl's daily walking assignment, I asked him to rate his enjoyment of activities over the following week using the Activity Rating Worksheet, and to read Module 2.

## Module 2

Carl reported that his mood over the past week had been a 5/10 (10=best). He had not left the house as much as he had hoped, and had felt sad and listless at times, but had enjoyed several activities, including visits to a farmer's market and the boardwalk with his wife.

Carl had read through Module 2, and done a good job adding activities to his Daily and Weekly Goals worksheet. Several had turned out to be more enjoyable or feasible than he had expected. Carl and I discussed the importance of testing his predicted enjoyment of activities he was hesitant to engage or in, or had not attempted recently, in order to see if they might be useful additions to his activity schedule. Carl had not been able to follow his plan of walking for 10 minutes each day, and had instead gone walking twice for much longer periods. On one of these days, he had attended physical therapy in addition to walking, and reported feeling very tired at the end of the day, so we touched on the importance of challenging himself but not overburdening himself and risking injury.

Carl and I discussed the concept of negative thoughts presented in Module 2, and Carl was able to provide a recent example in which pain in his legs after physical therapy was associated with predictions that this pain would prevent him from being able to sleep that night. Carl showed a good grasp of the rationale for documenting negative thoughts in the Thought Log, but struggled to frame his negative thoughts in concrete, declarative terms. Carl seemed interested in determining which component of the CBT model was most important, and had difficulty with my proposal that each was important in different ways.

We spent the last third of the session discussing Carl's Daily and Weekly Activity Goals for the next week. Carl's physical therapist had recommended that he exercise for 15 minutes each day, and he had expressed interest in biking, but worried whether he would be able to accomplish this task. Carl stated that one of his most significant obstacles in following through with exercise plans and other activities was his tendency to "rationalize" inactivity when he was feeling anxious or sad, and we discussed the usefulness of the concept of 'Acting In Accordance With Goals And Not Feelings', and the value of documenting instances in which ignoring negative feelings and persisting with an activity had a positive impact on mood. Carl seemed to feel this idea was presented in an overly simplistic way, and seemed intent on explaining to me how powerful the emotions that limited his activity were. I tried to balance validating his

experience and focusing on instances in which he had succeeded in not allowing them to limit his activity engagement.

In addition to reading Module 3, Carl's homework included adding to the exercise and social goals he had come up with for the following week, and setting aside 5-10 minutes at the end of each day to add any negative thoughts he had identified during the day to the Thought Log.

#### Module 3

When I checked in with Carl at the outset of our third session, Carl said that he had been feeling "well" over the last week, but that there had been "ups and down." He rated his overall mood for the week as 5/10 (10 = best). Carl described one instance in which his wife was driving in unfamiliar area in inclement weather, and he had become very concerned they would crash.

However, he had recognized that his anxiety was likely unwarranted, since they were not in a rush, and they had a GPS to redirect them if they got lost. I tried to highlight the role that Carl's thoughts had played in curbing his anxiety, and framed Carl's strategy of coping with this situation as an example of effective cognitive restructuring. Carl said his "primary concern in life" was his anxiety, and the frustration that he felt at not being able to overcome it. As an example, he described a worry that if he drove further than 5 miles away from his house, his "nerves" might get the best of him, leading to tremors that would cause him to lose control of the car. I told Carl that we would be focusing on strategies to cope with these fears over the next few modules.

Carl said he had been very busy in the last few days, and had not been able to read through Module 3 or fill out the Thought Log. We decided to use his negative prediction about losing control of the car as fodder for practicing the creation of a Thought Log entry. Carl did an excellent job describing the situation, his feelings and the negative thoughts that he was having at the time. However, as in the first session, he repeatedly shifted the focus of our conversation to the role of "the unconscious," in his struggles, and I worked hard to respectfully redirect our focus to program materials. I directed his attention to the list of Cognitive Distortions covered in Module 3, and we reviewed several that seemed most relevant to negative thoughts he had already mentioned (e.g. Catastrophizing). Carl recognized several of the listed thinking patterns from his own experience, although he said that he often had a hard time figuring out if his thinking was distorted or not in the moment, an issue which I told him would be addressed in upcoming modules.

Carl had filled in his Daily and Weekly Activity Goals worksheet, and had planned a trip to the Senior Center, which he and his wife had attended in the past for exercise classes and other activities, but had stopped attending when Carl's balance and leg strength had begun to deteriorate. Carl stated that, based on his PT therapist's feedback, he thought he was in better physical shape than when he had last attended the Senior Center, and wanted to see whether he would be able to participate in their exercise program. At the end of the session, Doris said she had something to share with me that related to family relationships, so we arranged to chat separately the following day.

#### Caretaker Session 1

In my conversation with Doris, she expressed great frustration with Carl's functioning in several areas, particularly in parenting their adult son. Doris complained that Carl did not support her when she cautioned their son about his profligate spending, and that he seemed to "freeze up" at the first sign of conflict, leaving her feeling undermined. We discussed the circumstances of these interactions, and it seemed that these exchanges between Doris and their son often became very heated, with raised voices and occasional breaking of household objects, but no physical violence. Carl had expressed concern that the interactions could get physical, and that in his current state he felt powerless to intervene if this occurred, leading him "freeze up" in these circumstances, which Doris interpreted as weakness. It seemed important to get Carl's side of the story as well, so I suggested that we discuss the issue further at our next scheduled session, and asked if Doris had any other concerns or information she wanted to share. She said she was frustrated that Carl's anxiety amplified her own when she was driving, that he left the door open, and left chores unfinished, but stated that she was most concerned about his role in parenting their son.

#### Module 4

Carl reported his mood over the previous week as a 6/10 (10 = best), and reported being less fatigued and more active than he had in a long time. Partly due to my sense that Carl had some misgivings about the TH-CBT philosophy, we took a moment to review his impressions of the program so far. Carl said the most significant thing he had learned was to question his interpretation of situations, and said this idea had been helping him work through anxious or catastrophizing thoughts when they arose. As an example, Carl had recently had a moment of panic when he had walked out of a barbershop and not been able to find his wife, who he thought would be waiting for him, and had the thought: "something terrible is going to happen to me." He had then found a nearby bench to sit on and "talked himself down" until Doris returned a few minutes later. We used this situation to practice the 'evidence for/against' cognitive restructuring technique. Carl shifted into storytelling mode as we began to look for evidence for and against this thought, and provided a host of extraneous detail regarding this particular occurrence, often concerning mystical or otherworldly aspects of his subjective experience.

However, when he did focus on the task of evidence-gathering, he did an excellent job, particularly in discriminating between strong and weak evidence, or identifying pieces of evidence that were actually other negative thoughts.

Carl continued to have difficulty with the 'Acting In Accordance With Goals And Not Feelings' idea, stating that for him, "emotions are the more powerful motivator." I offered examples of situations in which he had ignored his feelings and pursued activities consistent with his goals and seen a shift in his mood, but Carl pursued the idea that Module 4 seemed to be portraying emotions and thoughts in an "adversarial relationship." I clarified that the concept did not pertain to all feelings and all situations, only those in which negative feelings were potentially limiting activity engagement that could foster more positive feelings, and Carl and I discussed the value and pleasure inherent in emotional life, which Carl seemed to appreciate.

Carl clearly enjoyed taking a humanistic, philosophical perspective, and I wondered whether engaging him on this level, at least to some extent, would be important in maintaining our rapport.

Carl reported exercising intensely on two days (walking on the boardwalk for two hours and attending physical therapy) during the last week, and not the other days of the week, as he had reported when we last discussed exercise. I reiterated my concern about Carl "overdoing it," and Carl stated that although he recognized this risk, he felt it was worth taking because he had enjoyed the boardwalk so much. This led to a discussion of the aspects of this experience that Carl most enjoyed, my intention being to use this information to identify other activities that Carl might enjoy for similar reasons that could be added to his activity schedule. Carl stated that he liked "being around people" and taking in "natural beauty," so we came up with a few other activities that seemed relevant to these interests (e.g. an arts festival at a nearby public park that was coming up in the next week). Carl decided that walking 20 minutes each day in the next week was a good goal, but felt unsure of the best time to walk. He mentioned the afternoon as an option since he could nap afterwards, and I decided that it might be a good time to talk about sleep hygiene and the benefits to nighttime sleep of avoiding napping in the afternoon, since Carl had mentioned that his restless leg symptoms were already a barrier to sleep at night. Carl seemed interested in experimenting with eliminating naps to test whether this improved his sleep, and we ultimately agreed that part of his homework would be to avoid napping over the following week.

Wanting to follow up on my conversation with Doris the previous week, I asked her to explain what she had told me to Carl. She described her experience of feeling undermined by Carl when he did not support her in reprimanding their son. Carl explained that the arguments between Doris and their son sometimes became so heated that he worried that there might be a physical altercation, which he felt he would not be able to effectively prevent in his current physical condition. Doris stated that although she and her son did sometimes raise their voices during disagreements, they had never had a physical altercation, and that Carl need not worry about this. Carl agreed and said that he would try to make an effort to remind himself of this the next time Doris and their son had a disagreement. He also agreed with Doris that their son was careless with his money, but said he felt he had no right to express his concern about this issue because he felt responsible for promoting this carelessness. Doris said she felt Carl was taking too much responsibility, and that regardless of this origin of the problem, it was important to present a united front in addressing the issue with their son. Carl agreed to try to be more vocal in echoing Doris's concerns if Doris would try not to raise her voice as much during these disagreements, which Carl felt was unhelpful and distressing to everyone involved. Doris seemed somewhat irritated by this, but agreed to do her best. I complimented them both for working towards a compromise, and praised Carl for being open to evidence suggesting that his fear of a physical altercation between Doris and their son might be unjustified.

Carl and Doris had not gone to the senior center in the past week as they had planned, but as we discussed the idea further, Doris seemed quite enthusiastic about the idea, since it offered bible study class, food, music, and social opportunities. Carl said he was hesitant to go to the senior citizen's center because his wife tended to play arcade games when they went in the past,

which he did not enjoy, and thus he imagined that he would be on his own. When I asked him what worried him most about being on his own, he said that he often felt "separation anxiety" when he was apart from his wife, and that he thought this was left over from a time when his anxiety was worse and he was functioning more poorly, but that it was a hard feeling to shake off. It was clear to me that there were some important intermediate beliefs underlying Carl's anxiety, but we did not have enough time to address the topic fully, so we agreed to follow up on the topic in our next session.

For homework, Carl and Doris agreed to go to the senior center and read Module 5.

#### Module 5

At the outset of our fifth session, Carl rated his mood over the past week as a 6/10 (10 = best). He explained that he had pushed himself to test his abilities in several scenarios, felt proud of himself for making the effort, and had been pleasantly surprised by the results. For example, Doris had been ill and unable to drive, so Carl had taken it upon himself to bring their car in to the mechanic to get a broken taillight fixed. He had not driven on his own this far from home in several years, and prior to leaving had felt anxious and had the thought "I'm not going to make it back." However, he told himself that he would take the drive block by block and monitor his sense of control along the way, and ended up making it all the way to the auto shop without having the tremors and flood of anxiety he worried would compromise his driving abilities. I praised Carl's initiative, and framed this trip as an excellent example of a 'behavioral experiment' designed to test the validity of a negative prediction, and explained that this approach would be explained in greater depth in Module 6. In addition, Carl and Doris had gone to the Senior Center the previous week, and Carl said that it had been "nice" to be in a social environment, that the exercise class they participated in had gone smoothly, and that although he felt a bit isolated when Doris went to play the slot machines, he had found other activities to occupy him, e.g. listening in on the bible study group.

Doris, I suspect feeling more license to express her perspective after our individual conversation, presented a litany of complaints about Carl's behavior during the previous week, but also mentioned that a year and a half ago, Carl's neurologist had stated that he was "in no shape" to drive. Doris had delivered her complaints quite vehemently and left little room for Carl or I to interject for several minutes, and when she finished, Carl was quiet. I asked if Carl had a response, but he deferred to me. I validated Doris's frustration with Carl, but also said that at least in the area of driving, it seemed to me that recent events suggested that Carl might be more capable of driving than he was a year and a half ago, and cited his recent successful trip to the auto shop. I suggested that perhaps we could work towards lessening her burden by helping Carl continue to gain confidence in his driving. Doris responded by describing an instance in which Carl had driven up on the curb several months ago, and asserted that she did not think Carl was safe driving. Doris seemed entrenched in her position, 10 minutes remained in session, and we had not covered Module 5 material, so in the interest of concluding this discussion without offending Doris, I asked if she would agree to listen quietly while Carl responded, which she agreed to. After significant prompting, Carl shared that he did feel very guilty about the burden he placed on Doris, and was deeply fearful that he might have to cope without her. He also said

that he felt his driving ability had improved significantly compared to when a year and a half ago, and said that when he had driven up on the curb, he had been trying to avoid a small animal in the road. Doris interrupted him angrily, but I reminded her of her agreement to hear Carl out, and she grudgingly complied, allowing Carl to finish his description of this incident.

We ran out of time before we could address Module 5 material, so I asked Carl to read Module 6 for homework, and explained that we would cover Module 5 and Module 6 concepts in our next session. I told Carl and Doris that it was important to address the issues we had discussed in session, but that I also wanted to make sure that Carl got a chance to discuss the concepts from Modules 5 and 6, and to that end, asked if Doris would be willing to let Carl and I speak alone at our next session, and suggested that she and I speak separately, as we had the previous week. She agreed to Carl and I speaking one-on-one at the next session, but declined my offer of a separate session, stating that she had nothing more to share.

#### Module 6

At the outset of our sixth session, Carl described his mood over the last week as a 7/10 (10= best), although he and Doris had both been ill with colds, which had dampened his mood. Carl had continued to work towards meeting his behavioral goals despite his illness, and was pleased that he had been able to take on more household responsibilities while Doris was recovering from hers. In addition, he mentioned several instances in which he had been able to "talk back" to negative thoughts. In particular, he cited an instance in which he had recognized catastrophic thoughts in the context of a computer error message, had quelled his panicky feelings with positive self-talk, and successfully worked through the troubleshooting process.

Dr. Dobkin had provided me with Carl's midpoint assessment results, which suggested that negative thoughts continued to maintain Carl's depressive symptoms, so I suggested to Carl that we incorporate some of the negative thoughts the assessment had highlighted in our practice of the cognitive restructuring techniques covered in Module 5 and 6. Carl agreed, and we sought to apply cognitive restructuring techniques to Carl's negative prediction that his anxiety and depression, in combination with his physical PD symptoms would leave him functionally helpless, a negative thought identified in his most recent assessment. Carl was intent on discussing the origin of his negative thoughts in terms of unconscious mental processes, and I did my best to validate this interest and then refocus our conversation on the tools Modules 5 and 6 offered to help Carl deal with these thoughts. Eventually, Carl seemed to pick up on my redirection toward the concrete and the present, and did an excellent job applying the 'evidence for/against' technique to his negative prediction. Next, we turned to the 'cost/benefit analysis' technique using the same thought as an example, and Carl was able to readily recognize the thought's negative impact on his mood and behavior. We briefly reviewed the 'behavioral experiment' concept, and I framed Carl's trips to the beach, the auto shop, and the senior center as examples of this technique.

Although Carl clearly shown a solid grasp of each of these restructuring techniques, he mentioned after reviewing them that he felt cognitive restructuring was a "noble attempt to use reason" in situations where emotions were overwhelmingly powerful, and that he saw this was a

"very difficult undertaking," perhaps even "impossible." We had come to this impasse before, and I tried to validate that using cognitive restructuring was challenging, and took practice, but that research and clinical experience suggested that it was possible to use these techniques to change emotions, and I pointed out several prior instances in which I felt he had done so successfully. Carl shifted his focus to the instance from the past week in which he had experienced catastrophic thoughts in the context of a computer error message, and said at the time he received the message, he believed there was an entity in the computer that was "mocking him." Deciding to go with Carl's framing of the situation, I suggested that we call this entity the "depression genie," and described cognitive restructuring as an effort to prevent the "depression genie" from taking control of his mood and his behavior, which Carl seemed to enjoy. At the end of this discussion, Carl still voiced some doubts about the effectiveness of cognitive restructuring, but said that the concept of the "depression genie" had helped him make sense of cognitive restructuring. We agreed to discuss his concerns further in subsequent sessions.

For homework, I asked Carl to read Module 7 and to pick a negative thought to use as an example with which to complete the Extended Questioning Automatic Thoughts (QAT) worksheet. Carl expressed ambivalence about using the 'evidence for/against' technique that indicated to me that he had not fully grasped the difference between thoughts that expressed evaluable statements about the world, self or others, and thoughts that expressed feelings. I explained this difference and its implications for the 'evidence for/against' technique, praised Carl's progress in understanding of this technique, and encouraged him to continue his practice. As fodder for his homework assignment, I suggested that Carl use the thought "something terrible is going to happen to me," which had arisen when he had walked out of the barbershop and been unable to locate Doris, and which we had discussed in Module 5. Carl agreed, but in listening back to the session recording, he sounded disengaged as we discussed the details of the assignment, and I think he may have felt that I was dismissing his ambivalence about the 'evidence for/against' technique. In hindsight, it might have been a better idea for me to accept his original suggested practice thought ("I am afraid that I will lose my reason") and ask him to practice all cognitive restructuring techniques except 'evidence for/against' on this thought for homework.

## Module 7

In session 7, Carl reported his mood rating for the previous week as a 5-6/10 (10 = best). He mentioned that the thought "I would be helpless without my wife and son" had negatively influenced his mood. I asked Carl if he could describe the situations in which this thought had occurred, and apply restructuring techniques from the Extended QAT worksheet to this thought. Instead, Carl presented a scenario in which he had experienced a "wave of heat" while he was watching TV. He said that there were no preceding thoughts that explained this sensation, and wondered how analyzing thoughts could be helpful in this instance. I reminded Carl that CBT theory proposes that thoughts, feelings, behaviors and biology are seen as being in ongoing dynamic interplay, not occurring in any particular order, and that thoughts and behaviors were targeted in the treatment program because they were easier to directly engage with than feelings or biology, and could influence the other two components. Carl stated that in fact, prior to his experiencing the "wave of heat," he had been discussing his son's impending relocation, and that

this discussion had led to a flood of worries about his ability to visit his son and grand-daughter in their new location, given his concerns about driving long distances. I framed this thought as a manifestation of the negative thought Carl had mentioned at the outset of session: "I would be helpless without my wife and son," and suggested that Carl assess the evidence for and against the prediction that he would not be able to visit his son's family in their new location. Carl concluded that he could not be sure, since he did not know where his son would be, or how comfortable he would be driving long distances by the time his son did relocate. I suggested that in such a case, when evidence about the truth of a negative thought is lacking, that he might resort to one of the other cognitive restructuring techniques.

Before we were able to settle on another restructuring technique Carl could apply, Carl returned his attention to the inexplicability of the "wave of heat" he had experienced, and compared it to the "fires of Hell." This comparison seemed significant, and Carl went on to say that because he wanted to believe in a fair and just world, he could not help but conclude that his PD diagnosis must be a punishment for his sins. However, Carl observed that there were people he considered "good" (e.g. the Pope) who had been stricken with grave illnesses, which he took as evidence that the world was not fair, and that perhaps he was not being punished. He was uncomfortable with the idea of the world being unjust, but also recognized that the cost of believing the opposite was that he saw his suffering as deserved and inevitable, which led him to resist taking action to relieve it.

Carl then began to discuss his views on intelligent design and the existence of God, and asked me to share my thoughts on these topics. I allowed him to express his perspective, and then asked that we return to the task of examining the evidence for and against his "helpless" belief. Much of Carl's 'for' evidence consisted of emotional reasoning (e.g. "I feel panicky, therefore I must be in need of help"), we discussed why this type of thought did not qualify as strong evidence of his helplessness, and Carl was ultimately able to provide others that to me represented an encouraging willingness to "count the little things" (e.g. "I can take out the garbage," "I took the car to the shop when Doris was unable to").

Carl then stated that his "real concern" was that he would "lose his reason." When I asked him to estimate the likelihood that this would occur in the near future, he said he had no way of knowing. I took this opportunity to promote 'cost/benefit analysis' as a useful alternative to 'evidence for/against' when evidence of the validity of a thought was difficult to gather.

At the end of this discussion, I was unsure of its impact on Carl, and was concerned that we had little time left to discuss Module 7 topics. However, Carl said he felt it had been a worthwhile discussion, and that he was less convinced that his PD represented a punishment based on our review of the evidence. He also mentioned that the phrase "talking back to negative thoughts" had resonated with him, and that he imagined this process as being like "wrestling a bull." To me, this metaphor seemed in line with a 'thought stopping' or 'cost/benefit analysis' approach to cognitive restructuring, and I wondered whether this technique might be easier for Carl to accept and apply than 'evidence for/against.'

Unbeknownst to me, Carl had been unable to download of the audio recordings of relaxation techniques associated with Module 7, so we spent the last 15 minutes of session establishing a means for him to access these recordings and agreeing on a practice schedule for the following week. At the end of the session, Carl mentioned that he had gone to the Senior Center with Doris three times in the last week, and while there, he had exercised, eaten lunch, and attended bible study sessions. Carl said he had been surprised at how quickly he had overcome his initial hesitance to go, and said he had even begun to find activities he could engage in while Doris was playing the slot machine. I expressed how impressed I was at his sustained effort, and congratulated him on conducting a successful behavioral experiment.

### Module 8

In session 8, Carl rated his mood over the previous week as a 7/10 (10 = best). He and Doris had attended the Senior Center three times, and Carl mentioned that he felt "strength coming back to his legs," which he attributed to increased exercise. He had previously assumed that he would not be able to handle adding regular exercise to his PT sessions, and we reflected on the importance of testing predictions that stand in the way of healthier functioning.

Carl had read Module 8, and had engaged with the module material with a thoroughness and energy that I had not seen in previous sessions. Carl particularly appreciated the technique of writing down his worries, and said that doing so over the past week had made it easier for him to rebut them. As an example, he mentioned that on a recent trip to a restaurant with his family, he had worried that family members he had not seen for a long time would think he was speaking less clearly or having more difficulty with his balance than he had in the past, and that this would indicate that he was "deteriorating rapidly." Prior to the trip, Carl used 'best/worst/most realistic outcome' technique to conclude that this outcome was unlikely given that he had been doing "everything he could to improve his condition," his PT therapist had commented on his improvement in several areas, and he himself had noticed gains in strength and balance lately.

Carl reported that the trip to the restaurant had been "a lot of fun," and that the experience had yielded no evidence to suggest that other people had perceived his condition as deteriorating. In addition, Carl stated that he had been using the Progressive Muscle Relaxation (PMR) skills from Module 7 on a daily basis over the last week, and that this practice had helped him disconnect from his worries and "stay in the moment." Carl's report clearly represented a new level of initiative in implementing skills, which I took care to praise.

Carl and I revisited the thoughts "I'm helpless" and "I'm going to lose my reason," which we had discussed in session 7. Carl stated that variations of these thoughts had been present over the last week, and that he saw them as expressions of an underlying fear of aging independent of the PD disease process. Based on my intuition in session 6 that Carl might be more amenable to a 'cost/benefit analysis' approach to cognitive restructuring, and my sense, based on Carl's description of the aging process, that his fears were not clearly distorted, I encouraged him to take a 'cost/benefit analysis' approach to these thoughts. Carl quickly came to the conclusion that, given its negative impact on his mood, the certainty of age-related deterioration, and the difficulty in gathering evidence as to how this process would unfold for him, he needed to "talk

back" these thoughts and redirect his attention to more positive thoughts and activities, and he seemed energized by the idea of asserting control over these thoughts, again referencing his metaphor or "wrestling a bull." He then asked that we discuss the idea of his having multiple "selves." I did my best to validate his perspective by relating this topic to the idea of certain thoughts being generated by the "depression genie," and reemphasized his duty to "fight back" against this entity, which seemed to satisfy Carl.

Carl stated that he was entirely satisfied with his sleep, had been gradually cutting down on his naps, and was already abiding by the sleep hygiene principles described in Module 8, so we focused our attention on the worry control techniques we had not yet discussed. In line with his affinity for "talking back" to negative thoughts, Carl said he found the "Thought Stopping" concept useful, and described repelling worries while watching TV one night in the last week. Carl seemed to enjoy the idea of being a boxer who was "taking blows" from these thoughts, but "refusing to go down," and I encouraged Carl's use of this metaphor, as it seemed like a way to simplify and enliven the cognitive restructuring process for Carl. Overall, Carl demonstrated significantly more engagement and interest in the program material than he had in prior sessions, and I was impressed with his retention of concepts from prior modules.

For homework, I asked Carl to read Module 9, in addition to continuing with his activity scheduling and utilizing the skills we had covered in the program to date.

#### Module 9

At session 9, Carl rated his mood over the previous week as an 8/10 (10 = best). He reported that he had cleared a woodpile from the backyard the day before our session, which he said he "would not have been able to do two or three months ago without passing out." I framed this achievement as a successful behavioral experiment, which Carl acknowledged with some pride. Carl had also attended the Senior Center three times in the past week, and mentioned that the "smiling faces and 'good mornings' made his day."

He then described a "spooky" experience later in the day in which he had glanced at the cleared woodpile, and had a moment of doubt as to whether he had actually cleared it himself. I expected his point to be one of pleasant surprise at his physical abilities, but Carl focused on his doubt, stating that he had felt as if there were "two me's" discussing whether one or the other of them had actually cleared the woodpile. He then asked whether I thought he might be becoming schizophrenic. I was unsure how seriously to take this question, as it seemed far-fetched, but also was in keeping with Carl's affinity for the fanciful. He pursued the question seriously, so I briefly described the etiology and diagnostic criteria for schizophrenia, and explained why I felt the diagnosis was not appropriate for him, which Carl seemed to accept. However, Carl then asked if we could return to his experience of clearing the woodpile, and asked if he might have returned to an earlier stage in his life through "inadvertent self-hypnosis." I explained that I was unfamiliar with hypnosis, but that one could see his experience as the product of the hard work he had put in to build up his physical strength and cope with anxiety about the consequences of physical activity that he had harbored prior to the program. Carl sounded disappointed by this response, but accepted my request that we shift our focus to Module 9 topics.

In reviewing Carl's progress towards achieving the goals he established early in the program, Carl and I agreed that he had met his exercise goals, and had partially fulfilled his social goals, although he had not found an activity that allowed him to interact with peers as he had when he was part of the bowling league. In discussing how Carl could meet this goal, Carl focused on bowling, and began to speculate about whether he could make a comeback as a "respectable" bowler. I tried to expand the discussion to other possible settings in which Carl might be able to find camaraderie, and emphasized the objective of social connection. Carl mentioned that he had gone to the bowling alley just to "take in the atmosphere" several months ago, had run into several old bowling friends, and had enjoyed himself. He decided to set a goal to revisit the bowling alley on a night when his old bowling friends would be there, and work towards making this part of his weekly routine.

We briefly reviewed the worry control and relaxation techniques covered in the last two modules, and Carl stated that he continued to benefit from PMR and Thought Stopping, and described his use of these techniques in a manner that showed he had 'made them his own' through the use of metaphor. For example, he described imagining a calming substance filtering through his body as he did his PMR exercises.

Next, we reviewed the most important negative thoughts we had discussed during the program, and Carl asked that we focus on a prediction that he would lose all of the progress he had gained after we finished the program, which he saw as a variation of his "I'm helpless" thought. In discussing the evidence for and against this thought, I explained to Carl that I thought he had internalized many of the concepts from the program, and that I believed he would be able to put these concepts to use without my help in the future. I also reminded him that booster sessions would be available if he felt he needed further reinforcement of the techniques. We spent the remainder of the session focusing on finding a reframe for Carl's negative thought "I'm helpless." Carl did a good job reviewing the evidence we had gathered related to this thought, but had a hard time choosing a reframe thought that directly addressed the negative thought.

Deciding that coming up with a reframe thought was too much to expect of Carl given that our 'evidence for/against' restructuring efforts for this thought had stalled in the evidence-collecting stage in previous sessions, I took a more directive role in formulating the reframe thought, which ultimately was formulated as "Although there are some things I cannot do, I am doing the best I can, and I am not helpless."

For Carl's homework assignment, I him to read Module 10 and come up with reframe thoughts for several important negative thoughts we had not discussed (e.g. "PD is a punishment").

#### Module 10

In session 10, Carl characterized his mood over the past week as a 7/10 (10 = best). Carl reported that he had driven on the highway to his son's house and gone bowling with him over the weekend, both of which he had not done in many months. Carl described having the negative thought "You shouldn't do this" as he walked out the door before leaving to meet his son, but refuted this thought using an array of excellent evidence (e.g. "I have never gotten in an

accident," "I can drive in the right lane and pull over if I feel unsafe"). In addition, Carl reported that his legs felt tired while he and his son were bowling, and he worried that he might fall if he continued to bowl. However, he had experimented with an adjustment to his stance that he thought might him help maintain his balance, and that this adjustment had allowed him to bowl effectively and without fear of falling. I felt mildly concerned that bowling might have been risky, as Carl had said he did not feel comfortable bowling in our previous session, but Carl assured me that he had been appropriately cautious in assessing his capacity to bowl, and had asked his son to spot him for the first few rounds, which I praised. Carl had also attended the Senior Center three times and gone to the horseracing track with Doris, both of which he reported as being very enjoyable. Carl also reported 'talking back' to catastrophic thoughts that had arisen when the lights inexplicably went out while he was home alone one evening. As in past sessions, Carl wanted to explore the possibility that the "voices" of the negative thought and the reframe thought represented two separate selves or personalities, and that this might indicate evidence of schizophrenia. I tried to frame them as two sides of himself, focusing on the fact that Carl experienced each of these voices as his own.

Carl had read Module 10, but had not worked on identifying reframes for the negative thoughts we had identified in session 9. We began work on identifying reframe thoughts, but struggled to maintain focus on this topic, as Carl seemed more interested in describing instances of these thoughts rather than developing reframe thoughts, despite repeated reorienting efforts on my part. I decided it would be more useful to focus on Module 10's review of the most important concepts of the program, and discuss how Carl could utilize program concepts and techniques to navigate future challenges. During our program review, Carl demonstrated solid understanding of balanced evaluation of the likelihood of positive and negative outcomes, which I highlighted and praised. Carl decided that behavioral experiments, talking back to negative thoughts, and activity engagement were the most important ideas he had taken from the program, and we discussed how he might apply these concepts to specific future scenarios. In particular, we focused on how he would deal with the loss of certain physical and cognitive capacities, and decided that the 'cost/benefit analysis' technique was well suited to coping with negative thoughts related to this scenario. In addition, Carl asked "How do we differentiate between worrying about the future and judiciously preparing for the future?" and we discussed the difference between problem-solving and rumination, and the benefit of maximizing the former and minimizing the latter. At the end of the session, Carl summed up his experience of the program by saying, "negative thoughts still creep in, but I feel better-equipped to cope with them."

Finally, we set specific exercise goals and social goals that Carl felt would be useful to adhere to on an ongoing basis (e.g. continuing to exercise at the Senior Center three times each week). Carl and I arranged to have a booster session in two weeks.

#### **Booster Session 1**

At the outset of our booster session, Carl mentioned that he continued to experience thoughts suggesting that PD was a punishment for his sins. When I asked him whether he had examined the basis for these beliefs, Carl said he still felt guilty about being absent for his

mother's death, despite the fact that he felt had done everything in his power to be there. Carl stated that he felt this guilt might be related to his Catholic upbringing, and that although he identified as an atheist, he felt he could not completely disconnect from Catholic teachings around sin and guilt. I had assumed that Carl had brought up these thoughts because they had been causing him distress, but when I asked about their impact, he said that he had been able to rebut these thought using the concepts of the program, and that they had not significantly impacted on his mood.

Carl said he had been re-reading Module 1, and expressed interest in the idea that the interpretation of a situation, rather than the situation per se, was the key to its emotional impact. We used this idea to look at Carl's recent frustration with his mental acuity, and tried to generate multiple perspectives on this issue, ranging from those that were associated with negative feelings (e.g. "I'm a shell of myself") to positive feelings (e.g. "I'm doing the best that I can, and I have enough mental faculties to live a meaningful life"). Carl did an excellent job generating a number of different perspectives on this topic, and was able to use 'cost/benefit analysis' to identify the perspectives most conducive to a positive outlook.

I asked Carl whether there had been moments over the last two weeks when he had struggled with his mood, and he had difficulty identifying specific instances. He said he had been having some "what if" thoughts, but when I inquired further, he said these thoughts had been imaginative musings that arose in the context of watching a science fiction television program, and were not associated with fears about the future. Suspecting that fears about the future were likely still on Carl's mind to some extent, I assessed for their presence since our last session, but Carl did not endorse these or any other negative thoughts.

# Discussion of Carl and Doris's Case: Working with Tangentiality

Learning to manage Carl's persistent tangentiality in a way that was minimally invalidating, but also allowed us to cover the program's concepts, constituted the most important challenge in my treatment with Carl. Carl had a romantic, fantastical, philosophical flair to his thinking, and tended to guide our conversation towards topics that satisfied these interests. These topics included 'the unconscious mind,' whether or not it was possible for him have two different selves existing simultaneously within him (and whether this meant he was schizophrenic), atheism, the enigmatic nature of subjective experience, supernatural phenomena, and a host of others. A discussion of my effort to overcome this challenge may have general utility to other clinicians delivering treatments that are telephone-based, highly structured, and/or involve patients with proclivities for tangentiality. I will describe the nature of Carl's tangentiality in further detail, relate my attempts to deal with this aspect of our treatment, and discuss the lessons I drew from these efforts that I see as having the most general applicability to similar treatments.

Carl's tangentiality was challenging for a number of reasons. First, in addition to veering off topic frequently, Carl pursued his tangents persistently, and would often talk over my attempts at redirection in order to continue his thought. Second, it was frequently unclear to me in the midst of these tangents whether Carl and I would ultimately make a connection to a topic of relevance to the program or not. In some cases, giving Carl space to pursue what seemed like

a tangential topic ultimately yielded very important clinical information, and many more cases it did not. This can be seen as a variable ratio intermittent reinforcement schedule from my perspective, and made it difficult to know when to take an active role in redirecting the conversation, and when to let Carl guide the discussion. Third, the telephone-based format left me without the aid of non-verbal cues from Carl to help me gauge when and how to redirect him, and the aid of my own non-verbal means of communication in order to assist in this redirection. Fourth, over the course of our sessions, I noticed that when I did redirect the conversation away from a given tangential topic, Carl often returned to that topic unless my redirection used his topic as a starting point or acknowledged it in some way, which forced me to develop creative ways of tying tangential topics back to subjects that I felt were more relevant to the program.

To provide a flavor for the way that Carl's tangentiality played out in our sessions, I offer this example from our first session: we had been reviewing the basic principles of Activity Scheduling and were working towards setting an exercise goal for the following week (walking 10 minutes each day), when Carl mentioned that he used to run 5 miles per day in his Coast Guard days, and then began to describe other recreational activities that he had historically enjoyed.

Though this was a departure from the task of setting an exercise goal for the following week, I saw it as consistent with our broader goal of reviewing activities that had been meaningful or enjoyable for Carl in the past, which is often helpful in generating possible activities for Carl to add to his schedule. Carl described his abiding love of bowling, stating "The highlight of my life was bowling in a league for 7 years," and "I cannot describe my personal devastation when it became clear that I would not be able to bowl." At this point I tried to interject with the intention of assessing what aspects of the bowling league Carl most enjoyed, why he stopped bowling, and whether it might be possible to return to the bowling league, in a modified way if necessary, or to find an activity that offered similar benefits (e.g. camaraderie, social time with peers). However, in the midst of my asking these questions, Carl interrupted with a change in course: "I am going to tell you something that is going to blow your mind, my son is a state policeman...when he was little, I used to go to Fort Dix to practice shooting with him, and now the reverse is happening..." and Carl went on to describe his amusement at the fact that his son was now taking him to the shooting range. At this point, we had jumped to another topic that also seemed fruitful from an Activity Scheduling perspective, but I had not had an opportunity to frame the discussion in terms of Activity Scheduling, and I was concerned that Carl was focused on telling these stories for the their own sake rather than on analyzing them with the goal of getting increasing his current activity engagement. Worrying that we might continue to move from topic to topic without applying this information to the task of Activity Scheduling, I tried to interject again, and this time, I persisted when Carl talked over me. I apologized for interrupting, provided a brief review of the rationale for Activity Scheduling, and asked if we could return to the original task of setting an exercise goal for the week. However, in listening back to the session, Carl began to sound somewhat subdued and distant in his responses at this point, and it is possible that he experienced my redirection as abrupt and dismissive.

This vignette illustrates several of the challenges I described above. In particular, it exemplifies the situation in which a tangent shows potential to be clinically useful, and I feel

uncertain about whether or not to redirect the conversation. In this case, it was not the content of Carl's tangent, but the lack of treatment-specific framing that led me to decide to try to redirect the conversation. This vignette also demonstrates the way in which Carl's tendency to talk over me led me to feel torn between interrupting Carl firmly, which ran the risk of causing a rift in rapport (as I suspect occurred in the example described above), and simply waiting until Carl concluded his thought, which I worried might result in a significant loss of session time. I experimented with the latter approach early in our treatment, and found that Carl would often continue his monologues for long periods with little apparent interest in input from me.

The pattern described in the example above was repeated many times in our first few sessions, and I recognized that I needed to figure out a strategy to redirect our conversation in a way that did not lessen Carl's engagement. However, I had little success in this effort over the course of the first 5 sessions. In session 6, Carl returned to a favorite tangential topic of his, the idea that his negative predictions about the future had an unconscious origin. I did my best to validate this interest and then refocus our conversation on the cognitive restructuring tools Modules 5 and 6 offered to help Carl deal with these negative thoughts. Carl expressed doubt that "reason" could influence his emotions, which he saw as powerful and mysterious forces. I suggested that I thought he had already used reason successfully to influence his feelings in a positive way, and cited the example he had mentioned earlier in the session in which he had received a computer error message, automatically assumed the worst ("I screwed up my Windows 10 installation"), but then recognized that this was an untested assumption, and successfully diagnosed and resolved the error message. Carl's response did not indicate that he had registered my point about his effective use of cognitive restructuring skills, and instead, he focused on his belief that there was a "malevolent force" within or channeled through the computer that was trying to "mock" him. I suggested that we conceive of this "malevolent force" as the "depression genie," and that his job was to defend against the "depression genie" by 'talking back' to it. Carl was amused by the idea of a "depression genie," and interestingly, over the course of the next few sessions, Carl repeatedly framed his struggle to overcome his depression as a noble battle against an evil entity, and Carl's use of this metaphor seemed to help cognitive restructuring skills come alive for him.

Although I was not fully aware of this at the time, I believe the above example is an instance in which Carl's tangentiality had great clinical significance. I think his preoccupation with the unconscious, supernatural phenomena, and the mysterious power of emotions, were indirect expressions of ambivalence about the usefulness of cognitive restructuring skills, and possibly ways of communicating his concern that he could not be helped. At times, Carl was quite direct about his belief that "reason" was incapable of exerting control over emotions. When he began relating his thoughts about the "malevolent force" in the computer, instead of redirecting him to module materials in the concrete way I had used without success in the past, I tried to frame the situation in a way that was consistent with the principles of the program but also 'played by Carl's rules' in the sense that I accepted his premise of a mysterious, malevolent entity. This was not a conscious decision on my part, but after the session, it occurred to me that this might be a useful way to leverage Carl's tangentiality in a productive way. Not only did this approach seem to limit the likelihood of Carl feeling dismissed, but it helped me to communicate program concepts that I had previously struggled to get across.

In later sessions, I used this experience as a template: when Carl seemed to veer off topic, I tried to find some piece of what he was saying, preferably some element that seemed particularly likely to appeal to his fanciful side, and either a) describe a program concept using the language and logic expressed in the tangent, as in the above example, or if I could not figure out how to do this in the moment (which was often), to b) engage with the premises of the tangent briefly, and then attempt to gradually guide our conversation back to a more literal discussion of a program concept.

One instance in which strategy b) worked well was in session 7, when Carl was perseverating on the idea that emotions or physical sensations precede thought, but then made an association between an inexplicable "wave of heat" that he experienced during an episode of anxiety, and "the fires of Hell." This comment could easily have been dismissed as extraneous detail, especially given Carl's fondness for waxing poetic, but I asked him to expand on this comparison, and in doing so, Carl revealed that he felt that his PD diagnosis was a punishment for sins he had committed, which turned out to be a very powerful negative thought that we were able to effectively address later in the conversation using standard 'evidence for/against' strategy.

Both strategies place a premium on quick thinking, and I was not always successful in employing them, but when they worked, they seemed to yield the best results in terms of efficiently conveying program concepts and maintaining rapport.

In taking stock of the most generalizable lessons gleaned from my attempts to deal with Carl's tangentiality, one important lesson was that tangentiality can be successfully handled by using the content of the tangent as the basis for a reframing of a relevant concept, or by engaging with the content of the tangent to validate the patient's perspective before gradually guiding the conversation back to the desired treatment topic, as described above. The specifics of my approach to dealing with Carl's tangentiality (e.g. the use of metaphors that appealed to his interest in the romantic and supernatural) may not have broad applicability, but the general strategy of using some element of the tangent as the basis for redirection, as described above, may have general utility. Regardless of the particular strategy used to manage tangentiality, I propose that clinicians working with PD patients (Taylor and Saintcyr, 1995; Robertson and Flowers, 1990) or other populations with well-documented deficits in executive function, managing tangentiality is an important clinical skill to develop, particularly when implementing CBT treatments over the phone, since structured, time-limited treatments place more of a premium on efficient use of time, and the telephone-format limits the range of communicative tools at the clinician's disposal to manage tangentiality, as described above.

Looking back on our treatment in the context of what I have learned as a clinician since then, I think it might have been as or more effective for me to directly express my dilemma to Carl, and work to establish a mutually agreed upon procedure for handling situations in which we had different ideas about where our discussion should go. I considered taking this approach at times during Carl's treatment, but did not pursue it for a number of reasons. First, at that stage of my clinical development, I had little practice in commenting on interpersonal patterns with patients in the moment, perhaps because this skill had not been emphasized in my CBT training

to date, and I was concerned that I might not be able to deliver my message in a way that did not offend Carl. The fact that I would not be able to read Carl's body language or facial expression during this discussion also made me more reticent to take this approach. However, subsequent externship experiences gave me the opportunity to practice such conversations with patients, and I have learned that in many cases, the benefits of taking a direct approach to addressing problematic therapeutic dynamics outweigh the risks, and that my estimates of the likelihood of a patient taking offense at such an intervention were unrealistically high.

Lastly, working with Carl's tangentiality helped teach me the value of looking for tacit messages expressed in seemingly irrelevant tangents. For example, Carl's persistent reference to the unconscious, supernatural, and the inscrutability of subjective experience seemed unrelated to the goals and content of the program at first. However, I ultimately saw his concern with these topics as an indirect way of expressing his ambivalence about the cognitive interventions presented in the modules. Additionally, Carl often sounded animated and upbeat during his tangents, and more subdued when we were discussing his distress in a concrete way, and in listening back to our session recordings, I noticed that he often became tangential in the midst of discussions of distressing feelings. Based on this information, I suspect that Carl's tangentiality may also have served as a means, conscious or unconscious, of avoiding frank discussion of his distress. Thus, even when working with patients whose tangentiality might plausibly explained by executive functioning deficits alone, I think it is useful to consider the possibility of tangentiality as an avoidance mechanism.

# 4C. ETHAN'S ASSESSMENT: PRESENTING PROBLEMS, GOALS, STRENGTHS, AND HISTORY

# **Identifying Information**

Ethan presented for treatment as a 73-year old, married, domiciled, retired, Chinese-American man living in Western New York who had been diagnosed with PD 6 years prior to intake (2010). He reported that he had first noticed depressive symptoms in 2007, and that after a 6-month remission, the symptoms had returned in 2008 and been present ever since. Ethan had worked as an engineer for about 30 years, but had retired several years ago. Ethan stated that for much of his life, he had been an upbeat, active person with strong interests in tennis, singing, and digital technology. However, since his PD symptoms and deteriorating eyesight had begun to limit his physical and cognitive capacities over the last 10 years, he had become progressively less involved in activities outside the home.

Ethan's caregiver for the study, his wife Fay, was a 73-year old, Asian-American, retired female living with Ethan. Fay reported no prior psychiatric history, and stated that her medical history included breast cancer that had required a lumpectomy in 2001 and a mastectomy and chemotherapy in 2014, but was now well controlled with the help of medication.

Alice and Bob had known each for other for 48 years, and reported no significant marital discord. Alice and Bob had one daughter who was married and lived in the Northeastern United

States with her husband. Ethan and Fay reported a close relationship with their daughter, but stated that it had been harder for them to see her since she moved away from Western New York.

# Presenting Problem, Psychiatric History, and Assessment.

Ethan stated that since 2008, he has been feeling "sad" about 25% of the time, has experienced disturbed sleep and a significant shift in his sleep schedule, poor concentration, increased appetite, helplessness and hopelessness. Ethan reported minimal engagement with activities or other people aside from his wife, much of which he attributed to the physical symptoms of PD, although Ethan also stated that he felt his interest in activities that he was able to engage in had diminished. Ethan reported being highly focused on and distressed by his PD symptoms (e.g. abdominal pain, slow speech, memory difficulties), particularly when he spent time with friends and others who knew him "before PD." At intake, Ethan was taking 75 mg of Zoloft daily, and reported that he felt this medication provide moderate relief from his depressive symptoms.

Ethan reported one past depressive episode in 2007 after he was diagnosed with an atrial fibrillation. Ethan stated that his mood was very low during this time, he had negligible interest in socializing or other activities, and considered suicide, although he did not make an attempt. This depressive episode lasted about 6 months, but was followed by a period of 6 months that Ethan described as "happy." However, Ethan stated that sadness, fatigue and disinterest returned in 2008, and had been present to some degree ever since. Ethan participated in biweekly, supportive psychotherapy for 3 years starting in 2007, and reported that he found this treatment moderately helpful. Ethan denied any other psychiatric history.

At baseline, Ethan scored a 22 on the HAM-D, a 19 on the BDI, and a 23 on the HAM-A, indicating moderate depressive and anxiety symptoms. Correspondingly, Ethan received a CGI score of 5, indicating "Markedly III" psychiatric status. Fay's baseline score on the CDS was a 44, indicating a high degree of caregiver burden. Ethan scored a 22 on the MoCA, suggesting that he is experiencing mild cognitive impairment (MCI) (Nasreddine et al., 2005).

### Diagnoses

Axis I: Major Depression, Moderate, Recurrent (296.32)

Axis II: None

Axis III: Parkinson's Disease (ICD-9 Code 332) Axis IV: GAF Score: 52

# **5C. ETHAN'S CASE FORMULATION**

Based on the intake information and the guiding conception of this treatment approach, I conceptualized Ethan's symptoms of depression as originating from significant functional impairment resulting from PD and other medical conditions (e.g. a cataract, putative celiac disease, lingering musculoskeletal injuries), which led to disengagement with rewarding activities (e.g. tennis, socializing, singing), negative predictions about what activity engagement

would be like, and significant guilt about the impact of his functional impairment on others. Ethan endorsed negative automatic thoughts like "I am useless," "if I go to the exercise class, it will be unsafe," "if I go visit with friends, I will feel tired and unsocial, and I will feel embarrassed," which I believe were derived from conditional assumptions and automatic beliefs such as "if I cannot function at the level that I used to, I have no value" and "I cannot navigate the world anymore," and the core belief "I am worthless." I conceptualized Ethan's core belief that he is "worthless" as partly mediated by Ethan's collectivist cultural background, and specifically, the value placed on making material contributions to the great good collectivist cultures. Ethan's depression was also maintained through a self-reinforcing cycle of negative evaluation of his functional abilities and further withdrawal from rewarding activities.

In addition, I saw Ethan's caregiver, Fay, as contributing to Ethan's poor sense of self-efficacy, low self-worth and guilt by overemphasizing his deficits relative to his strengths, frequently communicating her frustration with his functional impairment, and positively reinforcing Ethan's inactivity by taking charge of many activities Ethan was capable of performing on his own (e.g. managing his PD medication).

## 6C. ETHAN'S COURSE OF TREATMENT

#### Module 1

At the outset of our first session, Ethan rated his mood over the previous week as a 5/10 (10=best), citing chronic pain, fatigue, and hopelessness about the future as primary contributors to his low mood. Ethan asked that we review the symptoms of depression listed in Module 1, and endorsed low mood, lack of concentration, constant worry, increased appetite, severe fatigue, poor sleep and worthlessness.

Ethan stated that he had been feeling sad about not being able to participate in his favorite activities any longer, and expressed doubt that this situation could change. I tried to validate Ethan's feelings of loss, but emphasized that in the course of the program, we would work together to identify activities that Ethan found meaningful and enjoyable, and were also feasible given his current physical and cognitive constraints. Ethan had attended a house party attended by old friends in the last week, during which he had felt "very bad" that he could not play tennis, sing or do many of the other activities that they used to share due to his PD symptoms and other physical ailments, and felt he had been withdrawn and unsociable as a result of these feelings. I emphasized the importance of modifying activities to accommodate changing physical and cognitive capacities, and mentioned that I had found patients were often pleasantly surprised at their enjoyment of modified activities. I also proposed that we look for new activities that were feasible for Ethan, and posited that involvement in meaningful activities, regardless of the details, was likely to improve his mood. Ethan responded positively to the idea that activities influenced mood: he offered examples of engrossing activities that helped him "forget about" physical pain and low mood (e.g. mah-jongg), and described several instances in which he had "not felt like participating" in such activities beforehand, but found them highly rewarding once he was engaged.

I framed the above scenario as a perfect illustration of the concept of 'Acting In Accordance With Goals And Not Feelings', and proposed that depression often involves a disinterest in or negative expectations about activity engagement, and that one of the most important means of overcoming depression involved pushing through these feelings by engaging in the activity in spite of them, and allowing the rewarding nature of the activity to improve mood.

Ethan expressed concern about the idea of "forcing yourself to do things," and describing a friend of his who had pushed himself to do strenuous exercises despite being physically frail, and ultimately suffered a serious fall. I emphasize that the point of the 'Acting In Accordance...' concept was not for the patient to ignore legitimate fear of a dangerous activity, but to help them overcome reluctance, lack of motivation that might be interfering with engagement in safe and meaningful activities.

Fay became involved in the conversation halfway through session, and described the same party Ethan had referred to earlier in the session, asserting that Ethan's engagement problems during the party had to do with his refusal to go to sleep at a reasonable time the night before. Ethan objected to this characterization, stating that he had little control of his sleep schedule. Fay maintained that once he was in bed, he had no trouble falling asleep, but that he often chose to spend time working on his computer late into the night, and ended up missing beneficial activities because he slept too late, or was unable to enjoy activities due to fatigue resulting from poor sleep.

For homework, I asked Ethan to read Module 2, and write down activities that were enjoyable or meaningful, either currently or in the past, as a starting point for the development of an Activity Schedule. Ethan agreed tentatively, and when I asked him how he felt about the homework assignment, he said he had noticed the Exercise Goals category in Module 1, and had significant fears about rejoining an exercise class he had participated enjoyed in the past. I tried to validate his concerns and refocus on the process of brainstorming possible activities, stating that evaluation of the feasibility of particular activities could be saved for the next session.

#### Module 2

At the outset of our second session, Ethan reported his mood rating over the last week as a 6/10 (10=best), with a high of "8 or 9." However, Fay disputed Ethan's report, saying that she felt he had been persistently irritable and "out of sorts." Ethan seemed embarrassed by this, allowed that he had been irritable at times, and fell silent as Fay speculated on a variety of reasons for this behavior, all of which she characterized as resulting from Ethan's "irrationality" or poor decision- making. I was taken aback by the vehemence of Fay's criticism, and did not address it directly. Instead, I shifted our attention to a review of the previous week's homework.

In reviewing the list of current and past pleasurable activities Ethan had come up with, it became clear that his physical limitations, PD-related and otherwise, posed significant barriers to activity engagement: he had a cataract that compromised his vision and made it difficult for him to drive, he reported being in almost constant pain from what he believed to be PD-related constipation, he had a torn rotator cuff that had been surgically repaired, but still caused Ethan

pain and limited his movement, he had been losing strength and balance according to his neurologist, and his tremors were significant enough to make working on his computer, one of Ethan's favorite pastimes, arduous and frustrating. Ethan's most meaningful current activities were playing mah-jongg with friends once weekly, evening get-togethers with Fay and other couples roughly once every two weeks, and working on his computer. The latter activity took up a great deal of Ethan's time, and was characterized as mindless and unhealthy by Fay. Ethan said he spent his time on the computer addressing problems (e.g. diagnosing bugs) or doing chores (e.g. monitoring finances), and said that these activities were important to him because they helped him feel "useful."

After Ethan and I had discussed his most significant current and past activities, we worked to finalize the treatment goals discussed in our first session. In addition to improving his mood, Ethan set goals to increase his participation in exercise and social activities, and shift his sleep schedule earlier so he could be more active during the day.

In discussing these goals further, it became clear that Ethan had been involved in an exercise class in his community until two years prior, but had stopped attending the class when it ended and never returned. Fay felt that Ethan should return to this class, but Ethan presented a number of concerns with this plan. First, he worried that his poor balance and strength might prevent him from participating in the exercise class. Ethan also expressed fear that the class might not be safe, and mentioned that another group member had fallen at the class about a year earlier. Ethan further reported that when he stopped attending the group, class leaders and others had encouraged him to return, but he had not returned their calls, and felt embarrassed to face them again. Fay refuted Ethan's concerns in an irritated tone, stating that the class was designed to accommodate people with a range of physical limitations and that Ethan should not be worried that he would be unable to benefit from it, that the fall suffered by a class member had happened in the parking lot, not in the class. In addition, Fay stated that Ethan "had no reason to be worried" about facing class members and leaders again because they were unlikely to remember his failure to return their calls. Ethan had little response to Fay's points, and asked me for my opinion. Seeing Fay's points as potentially useful counterevidence for Ethan's negative prediction, I introduced the Thought Log as a means of documenting negative thoughts, along with associated situations and emotion, with the ultimate goal of assessing the validity and usefulness of these thoughts. Ethan and Fay responded with bewilderment, and I realized that in an effort to provide the rationale for completing the Thought Log, I had presented too much information too quickly. I apologized, and backtracked by asking Ethan to document thoughts during the coming week that were associated with negative feelings or behaviors with Fay's assistance.

In the interest of helping Ethan and Fay become accustomed to the process of translating treatment goals into Daily and Weekly Goals, I asked Ethan to pick one step that they could take in the direction of assessing whether participation in the exercise class would be feasible. Ethan committed to calling the community center where the class was held to confirm the class schedule.

In reflecting on this session, the critical tone with which Fay delivered her refutation of Ethan's concerns about the exercise class stood out to me, particularly in light of her similarly critical evaluation of Ethan's difficulty engaging in the party at our previous session. I thought that the content of Fay's contributions, if accurate, had the potential to be very useful in addressing Ethan's negative thoughts, but thus far, Ethan had responded to her by shutting down, and I was alerted to the possibility that relational difficulties between Ethan and Fay might become a barrier to treatment progress.

#### Module 3

At the beginning of our third session, Ethan reported that his mood over the last week had been a 5/10 (10=best). Ethan had confirmed the schedule of the exercise class, but forgotten to utilize the Thought Log or read Module 3. Ethan had played his weekly mah-jongg game with friends, and had spent an evening socializing with Fay and several other couples. Ethan had enjoyed his mah-jongg game, but was disappointed that he had lost energy over the course of the 6-hour game, and worried that other players became frustrated with his slow playing pace. In addition, Ethan had been very hesitant to participate in the evening out with friends due to fatigue, tremors, and acute abdominal pain. In the early part of the evening, Ethan felt embarrassed about his motor symptoms and had difficulty engaging in conversation, but had gradually grown more comfortable, and ultimately reported having a good time. I praised Ethan for his willingness to attend the event despite his feelings, and highlighted the discrepancy between his anticipated and actual enjoyment of the evening. I emphasized that paying attention to instances in which he underestimated the value or enjoyment of various activities would be useful in generating evidence to support "Acting In Accordance..." in the future, and might also help us identify activities to add to his Activity Schedule.

Since Ethan had not completed his Thought Log homework or read Module 3, I decided to use negative thoughts related to Ethan's mah-jongg game and evening out with friends to generate Thought Log entries and explore the concept of Cognitive Distortions in session. Ethan, with significant assistance from Fay, was able to create several Thought Log entries, and recognized the influence of his thoughts and behaviors on his mood by comparing these aspects of his experience at several different points over the course of the social event from the previous week. Ethan had difficulty grasping Cognitive Distortions as abstract categories, but was able to come up with examples of the 'Fortunetelling' distortion related to his perception of his inability to cope with social situations, exercise class, and coping with PD.

Fay expressed concern that Ethan would not be able to attend the exercise class unless he made a concerted effort to go to bed and wake up earlier. Ethan said this was necessary, and felt he could wake up earlier if he needed to. Fay angrily described several recent instances in which he had good reason to get up early, but had not done so. Ethan said that he had missed these activities because he was "slow to get ready," not because of his sleep schedule. Fay responded that he should adjust his sleep schedule in order to account for how long it takes him to get ready. Ethan acknowledge that this was a fair point, and asked me what we should do about his sleep. Hoping to create space for Ethan's perspective, I asked him to describe his view of the pros and cons of shifting his sleep schedule. Ethan agreed that his sleep patterns caused him to

miss out on activities, but that staying up to work on his computer gave him a sense of accomplishment, and helped him "forget about" his pain and PD symptoms.

Fay stated that she felt Ethan had been procrastinating on his program homework, as he had put off reading Module 3 and prioritized other activities. Ethan agreed with this assessment, but also stated that pain, physical slowness, and difficulty with his vision contributed to his difficulty in completing homework assignments. Fay said: "I can remind him, but I don't want to be a drill sergeant." Ethan stated that he had hoped to type up the homework on his computer, but had misplaced my e-mail detailing his homework assignment and could not find the Thought Log.

Next, we focused on scheduling Ethan's attendance at the exercise class discussed in previous sessions. Ethan continued to endorse the same reservations about attending the class he had mentioned in our first session, but when we discussed the discrepancy between his predicted and actual enjoyment of his subsequent evening out with friends, he agreed to give the class a try the next week. In addition, Ethan, Fay and I discussed other activities that might be added to Ethan's schedule based on our earlier review of past and current activities that Ethan enjoyed. Ethan was open to increasing activity in general, but Fay stated that she thought scheduling new activities, particularly social activities, would be difficult given their friends' limited availability and Ethan's difficulty in "getting himself together" for social events. Fay mentioned that the party discussed in the first session was the last time they had tried adding a new activity to Ethan's schedule, and it had been "a disaster" for Ethan. Based on Fay's tone, I surmised that Ethan's lack of engagement had been a source of embarrassment for her, which led me to wonder whether Fay had her own negative predictions about Ethan's activity engagement. I considered addressing this hypothesis with Fay in the moment, but wanted to focus on establishing the homework assignment for the next week.

In addition to attending the exercise class, reading Module 4, and making at least one Thought Log entry, Ethan agreed to begin the process of shifting his sleep schedule by eliminating his afternoon naps on two days in the next week.

#### Module 4

Ethan reported his mood over the previous week as a 5/10 (10 = best) at the outset of our fourth session, although it became clear that he had experienced periods of very low mood related to conflict with Fay over his time management and sleep schedule, and discouragement about his physical and cognitive limitations. A large portion of the session focused on evaluating Ethan's negative thought that his physical limitations prevented him from being "useful" to others.

Ethan reported that he had not attended the exercise class because he had overslept. Ethan explained that he had felt obligated to work on a computer problem the night before the class, had worked to resolve the issue until 3 AM, and been too tired to go to class. \*\*\*\*This admission led to an argument between Ethan and Fay in which Fay criticized Ethan's time management and Ethan maintained that his use of use was valuable. Ethan also had not completed his Thought Log assignment, so I decided to try to help him develop a Thought Log

entry based on his thought that he was "useless" when we practiced cognitive restructuring later in the session. Ethan reported that he had been unable to eliminate afternoon naps over the past week due to the sleep deficit he had incurred in trying to resolve the computer issue, but agreed to try again the following week.

Ethan and Fay had both read through Module 4, and Ethan had several questions about the cognitive restructuring process. In reviewing examples of cognitive restructuring in Module 4. Ethan had difficulty understanding how a negative thought could be revised based on evidence, and struggled to evaluate the strength of different pieces of evidence, while Fay demonstrated strong command of the "Evidence For And Against" approach. We discussed Ethan's concerns about being "useless" to others in an attempt to make the cognitive restructuring process more concrete for Ethan. Ethan defined his negative thought as: "I'm no use to anyone anymore," and that it was associated with feelings of sadness and worthlessness... Ethan struggled to gather evidence against the thought, but with Fay's help, Ethan recognized contributions he makes to their household (e.g. keeping track of bills, solving computer and telephone problems). However, Ethan said these capacities did not constitute "usefulness to him," stating that he was much more useful when he was the family's primary provider. I asked him if he felt that his retired friends were currently "useful," and he said he did, citing the charities, hobbies and community work they were involved in. I asked what he would need to do in order to be sufficiently productive, and he mentioned being able to carry groceries, mow the lawn, drive long distances, and do other chores around the house. I stated that I respected his right to define his own values, but wondered whether there was an element of the cognitive distortion "Unfair Comparisons" in his thinking, since it seemed like he was evaluating his productivity negatively in comparison to a younger, PD-free version of himself, and other friends who were without PD or other significant medical ailments, and when he did compare himself to more functionally limited friends, he showed a deference for their limitations that he refused to show himself. Ethan struggled with the idea that he might be evaluating himself in a biased way, repeating that he simply "felt useless." The discussion ended with Ethan recognizing that different definitions of "useful" were possible, but remaining unconvinced that his assessment of himself was biased.

Ethan's homework assignment was to try again to attend his exercise class, read Module 5, eliminate two afternoon naps, and continue to add negative thoughts to his Thought Log. I had hoped to assign cognitive restructuring practice for homework, but based on the conceptual difficulties Ethan seemed to have in session with this topic, I decided against this.

#### Module 5

Ethan reported a mood rating of 6/10 (10=best) for the week preceding our fifth session. He continued to endorse significant abdominal pain related to constipation, as well as ongoing frustration with his physical and cognitive abilities. Ethan had attended the exercise class, and contrary to his expectations, he had been welcomed back by class members and leaders. He had found the exercises strenuous, but had not felt in danger of falling or otherwise injuring himself.

He reported feeling very positive about his experience at the class, and emphasized that Fay's presence was very helpful to him.

Despite me doubts about Ethan's ability to benefit from the 'evidence for/against' technique, I felt obligated to maintain focus on this skill given its prominence in the program, and I was encouraged by the fact that Ethan had recognized that his negative expectations about the exercise class had been violated. We spent much of the session focusing on how to translate Ethan's experience at the exercise class into insight into 'evidence for/against' restructuring approach.

Ethan remained concerned that he would be injured in class, so we worked to define his negative thought around this issue. Ethan had trouble formulating in the thought in a way that made it amenable to evaluation, likely in part due to his struggles with English and with abstract thinking, but with assistance from Fay and I, he defined his thought as: "If I go to the exercise class, I will get injured." In support of this thought, Ethan stated that a friend had been injured at the class, and that another class member had fallen several years ago. Fay angrily refuted this evidence, saying that the first individual was injured as a result of exercising too intensely, and not because of any problem with the class itself, and that class leaders were very careful about keeping people safe. In addition, she said that the class member who had fallen had done so in the parking lot, not in class. Ethan agreed with Fay's feedback and added additional counterevidence, stating that the class instructors had told him that he looked in "good shape," and that some other class members were more physically limited than he was, but did not seem at risk of injury. I saw his spontaneous generation of effective counterevidence as an advance in Ethan's understanding of the 'evidence for/against' technique. At several points, Ethan shifted his attention to other negative thoughts or feelings related to the exercise class or his physical functioning in general, and Fay expressed frustration with Ethan's difficulty staying on task.

Ethan had eliminated an afternoon nap one day in the past week, and had gone to bed several hours earlier than usual one night. Ethan reported this information apologetically, but I took pains to praise his incremental progress, and reminded him that adjusting his sleep would be a gradual process.

Since Ethan had shown better understanding of the 'evidence for/against' technique, I asked him to focus on his other primary worry about the exercise class ("I will feel embarrassed to see the class members and leaders after being away from the class for so long"), and evaluate the evidence for and against this thought for homework using the Questioning Automatic Thoughts (QAT) worksheet in Module 5. In addition, I asked him to continue adding thoughts to his Thought Log.

#### Module 6

Ethan rated his mood as a 5/10 (10 = best) over the previous week. Again, he mentioned feeling sad in situations in which he felt his physical capacities were limiting him, in particularly a concert that he had not attended due to leg pain. We discussed whether the pain might be a result of increased exercise, but this seemed unlikely given the timing of the increase in pain. On

the positive side, Ethan had watched movies with Fay and friends the previous Friday evening despite being in pain, and had "forgotten" his discomfort and enjoyed himself thoroughly.

Ethan had attended the exercise class again, and reported a positive experience. Fay said the class instructor had told her that no one had been injured in class, as Ethan had believed, highlighting Ethan's mistaken memory in a cutting tone. I framed this information gathering as a good way to add to the evidence we had collected relevant to Ethan's prediction. However, Ethan became more subdued after this exchange, and I worried that the hostile delivery of the message had obscured its value.

Ethan had avoided naps the previous week, but had stayed up late several nights working on filing his taxes, and been fatigued the day after. I praised Ethan's completion of the homework assignment, and suggested that we add to Ethan's sleep-related homework assignments for next week. In attempting to apply the QAT worksheet to the thought "I will feel embarrassed to see the class members and leaders after being away from the class for so long," Ethan had used evidence that related to his fear of falling and becoming injured, explaining that this was a "bigger fear" than the assigned negative thought, which seemed like a non sequitur to me. Ethan then had significant trouble identifying relevant pieces of evidence when we tried to apply "evidence for/against" to the assigned thought in session, which surprised me given his relative success in identifying pertinent evidence in the last session.

Ethan had read through the Module over the past week, but remembered little of the content.

I decided to focus on the 'behavioral experiment' strategy, since I felt Ethan's experience at the exercise class could be framed as an effective behavioral experiment that helped generate new evidence relating to his negative predictions about the class. Interestingly, Ethan did a good job recognizing the specific pieces of evidence his attendance at the class had added. Ethan struggled to apply the concept of 'cost/benefit analysis' concept to a thought, and seemed stuck on the economic sense of the term. We agreed to revisit this concept at the next session.

For homework, we agreed that Ethan would read Module 7, continue to attend the exercise class, and complete an Extended QAT worksheet on a negative thought of his choice. In addition to eliminating afternoon naps, he also agreed to observe a 12 AM bedtime each night in the coming week.

#### Module 7

At our seventh session, Ethan rated his mood over the previous week as a 6-7/10 (10=best). He said he had been feeling more "assertive" and "confident" in the past week as a result of our analysis of his negative thoughts. Fay mentioned that Ethan had reminded Fay to go to the exercise class when she had forgotten, and said that he seems more relaxed and comfortable during the class, which she characterized as a "big improvement."

Ethan had struggled to go to sleep at our agreed upon time of 12 AM over the last week, and had stayed up "all night" on two nights finishing his taxes and troubleshooting two urgent

computer problems. Ethan said he "needed" to go to bed earlier this coming week, since he had noticed a significant reduction in energy and mental acuity after losing so much sleep. Ethan had been confused about the homework assignment, and had not completed the Extended QAT worksheet on a new negative thought as assigned, so I focused our practice of the supplementary restructuring techniques on a thought we had discussed the previous session: "I will feel embarrassed to see the class members and leaders after being away from the class for so long." Ethan said that finishing his taxes had prevented him from reading through Module 7 or listening to the associated relaxation recordings, but Fay disagreed, stating that Ethan had wasted significant time watching sports or engaged in unnecessary computer activities. She sounded quite upset, and, not wanting to divert focus from the session agenda, I offered to discuss her thoughts at a separate caregiver session, which she declined.

Ethan's belief in his "I will feel embarrassed..." negative thought had reduced significantly since he had begun regular attendance at the exercise class, and he had difficulty approaching the practice session as if he still believed the thought. Nevertheless, Ethan showed improved understanding of several supplementary restructuring techniques over the course of the session, particularly the 'best/worst/most likely' strategy for restructuring negative predictions. Ethan also expressed interest in the 'cost/benefit analysis' strategy, and although it took time for him to understand the idea that thoughts could have costs and benefits, once he did, he was able to recognize costs of his negative thinking, e.g. that negative predictions about activities can interfere with positive experiences,.

Since Ethan had not read through Module 7 for homework, we agreed that he would read both Modules 7 and 8 and listen to the relaxation recordings included with Module 7 prior to our next session. I decided that recent homework assignments had been too ambitious, and did not assign further homework.

#### Module 8

At the outset of our eighth session, Ethan rated his mood over the past week as a 7/10 (10 = best). He said he had been feeling more energetic, and noticed growing confidence at exercise class, but had been frustrated by increases in abdominal pain.

Ethan had read Modules 7 and 8, but had not been able to listen to the relaxation recordings from Module 7 due to a computer problem. Ethan and I spent 10 to 15 minutes of session time trying to diagnose the problem, and finally succeeded in getting the recordings to play. Since Ethan had not listened to the relaxation recordings from Module 7, and since sleep difficulties continued to be a significant issue for him, I initially focused on the Sleep Hygiene strategies covered in Module 8. An assessment of Ethan's adherence to the listed sleep hygiene principles indicated he had little to improve on, Ethan reported minimal difficulty falling asleep once he got in bed.

Ethan explained his late-night computer use by saying that it was one of the few activities engrossing enough to take his mind off his abdominal pain and negative thoughts, and that he often lost track of time, and ended up staying up later than intended. We revisited the pros and cons of adjusting his sleep schedule, and he concluded that he wanted to get to bed earlier, even

if it meant giving up time on his computer at night. Ethan agreed to refrain from napping on Monday, Wednesday and Friday, and to go to bed by 11 PM on Monday, Tuesday and Wednesday of the following week.

Ethan then brought up a situation that he saw as relevant to the worry control techniques described in Module 8: he had recently received a call from a good friend, and had been putting off returning the call because he worried that his friend would be disappointed or feel uncomfortable that Ethan had "nothing positive to report" about his health. We applied the 'worst case/best case/most likely' strategy to this thought, and in reviewing past conversations with this friend, could find no evidence supporting the likelihood of the 'worst case' scenario, which Ethan defined as his friend ignoring or pitying him. Fay was helpful in reminding Ethan of past instances in which he had called his friend, and offered her input with a lighter touch than she had in previous sessions. Ethan decided that the 'most likely' outcome of the call was that he would feel uncomfortable sharing his difficulties with his friend, but that ultimately the conversation would lift his spirits, and provide him a refreshing perspective on his situation. At the end of the discussion, Ethan resolved to give his friend a call during the next week.

As additional homework, I asked Ethan to read Module 9, listen to the relaxation recordings associated with Module 7, and continue his exercise class attendance.

## Module 9

At the beginning of our ninth session, Ethan rated his mood over the past week as a 7/10 (10= best). Ethan said he felt his activity engagement had left him "exhausted." He reported exercising twice, playing mah-jongg, spending two evenings socializing with friends, and had also stayed up late on several nights.

Ethan had listened to the relaxation recordings, but had trouble engaging with the guided visualizations, stating that he found himself unable to "picture images in his head." Thus, we agreed he would focus on the Complete Natural Breathing and Progressive Muscle Relaxation exercises for the following week's homework. Ethan had tried both, and had found Complete Natural Breathing to be helpful in distracting himself from pain. Ethan had met his goal of going to go to bed around 11 PM on two of the three nights we had agreed on at the previous session, but had stayed up late trying to fix a printer problem on the third night. Ethan said that his commitment to go to be at 11 had crossed his mind that night, but that he had gotten too "excited" about the fixing the printer. It became clear that Ethan's excitement was directly related to his negative thought that he was "useless" mentioned in session 4: Ethan saw his usefulness as so limited that he could not pass up any opportunity to be useful. The degree of value Ethan placed on usefulness was striking to me, but I recognized it as consistent with my understanding of the worldview of members of a collectivist culture. It seemed likely there were important negative thoughts associated with the idea of usefulness, but I wanted time to prepare to approach these thoughts in a culturally sensitive way, so I decided to table the topic for the moment.

Ethan had exercised both Monday and Wednesday, and played mah-jongg on Tuesday, which I took care to praise. However, Ethan said he felt exhausted each of these days, and

worried that he was "doing too much." Since exercise class scheduled was fixed, we discussed whether he could play mah-jongg for a shorter time, or at a time later in the week, so that he would not have so much activity concentrated early in the week. However, due to the constraints of other players' schedules and the nature of the game, Ethan decided these were not viable options.

For the rest of the session, we discussed the central topic of Module 9, 'simplified cognitive restructuring.' I attempted to engage Ethan in a review of the important negative automatic thoughts we had restructured in treatment to date, but he focused on his belief that he was "useless," which had not been fully reframed previously, and due to my sense that this thought was of paramount importance, I decided to spend time discussing this thought first.

During this discussion, Fay provided counterevidence for this thought in a way that emphasized her being "right," and I became concerned that her delivery might make it harder for Ethan to digest and incorporate the Fay valid evidence. I emphasized the importance of Ethan's perspective on the evidence Fay presented, while validating the relevance of the information Fay was bringing to the table. However, it seemed that my attempt came too late, as Ethan seemed shut down after this point, and deferred to my opinion or Fay's opinion on the relative importance of various pieces of evidence. I was conflicted about whether to continue with the 'evidence for/against' approach, since from my perspective, there was convincing counterevidence for this thought, but I did not want to be dismissive of his definition of usefulness, and I worried that continuing to use this approach ran the risk of Fay continuing to attack Ethan, so I suggested that we try to apply a 'cost/benefit analysis' approach to the thought. Ethan initially had trouble shifting his focus away from evaluating the validity of the belief, but ultimately was able to consider its impact on his mood, which he recognized as decidedly negative. In retrospect, I think I became distracted by the interpersonal dynamics between Ethan and Fay, and we ultimately focused on the "useless" thought for much of the session, and never returned to the topic of 'simplified cognitive restructuring.'

In addition to reading Module 10 and continuing to pursue his sleep goals, I asked Ethan and Fay to collaborate on filling out an Extended QAT worksheet on his thought "I am useless" for homework. I had some misgivings about asking them to collaborate on this homework, given their interpersonal difficulties in session, but I decided to give them the benefit of the doubt.

## Module 10

At the outset of our 10<sup>th</sup> session, Ethan rated his mood for the past week as a 5/10 (10 = best). He said his abdominal pain had been significantly worse, and had learned that he would need a surgical procedure to correct an eye problem, both of which had negatively impacted his mood. However, he said that considering these challenges, he felt he had done a good job maintaining a positive outlook and engaging in planned activities. Additionally, although he had lost in mah-jongg, this had not lowered his mood as it had in the past. When I asked why he thought the loss had not bothered him, he said he had "just thought positive," but had a hard time explaining further. Ethan had attended exercise class twice, refrained from napping during the

day, and gone to bed earlier than usual, although there were two nights when he stayed up well past 2 AM working to resolve computer problems.

As I had feared, Ethan and Fay had struggled to complete the Extended QAT worksheet together. They had made an effort to complete the worksheet early in the week, but this had ended in an argument, and they had not made further attempts. The argument seemed to have developed out of Fay's frustration with Ethan over his inability to do 'evidence for/against' technique the "right way" from her perspective, and Ethan's resentment of her criticism. Since it seemed that the 'evidence for/against' technique leant itself to conflict between Ethan and Fay, and it was our last formal session, I felt it was important to focus on one of the additional cognitive restructuring approaches as an alternative. After reviewing the main concepts and skills from the program described in Module 10, we spent the rest of the session focusing on the 'cost/benefit analysis' cognitive restructuring technique, which I Ethan had responded positively already, would relatively straightforward, and seemed less conducive to conflict than "evidence for/against.' In discussing 'cost/benefit analysis' in session, Ethan again struggled with the idea of a thought having a "cost" or "benefit." Fay suggested that Ethan's thoughts played a role in their conflict earlier that week, and I thought this situation might be a fruitful example, and framed Fay's contribution as "one cost of a thought might be that it influences your behavior in a way that interferes with relationships." Ethan stated that he had been quite upset after their argument, and recognized this distress as a 'cost' directly related to thoughts about Fay and about himself stemming from their interaction.

For homework, I asked Ethan and Fay to do a 'cost/benefit analysis' of the thought "I am useless." Feeling that addressing the interpersonal problems between Ethan and Fay directly with Fay was crucial to the success of Ethan's treatment, I asked Fay if she would be willing to have a private conversation with me about her role in helping Ethan benefit from the program after its conclusion. Fay agreed, and we set up our call in addition to Ethan's first booster session.

## Fay, Bob's Caregiver, and Booster Session 1

In my conversation with Fay, I first tried to validate her frustration with Ethan's resistance to taking steps to improve his health and functioning (e.g., altering his sleep schedule), expressed my appreciation for her consistent involvement in our sessions, and complimented her understanding of program concepts. I also shared my hypothesis that Ethan sometimes experienced her feedback as critical rather than constructive, explained the observations that had led me to this hypothesis, and emphasized that if my hypothesis were correct, there might be ways for her to alter her approach to providing feedback that would help Ethan incorporate her input more effectively, which would in turn reduce her frustration with him and promote a more positive relationship. Initially, Fay was defensive, emphasized Ethan's role in their conflicts, and defended her style of delivering feedback. I suggested that we look at her approach to Ethan from a 'cost/benefit analysis' perspective. We agreed that it was useful for her to provide Ethan with input in general, but the primary cost to Fay's current approach was that both she and Ethan were frequently arguing, which distressed them both and interfered with engagement in positive activities (e.g. socializing with friends). I asked if Fay was willing to try an experiment to test whether there might be a way to keep the benefits of offering Ethan feedback while avoiding

conflict. Fay was incredulous, but admitted that she did not usually think about how she delivered feedback to Ethan, and could not be sure whether another approach might be more effective. I proposed several possible techniques Fay might use as part of an alternative approach (e.g. think about what Ethan's perspective might be before addressing a grievance, start her feedback with compliments or validating remarks to communicate care and respect). Fay then described a conflict that had arisen in a social setting and had created particular tension, and she and I discussed how she and Ethan might handle a similar situation in the future. Over the course of the conversation, Fay grew more open to the idea that she might have a role in her conflict with Ethan.

Ethan, Fay and I spent the booster session reviewing the situation Fay had mentioned in our private session, and working on a plan to resolve conflict in similar situations in the future. In this situation, Ethan to become offended by a comment Fay had made. He had not expressed his feelings in the moment and had withdrawn from others at the party, but later expressed anger with Fay for not apologizing for her comment and for not acknowledging his distress after this incident. Fay had refuted his interpretation of her comment, and felt Ethan's criticism was unfair and "irrational." One important negative thought derived from this incident was that he "did not matter" to Fay. During the discussion of this incident, both Fay and Ethan seemed to be embodying their attitudes and behaviors in that moment, so I used their interactions in session as a way to review for Fay, and introduce to Ethan, the effective communication principles I had discussed with Fay, which I had loosely adapted from the 'Interpersonal Effectiveness' skills module of Dialectical Behavioral Therapy (Linehan, 1993). We devised a plan for preventing similar conflict at future social events in which Ethan would use an agreed-upon signal to indicate to Fay if he was feeling upset and needed to touch base with her, and they would then find a private location to discuss his feelings. I had hoped to address the 'cost/benefit analysis' homework from the previous session as well, but felt that our discussion about conflict resolution should be a top priority, and agreeing on a workable plan ultimately took the full session time.

For homework, I asked Fay and Ethan to try to put their plan into action if the opportunity arose, and to schedule a positive, one-on-one activity together. We scheduled our next booster session for two weeks later.

#### **Booster Session 2**

At our second booster session, Fay and Ethan reported that they had not had an opportunity to put their conflict resolution plan in action, as many of their friends had been on summer vacation, limiting social engagements. They had decided to take a walk together as their positive joint activity, but had ended it early because Ethan had felt he was "too slow" for Fay. Ethan reported that his mood over the last two weeks had been "positive" despite ongoing uncertainty about the source of his steadily increasing abdominal pain. He attributed his mood in part to the recent birth of his granddaughter. However, Ethan also said it was very difficult for him to be unable to help his daughter and her husband as much as other family members following the child's birth due to his physical condition.

We revisited Ethan's 'cost/benefit analysis' of his negative thought "I am useless," which Ethan and Fay had completed prior to our last session. Fay occasionally veered into 'evidence for/against' territory by pointing out instances in which Ethan was useful (e.g. holding the door, carrying a bag), but I worked hard to keep the focus on the consequences of Ethan's thought. Fay then expressed the concern she and other family members had felt at seeing Ethan withdrawn and morose during their visit with their granddaughter. This information seemed to take Ethan by surprise. He said he had not realized that his mood could affect those around him in such a significant way, and that this was a very significant negative consequence of his negative thoughts.

Much of the remainder of the session was spent discussing Ethan's and Fay's experience using the principles of effective communication we had discussed at our last session. Fay said she had used these principles several times, and reported being surprised that Ethan responded more openly to her feedback when she opened her statement with a compliment or validation of his perspective. Ethan said he had not remembered to use the principles as much as Fay, but expressed his appreciation for the effort Fay had been making to do so, and said he had experienced Fay as "less angry" in recent weeks, which had made it easier for them to talk. I praised their willingness to change their interaction style, and to discussing their experience of this process with each other and with me.

## Discussion of Ethan and Fay's Case

## Working with a Hostile Caregiver

Several aspects of Ethan's treatment warrant further discussion. I will focus on Fay's role in treatment, but also discuss the role of cognitive deficits, communication difficulties, and cultural background in treatment. My hope is that these discussions will yield insights that may be valuable to other clinicians working with similar cases.

Fay's participation in Ethan's treatment was both a great blessing and an enormous challenge. Fay was present for most of our sessions, read the modules religiously, had a stronger grasp of the program concepts than Ethan, and helped translate when I had difficulty understanding Ethan. In all these ways, she was an invaluable asset to Ethan's treatment. However, she frequently delivered her perspective on Ethan's difficulties in a harsh, critical manner, and frequently implied or stated that Ethan's difficulties were a result of his laziness, obstinacy or irrationality. I saw my task as maximizing Fay's positive contributions while limiting her negative impact on Ethan's treatment. In the following pages, I describe a representative example of Fay's impact on treatment. I then describe my efforts to accomplish the task stated above, including discussion of relevant contextual factors related to the treatment modality and my own identity as a clinician. Finally, I review the lessons learned from these efforts that I feel will be most useful to clinicians working with caregivers.

Throughout Ethan's treatment, Fay frequently presented very useful feedback in a manner that left Ethan feeling attacked, and, I hypothesize, limited his ability to incorporate the feedback or engage with program material. A particularly notable example of this scenario occurred in our second session as we discussed adding the exercise class to Ethan's Activity

Schedule. Ethan had voiced concerns about the exercise class: a) that he would be too physically compromised to benefit from the class, b) that he would fall and injure himself, as others class members had in the past, and c) that he would feel embarrassed to face the class leaders and other class members after having ignored their phone calls encouraging him to return to the class two years ago. Fay responded to each of these points with cogent and convincing counterevidence: in response to a), she stated that the class was designed to accommodate people with a wide range of physical abilities, and pointed out that there had been people in the class who were more physically limited than Ethan. In response to b), she stated that the class member who had been injured had fallen in the parking lot, not in the class itself, indicating that the class itself did not pose a danger, and added that the class leaders were well trained and attentive to class members' safety. In response to c), she said she thought it was unclear how many of the class members or leaders from two years ago would still be involved in the class, and that those who were would likely not remember the circumstances surrounding Ethan's failure to return to the class. However, the tone with which she delivered this evidence was caustic, and seemed to have the effect of shutting down Ethan's engagement in the discussion: when I asked him what he thought about the points Fay was bringing up, he said he "didn't know," and asked me what I thought about them.

This situation, and others like it, presented me with a dilemma as to whether to address the positive parts or the negative parts of Fay's contribution. On one hand, it seemed important to capitalize on the useful parts of Fay's feedback, and to do so quickly, since Ethan's difficulties with working memory often left a narrow window of opportunity for consolidating skill acquisition. In the example above, Ethan and Fay were engaged in an evaluation of Ethan's thought that anticipated the 'evidence for/against' cognitive restructuring technique, and I saw an opportunity to preview cognitive restructuring skills and introduce the importance of recording negative thoughts using the Thought Log. In addition, at this point in treatment, I did not know Fay or Ethan very well, this was the first instance in which Fay had expressed such pointed criticism, and given Ethan's clear cognitive and functional deficits, I saw Fay's participation as crucial to Ethan's treatment, and I was very concerned that I might alienate her if I suggested that her communication style was unproductive. On the other hand, Ethan's reaction to the criticism in Fay's delivery made it harder for him to process Fay's input or mine in these moments. In addition, I worried that by not addressing the hostility in Fay's message, I might be tacitly condoning her behavior, and that waiting to address this issue early on might make it more difficult to address later.

Early in treatment, my fear of alienating Fay held sway, and my solution to the dilemma described above was to focus on the productive parts of Fay's comments, and not directly address my concerns with Fay's critical delivery. However, as treatment continued, I realized that this interpersonal pattern was a pervasive part of the relationship between Ethan and Fay, and I began to worry that if not addressed, it might have a lasting impact on Ethan's ability to benefit from the program. The turning point in my thinking on the issue was the discussion of the conflict between Ethan and Fay resulting from their attempt to collaborate on the Extended QAT homework assignment in our 10th session. At this point, I became convinced that it was of paramount clinical importance to help Ethan and Fay improve their communication and strengthen their relationship.

For several reasons, my first step in addressing the conflict between Ethan and Fay would be to speak to Fay individually about my concerns. First, I wanted Fay to feel that I respected her perspective, and felt that setting aside time to speak with her individually was important in communicating this message. In addition, I worried that if Ethan were present during this discussion, Fay might not feel that she could be fully honest about her frustrations, and I also wanted to shield Ethan from Fay's criticism as much as possible. In addition, I planned to suggest to Fay that the harsh, critical way in which she delivered feedback to Ethan was counterproductive, and I worried that Ethan's presence during this discussion might make her feel embarrassed or ganged up on, and make her more likely to be defensive or resistant to my input. My conversation with Fay went as well as I could have hoped: she did vent a great deal of frustration with Ethan, and was initially defensive when I asked her to consider her role in their difficulties, but she also expressed respect for my opinion, and genuine interest in improving her relationship with Ethan. In an interesting parallel to Ethan's response to cognitive restructuring, Fay responded best to my input when I shifted her focus from justifying the validity of her frustration to a 'cost/benefit analysis' of the manner in which she expressed her frustration. She said she had not given much thought to the way she communicated with Ethan, but when I cited several interactions in which I felt Ethan had become disengaged or distant after she expressed herself in a way that seemed overly critical, and suggested that taking a different approach might help promote the changes she hoped to see in Ethan, Fay expressed openness to the possibility that he might respond differently to a softer approach. We reviewed a number of Interpersonal Effectiveness (Linehan, 1993) principles that I thought were particularly relevant to Fay (e.g. demonstrating care and respect for the other person's perspective even if you disagree with it, demonstrating willingness to compromise, rewarding incremental concessions to your agenda). Although Fay was doubtful they would be effective, she agreed that they were worth trying. I provided some examples of how she might apply these principles in communicating with Ethan, and in our next session, I noticed her implementing these principles.

The next step was to bring Ethan into the conversation at the next session, and in doing so, I felt it was important to keep several principles in mind. First, I introduced Ethan to the same Interpersonal Effectiveness principles I had presented to Fay, both because I did not want her to feel that she was the only one who needed to make an effort to adjust her communication style, and because I thought Ethan might benefit from using the same principles, although given Ethan's difficulties with abstraction and memory and the minimal session time we would be able to devote to these skills in the booster phase of treatment, my intent was for Fay to be the primary practitioner of these skills. Second, given Ethan's concreteness, I thought it would be useful for us to collaborate on a conflict resolution technique based on a recent instance, and the most readily available example involved the incident that Fay had brought up in our individual session, in which Ethan felt dismissed by Fay, and Fay felt inappropriately blamed for not perceiving Ethan's distress. It later became clear to me that practicing this strategy would be difficult for Ethan and Fay due to the unavailability of social engagement over the summer, and in retrospect, it likely would have been more useful to instead focus on techniques for managing conflict around ongoing issues between Ethan and Fay, e.g. his sleep schedule.

Based on our discussion in the second booster session and the exit interview, it seemed that Fay had been able to elaborate the Interpersonal Effectiveness principles we had discussed in

a number of very helpful ways. In the exit interview, Fay mentioned that since our last conversation, she had decided to experiment with monitoring Ethan's activities less closely and "give him more space," and had noticed that, much to her surprise, he had been largely successful in managing his medication regimen and other routine chores, the frequency of their arguments had dropped considerably, and Ethan seemed more self-confident. She also said that instead of imposing her perspective on Ethan's negative thoughts, which had been her habit in the past, she had begun to "put the ball in Ethan's court" by suggesting that he try to restructure his thought, and only offering her opinion when he asked for it. She reported that this approach had lead Ethan to more readily accept the input she had to offer, and had also pushed him to continue to develop his cognitive restructuring skills. In addition, she said that our discussion about her interactions with Ethan had helped her put herself in his shoes, and had recognized that some of her expectations of Ethan (e.g. how fast he could prepare for social events) were unreasonable. Ethan also stated that he felt his relationship with Fav had improved considerably since the end of the program, and that they were better able to work together to resolve issues, rather than arguing about or avoiding them. Overall, I was very pleased and impressed by the way Ethan and Fay had built upon the work we had done to improve their interactions at the end of the treatment.

In reviewing the lessons learned from my efforts to optimize Fay's participation in treatment, one of the most significant was that being willing to directly address problematic interpersonal dynamics between patient and caregiver can be crucially important to treatment success. In retrospect, I wish I had addressed this issue with Ethan and Fay sooner. Although the exit interview led me to believe that they benefited a great deal from the time we did spend working on their relationship difficulties, spending more time on this topic very likely would have increased Ethan's ability to benefit from the program, and made the experience of participating in the program more pleasant for both he and Fay. As mentioned above, I think my fear of alienating Fay played a primary role in my hesitance to address this issue early in treatment, as well as my sense of obligation to spend as much session time on the content of the TH-CBT program as possible. Physical, psychological and functional impairment are common amongst caregivers of PD patients and others with chronic medical illnesses (Martinez-Martin et al., 2005; Happe & Berger, 2002; Glueckauf, 2003). Thus, it is important for clinicians working with caregivers of patients in these populations to assess caregiver burden. This can be achieved through formal assessments, like the Caregiving Distress Scale (Cousins et al., 2002) that was used in Dr. Dobkin's research, and also by paying attention to interpersonal dynamics in session (if both are present), or by asking both patient and caregiver about the quality of their relationship.

In addition, in a skills-based treatment like the TH-CBT protocol with a patient who has significant cognitive and functional limitations, as Ethan did, I think it is particularly important to address interpersonal problems between the caregiver and the patient. If such issues are left unresolved, they may interfere with the caregiver's ability to support the patient's skill utilization, running the risk that much of the benefit of the program may be lost. It is hard to predict Ethan's progress in the program had the difficulties in his relationship with Fay been addressed earlier, but it did seem clear to me that once these issues were addressed, they were

able to work together much more effectively to apply program concepts and skills to Ethan's challenges.

Lastly, if making adjustments to the patient-caregiver relationship is likely to be driven by the caregiver, as was the case with Ethan and Fay, I think it is important for the clinician to clearly highlight the ways in which these changes may benefit the caregiver in order to make the their effort seem worth while, and not just "something else I have to do," as Fay initially described my proposal in our individual session. I think my focus on how changing her communication style with Ethan might help her get needs met (e.g. help Ethan benefit from the study and improve his mood, reduce Ethan's dependence on her, was very helpful in persuading Fay to give these suggestions a try.

# **Working With Cognitive Deficits**

Ethan's cognitive deficits also played a significant role in the course of our treatment, and a discussion of these deficits, their relationship to the treatment setting and protocol, and my efforts to cope with them, may be instructive to clinicians treating patients with similar difficulties. Based on Ethan's MoCA score, he would likely have been classified as having mild cognitive impairment (MCI) (Nasreddine et al., 2005), which is defined as "cognitive decline greater than expected for an individual's age and education level but that does not interfere notably with activities of daily life" (Gauthier et al., 2006), and applies to cognitive domains including memory, reasoning and language. MCI is twice as common in PD patients as in healthy age-matched controls (Aarsland et al., 2009; Foltynie et al., 2004), and is present in 27-50% of PD patients within 3-5 years following diagnosis (Williams-Gray et al., 2007; Janvin, Larsen, Aarsland & Hugdahl, 2006; Caviness et al., 2007). PD patients who demonstrate MCI show particular deficits in executive functioning, working memory, set shifting and reinforcement learning (Bowen, Kamienny, Burns & Yahr, 1975; Owen et al., 1992; Morris et al., 1988; Taylor & Saint-Cyr, 1995; Cools, Barker, Sehakian & Robbins, 2003; Kehagia, Cools, Barker & Robbins, 2009). Ethan showed particular deficits in short and long-term memory, abstract reasoning and learning, and these deficits created significant challenges in implementing treatment.

I experienced Ethan's memory as one of the poorest among all the patients I treated in the TH-GSH-dPD studies. He regularly forgot to do homework assignments despite my sending him reminder e-mails outlining the assignments in detail, and had significant difficulty retaining knowledge of program concepts from week to week. In addition, he often relied on Fay to remind him of names, dates, and the details of past events, and at times his memory issues became a point of contention between he and Fay, e.g. when he erroneously recalled an exercise class member injuring themselves during class. At the exit interview, when I asked him what program concepts or skills he found to be most useful, he had trouble coming up with anything other than "thinking positive," and required significant prompting before recalling the impact of applying 'cost/benefit analysis' to negative thoughts relating to his sense of uselessness, which I saw as one of the most important successes in his treatment. In addition, Ethan's working memory seemed to be poor, as evidenced by his tendency to change the subject to a tangentially or seemingly unrelated topic during session, and seemed unaware that he had taken the

conversation in another direction. In addition, Fay often complained of his forgetfulness and poor time management, particularly in the context of getting ready for social engagements. It is possible that avoidance, or miscommunication resulting from cultural differences or English being Ethan's second language, contributed to this pattern, but I think it is likely that Ethan's cognitive deficits were primarily responsible.

Ethan also showed significant difficulty with abstract reasoning and learning. The former was particularly evident in our work on cognitive restructuring, which I believe is the most conceptually demanding skill in the TH-CBT program. Ethan struggled to internalize the essential properties of cognitive distortions such that he could accurately identify the distortion at play in a novel example scenario. In addition, Ethan had great difficulty formulating negative thoughts in a way that made them amenable to evaluation (i.e. that made a statement about the world, self or future), often struggled to come up with salient pieces of evidence, and had trouble synthesizing the 'for' and 'against' evidence in order to come to a conclusion about the validity of a given negative thought, or generate alternative perspectives based on the evidence.

Ethan struggled to shift cognitive sets, and frequently perseverated on his initial understanding of a concept despite receiving feedback to the effect that his understanding needed adjustment. For example, when the 'cost/benefit analysis' skill was introduced, Ethan expressed familiarity with this term in an economic context, and had great difficulty applying the term to a psychological context, often seeking to connect our discussion of this skill to his financial status or some other economic topic. Ethan ultimately was able to develop an understanding of the 'cost/benefit analysis' skill as described in the program, but this required an unusual amount of support and guidance from Fay and myself.

Ethan's cognitive deficits had significant impact on treatment. First, they increased the importance of Fay's involvement in treatment, since her understanding of the material could help compensate for Ethan's comprehension difficulties, both in terms of practicing skills between sessions and maximizing Ethan's benefit from the program over the long term. As a result, I encouraged Fay's presence at as many of our phone sessions as possible, and felt more hesitant to risk alienating her by addressing her critical attitude towards Ethan. Once it became clear to me that the interpersonal difficulties between Ethan and Fay were significant and pervasive, finding a way for Ethan and Fay to communicate more effectively became a top priority, because I felt that Ethan's cognitive deficits would make it difficult for him to continue to engage with and benefit from program skills without significant assistance from Fay.

Additionally, Ethan's difficulties with abstract reasoning and learning ultimately led me to deemphasize 'evidence for/against' skill and focus our cognitive skill building on the 'cost/benefit analysis.' In retrospect, I wish I had made this shift in emphasis earlier in treatment, as I suspect that our session time would have been better spent on more tractable skills. I think I waited as long as I did because the program emphasizes 'evidence for/against' so much, because I have seen it become a very powerful tool for other patients, and because Ethan showed occasional flashes of comprehension that gave me false hope he would eventually be able to develop reliable facility with this skill.

There are several important lessons I took away from my experience managing Ethan's cognitive deficits that may be useful to clinicians working in a similar treatment modality with cognitively challenged patients. First, if the patient's cognitive deficits seem to be interfering with acquisition of a particular skill, it may be useful to search for a different skill that serves the same function (e.g. aids in cognitive restructuring) but makes fewer demands on the patient's cognitive capacities. Understanding the particular domains in which the patient shows cognitive deficits can help with this process. For example, since new learning and set shifting are particular challenges for PD patients, seeking to capitalize on previously learned skills, concepts or analogies may be useful in determining which skills to emphasize and how best to present these skills. In Ethan's case, although his set-shifting difficulties initially interfered with his integrating the 'cost/benefit analysis' skill, I hypothesize that his prior familiarity with this concept in an economic context was helpful in his long-term integration of this skill. When the 'cost/benefit analysis' skill was reintroduced in session. Ethan would often "retrace" his route of understanding from the economic sense of the term to its meaning in the context of the program, leading me to believe that his familiarity with the economic sense of the concept served as a useful foundation for understanding the CBT skill.

Secondly, promoting the caregiver's understanding of skills and concepts, and helping them practice facilitating the patient's use of these skills, are very important means of mitigating the effects of a patient's cognitive deficits on treatment. Strong cognitive functioning on the part of the caregiver is important for this process to take place. Luckily, Fay's cognitive capacities were excellent, and my challenge was not in helping her grasp the program material, but in helping her communicate with Ethan in a way that did not interfere with her support of his skill use. In scenarios in which a patient has significant cognitive deficits prior to treatment and multiple potential caregivers are available to choose from, it is recommended that prospective caregivers' cognitive capacities be assessed and weighted more heavily in the caregiver selection process.

Lastly, I suspect that Fay was not fully informed about the cognitive impacts of PD and MCI, and given the fact that she frequently complained about Ethan's forgetfulness, poor time management and lapses in reasoning, I think it would have been helpful for me to spend more time educating Fay on these issues. This might have helped her approach Ethan with more patience and compassion, thus improving their relationship, and also may have empowered her to come up with problem-solving strategies to cope with Ethan's deficits, thereby reducing her caregiver burden. For clinicians working with patients with cognitive deficits and their caregiver, I recommend that the clinician at least assess the caregiver's understanding of the patient's cognitive deficits and their implications, and provide psychoeducation and problem-solving support regarding these deficits to the caregiver if needed.

# Working With Communication Difficulties

From my perspective, Ethan's case was complicated by language/communication difficulties and cultural differences. Ethan was a first generation immigrant from China, and had learned English as a second language, and although his English was clearly good enough for him to have functioned at a high level professionally in the United States, I had significant difficulty

understanding him over the phone throughout our treatment, and based on his patterns of response, I suspect that he struggled to understand me at times, although this was never confirmed. To some extent, I believe our communication difficulties resulted from idiosyncrasies and deficits in Ethan's usage of English, and my difficulties in simplifying my speech and deciphering his. In addition, I suspect that PD-related speech problems, his accent, and the telephone-based treatment modality contributed to this difficulty.

Ethan was not thoroughly evaluated for verbal fluency, so it is hard to quantify his facility with the English language, but my experience was that his vocabulary was limited, and that he often left out parts of speech (e.g. articles, prepositions) in a way that made it difficult to grasp his meaning, particularly in combination with the other factors listed above. My impression that Ethan had trouble understanding me was not directly assessed, but he had a tendency to change the subject or respond in a way that did not follow from my previous statement, and although this may have more to do with avoidance or general cognitive deficits than language problems, I suspect that comprehension problems were at play to some extent. Additionally, research suggests that 49-70% of PD patients exhibit speech deficits (Hartelius & Svennson, 1994; Logemann, Fisher, Boshes & Blonsky, 1978). These deficits include more frequent and significant hesitation during speech, decreased speech volume, and poorer articulation (Illes, Metter, Hanson & Iritani, 1988; Ho et al., 1998). Ethan was not formally assessed for speech pathology, but in my experience, his volume was sufficient, but poor articulation and high speech latency were present. I often had trouble distinguishing one word from another when Ethan spoke, and the halting quality of his speech made it difficult to know when he had finished a thought, which led me unintentionally interrupt him on a regular basis. In addition, Ethan's accent, which led the inflection of his speech to differ from my expectation, added to my difficulty in understanding him. Additionally, over the course of treatment, it became clear that the quality of my telephone connection significantly impacted my ability to understand Ethan. I found landlines to be generally more effective, that my cell phone provided a clearer signal than calling from my laptop, and that certain parts of my apartment allowed for a clearer signal as well.

The main impact of my difficulty in understanding Ethan was that our sessions were less efficient. I frequently asked Ethan to repeat himself, and based on prior experience, worried that this might interfere with our rapport, but luckily, Ethan never seemed bothered by these requests. However, the inefficiency of our communication, on top of the difficulty keeping Ethan on topic, influenced my decision-making during the course of our sessions. Later in treatment, I began factoring in communication inefficiency as I prioritized the material I planned to cover in session, and if communication issues were slowing our progress in session, I would sometimes decide to either focus on the current topic even if that meant other topics would fall by the wayside, or to table the current discussion and move on to more important topics.

In managing my communication difficulties with Ethan, I learned that simplifying my language seemed to improve Ethan's comprehension, and modeling slow, loud, over-enunciated speech seemed to encourage Ethan to alter his speech in the same ways, thus improving my comprehension. It found it challenging to keep these strategies in mind while focusing on session material, but as treatment progressed, I was able to integrate these tasks more easily. In addition,

I learned that the details of my telephone connection made a significant difference in my ability to understand Ethan, and, I believe, to be understood by him. The optimal combination of factors may vary, but I would encourage clinicians conducting telephone sessions with patients who have communication problems to experiment with the type of device used, the type of connection used (i.e. landline vs. wi-fi), and the location from which the call is made when using a cellular device.

## Working With Cultural Differences

I believe Ethan's cultural background and its interaction with program concepts and skills also played a significant role in his treatment. The automatic thoughts derived from Ethan's negative appraisal of his "usefulness" were a major focus of cognitive restructuring in treatment. Ethan's concern with being a burden and contributing to the greater good were not unusual, but I was struck by the profound importance Ethan attached to this issue, and the rigidity with which he held to expectations of his usefulness that seemed unreasonable to me. Ethan seemed preoccupied with his "usefulness" much of the time, and in Session 9, it became clear that his pattern of staying up late to fix various computer problems stemmed from his belief that completing these tasks was one of the few remaining ways in which he still felt he could be "useful." Collectivist cultures, including traditional Chinese culture, promote interconnectedness, respect for elders, and deference to the needs of the family unit or wider community, in contrast to Western values, which traditionally promote independence, autonomy, and personal attainment (McGoldrick, Giordano & Garcia-Preto, 2005). Thus, I interpreted Ethan's focus on being useful as culturally mediated and appropriate.

In treatment, I first tried to apply the 'evidence for/against' cognitive restructuring technique to these thoughts, but despite being provided with what I saw as a significant amount of evidence that his expectations of his usefulness were unfair given his current condition, I was unable to help Ethan recognize alternative perspectives or loosen his attachment to the negative thought. However, thoughts related to his uselessness were causing him significant guilt and sadness, and I felt it was imperative that we find a way to help him cope with these. I decided to shift our focus to a 'cost/benefit analysis' of his 'useless thoughts,' and although initial gains were small, but in Booster Session 2, an opportunity to leverage Ethan's concern for the greater good to help him combat these thoughts. He had been feeling very guilty and ashamed about not being able to assist his family members as much as he would have liked during a recent trip, and Fay mentioned that his subsequent withdrawal and low mood had made his family members very concerned about him. Ethan seemed surprised at how much his low mood had impacted his family members, and was able to recognize this impact as a significant "cost" of his negative thoughts.

At our exit interview, Ethan said that this discussion had made a lasting impression on him, and that framing the impact his low mood had on others as a "cost" of his negative thinking had been very helpful in motivating him to reject negative thoughts, regardless of their validity, and search for the "most positive way" to look at a situation. Ethan said he believed this approach had led to significant improvements in his mood, and Fay agreed. From my perspective, Ethan had leveraged the collectivist cultural emphasis on putting the needs of the

group ahead of those of the individual in a way that helped him combat his negative thinking and improve his mood.

The most important lesson I learned in working with issues of culture in Ethan's treatment was the importance of assessing how a patient's cultural background meshes with certain treatment approaches. I think this principle is particularly applicable to cognitive approaches like those presented in the TH-CBT program, because their engagement of patients' beliefs and worldview makes them more likely to interact with a patients' cultural values. In the case of Ethan, after making an initial attempt to use 'evidence for/against' to restructure his negative thoughts around his perceived uselessness, I concluded that pursuing this technique was unlikely to be successful, and risked showing insensitivity to Ethan's cultural background. The 'evidence for/against' technique relies on the idea that the validity of a thought can be evaluated through consideration of relevant evidence, but values, including cultural values, influence the weight attached to various pieces of evidence, and thus, whether the patient will find gathered evidence convincing. When Ethan maintained the validity of his assessment that he was "useless" in the face of what I considered strong counterevidence, I hypothesized that his cultural values might be leading him to dismiss the significance of this evidence, a perspective that might be summarized as 'although I recognize that I may not be capable of meeting my standards of 'usefulness,' these standards are dictated by my cultural beliefs, and maintaining them is essential for me.' Thus, I decided to address these thoughts using the 'cost/benefit analysis' approach, which focuses on a thought's positive and negative consequences instead of its validity. Certainly, this technique could have run into problems similar to the 'evidence for/against' technique faced, since Ethan's cultural values might have influenced the relative importance of the costs and benefits of his 'useless' thoughts, and Ethan might have concluded, as an example, that 'although the costs of seeing myself as 'useless' lead me to feel sad, guilty and ashamed, maintaining this perspective helps me stay connected to my heritage, a benefit I am unwilling to give up.' However, this scenario seemed unlikely to me, and luckily, the 'cost/benefit analysis' technique became an effective tool to help combat Ethan's 'useless' thoughts, arguably because of his collectivist cultural beliefs.

# 4D. GARY'S ASSESSMENT: PRESENTING PROBLEMS, GOALS, STRENGTHS, AND HISTORY

# **Identifying Information**

Gary presented for treatment as a 42-year old, divorced, employed, Caucasian man living in Central New Jersey who had been diagnosed with PD 6 months prior to intake (2014), and reported struggling with significant depression and anxiety symptoms since then. Gary stated that he had always "hated school," was a mediocre student throughout high school, and had taken some college courses, but had not completed a college degree. At the time of intake, Gary was employed as a sales representative, and stated that he had worked in this capacity for most of his professional career.

Gary reported intermittent contact with his mother, but stated that he did not have close relationships with the rest of his family of origin. Gary had a 12-year old son with his recent ex-

wife. His ex-wife had primary custody of the child and lived within driving distance of Gary. Gary spent every other weekend with his son. Gary reported having few social connections at intake, and we decided that the best candidate for a study caregiver was his mother, although he was not interested in her participating significantly in his treatment.

Gary did not report significant medical history aside from PD. He stated that since his diagnosis, he had initiated a regimen of herbal and dietary supplements on the recommendation of a holistic healer, and was doing his best to exercise regularly, with moderate success.

## Presenting Problem, Psychiatric History, and Assessment

When we began treatment, the patient reported that he was not experiencing significant physical symptoms of PD, but felt hopeless and fearful about the progressive nature of the disease, and spent a great deal of time ruminating about how he would deal with more advanced stages of PD. Gary characterized his mood as "terrible," and reported that co-workers had noticed him experiencing mild tremors at work, particularly when he was feeling anxious, and that he feared he would be fired or demoted as a result. In addition, Gary stated that his work required that he maintain a grueling travel schedule, which he had found increasingly difficult in recent months due to an increase in fatigue that he attributed primarily to PD.

Gary denied having been previously diagnosed with a psychiatric condition other than depression at intake, but reported experiencing low mood and irritability more than half the time for several years, and met criteria for Dysthymic Disorder. Gary reported that he had struggled with gambling in his 20's, and that he and others had noticed his tendency to act impulsively. Gary believed he would meet criteria for ADHD, though he had never been formally diagnosed, citing significant concentration and hyperactivity problems as a child. During the initial assessment, Gary reported that he had been prescribed nortriptyline for his depressive symptoms by his neurologist several weeks ago, but was quite dissatisfied with its impact, stating that the medication had not reduced his depressive symptoms, and that he believed it was contributing to his diminished energy.

Gary reported engaging in heavy drinking in his 20's, but had been sober for 1 year at intake. Gary stated that he regularly used a variety of recreational drugs in his 20's, but that his recent drug use was restricted to smoking marijuana roughly twice per week, which he said helped relieve his anxiety.

# **Diagnoses**

Axis I: Dysthymia (300.40); Generalized Anxiety Disorder (300.02); 305.00 Alcohol Abuse in Sustained Full Remission

Axis II: None

Axis III: Parkinson's Disease (ICD-9 Code 332)

Axis IV: Problems with primary support group, Occupational problems, Economic problems

Global Assessment of Functioning (GAF): 53

## **5D. GARY'S CASE FORMULATION**

Gary's primary symptoms at intake were low mood, anhedonia, anxiety about his future in light of his PD diagnosis and life situation, and hypochondriasis related to his PD symptoms. Based on the guiding conception of this treatment approach, I conceptualized Gary's low mood and anhedonia as driven by negative predictions about the future and regrets about the past, along with an absence of rewarding activities. Gary reported negative automatic thoughts like "I will be unemployable in 10 years," "I will not be able to cope with this disease," and "my life is over." I conceptualized these negative thoughts as stemming from intermediate assumptions like "if I try to live a meaningful life with PD, I will fail," and the core belief "I am fundamentally flawed." Significant psychosocial stressors—unstable finances, a difficult relationship with his ex-wife and son, and a general lack of social support—contributed significantly to Gary's worries about how PD would impact his future. Gary's efforts to manage these stressors also reduced his ability to engage in meaningful activities. I believe these stressors also served as a barrier to the formation of a strong therapeutic alliance, since they represented differences between Gary and I that contributed to Gary's belief that I was incapable of fully understanding his predicament, and thus unable to be helpful to him.

Gary demonstrated a tendency towards extreme externalization and internalization in making sense of his difficulties: he expressed guilt and self-criticism at not having used his time prior to his PD diagnosis more productively, but also blamed his ex-wife, his healthcare providers, co-workers, and his mother for the distress he was experiencing. His internalizing tendencies helped maintain his low mood and anhedonia by generating feelings of powerlessness and undermining his self-efficacy, and his externalizing tendencies made it difficult for him to work collaboratively with others to address his symptoms.

Gary's anxiety symptoms were maintained by the catastrophic predictions described above, Gary's life stressors and the uncertainty of his PD prognosis, and the reinforcement provided by the process of worrying, which Gary saw as a necessary part of successfully managing the challenges he faced.

## 6D. GARY'S COURSE OF TREATMENT

## Module 1

At our first session, Gary rated his mood over the last week a 3/10 (10 = best), stating that he had felt "panicked" trying to find time to visit his son (who was ill), keep up with his travel schedule for work, and prepare to sell his house, while dealing with worsening physical PD symptoms. Gary seemed particularly upset by his tremors, particularly the fact that anxiety exacerbated them. When Gary described the frequency and intensity of his tremors, they sounded relatively mild in intensity, and were barely noticeable when Gary was not feeling anxious, but their presence, and Gary's conviction that they would soon be considerably worse, were both very distressing to him. The previous week, Gary had attended a business meeting in which his sales team received feedback on their performance. Due to the evaluative nature of the meeting, Gary had become anxious, and begun to experience tremors. He had tried to conceal them from

his co-workers, since they were not aware of his diagnosis, and he was intent on hiding it from them. However, he reported that his attempts to conceal his tremors made him even more anxious, which made the tremors more severe, and Gary felt sure that some of his co-workers had noticed them. I was struck by the strength of Gary's commitment to conceal his symptoms and his diagnosis, and reflected this to Gary. He stated that given his financial situation, he could not afford to lose sales assignments or his job, and that anyone in his position would conceal their PD symptoms.

Gary said that he had looked over Module 1 quickly because much of the material he remembered from college courses in psychology. However, when we discussed specific concepts from Module 1, Gary demonstrated little grasp of them, and seemed more interested in describing the challenges he was facing in detail. I attempted to re-orient Gary to the structured nature of the program, and my interest in trying to help him develop skills to combat the issues he was mentioning.

Gary initially seemed agreeable to this, but as we began to work through some of Module 1's main themes, his responses implied a lack of confidence in the efficacy of the program. For example, when I asked him what he thought of the idea of working to increase his engagement in meaningful and enjoyable activities, Gary responded with "you seem like a good guy, and I know you're trying to help, but I don't have time for nice activities." I asked him to review his activity schedule over the last week to help me understand how busy he was in an effort to validate his perspective and also advance the Activity Scheduling goals of the session. Gary described a number of essential and time-consuming activities (e.g. visiting his son, searching for a realtor and house inspector in preparation for selling his house, a busy travel schedule for work), but also made clear that he spent much of his free time conducting online research on PD, and in particular, on dietary and herbal remedies that he hoped might help alleviate his PD symptoms.

He described the experience of trying to learn about PD as "overwhelming" and "paralyzing," and said that these feelings were often so strong they interfered with his ability to process what he read in the course of his research efforts. Gary also expressed dissatisfaction with the effects of the antidepressant medication (nortriptyline) he had been prescribed by his neurologist, which he said made him feel like a "zombie" and "did nothing" to improve his mood. He said he felt very frustrated with how long he would need to wait to see his neurologist for a follow-up appointment to discuss these issues, and had been spending a significant amount of time researching alternative medications.

In retrospect, I interpret Gary's exhaustive research efforts as, at least in part, an attempt to cope with feelings of helplessness. Based on Gary's description, these efforts seemed to generate more questions than they answered, thus adding to his anxiety and sense of helplessness. However, it was clear that Gary was wedded to these activities, and I felt hesitant to suggest that he substitute other activities. When I mentioned that it sounded overwhelming to sort through so much information on his own, Gary seemed offended, saying "Of course it's overwhelming, I just found out I have Parkinson's." At the end of the session, we had covered

very little of Module 1, and I was unsure about how best to promote engagement with the program while maintaining rapport.

Since Gary seemed interested in learning more about PD, and because I wanted to find some way of promoting positive activity engagement, I suggested that he research support groups in his area where he could learn more about PD and make connections with others in his position.

Gary initially objected to this idea on the grounds that everyone at the groups would be "much older" than him, and unable to relate to his situation, and because he felt it would be "depressing" to be around people in more advanced stages of PD. However, Gary ultimately agreed to this homework assignment, in addition to reading Module 2.

#### Module 2

At the beginning of our second session, Gary rated his mood over the past week as a 4-5/10 (10 = best), and when I asked about the improvement over last week, Gary stated that he had had a job interview that he thought had gone well, and had inspired him to intensify his job search.

However, he stated that he had been plagued by despairing thoughts about his future for much of the week, and felt that a sense of hopelessness, in addition to his medication and PD, had been sapping his strength, leading to low activity engagement outside of work.

Gary had attended a lecture by a local university professor on the biology of PD at a local support group, but had not stayed for the full lecture because he felt uncomfortable about being the youngest person there, and because it had taken place during the week, and he felt obligated to return to work before it ended. I was surprised and encouraged by his attendance at the group, and tried to validate his follow-through. However, Gary made clear that the group had been "depressing," as he had expected, and that he had found it difficult to make sense of the professor's presentation, and thus had decided not to pursue support groups for the time being. I suggested that it might be possible to find a support group that fit his interests and schedule better, but Gary firmly refused.

Gary had not read Module 2, so we spent time reviewing of the more important concepts from Modules 1 and 2. Gary questioned the importance of interpretation in determining mood, stating that he felt the reality of PD, and not his thinking about it, was the primary issue. We reviewed the "Newlyweds" example, which is intended to illustrate how interpretation of a situation can influence emotional reactions to it. Gary focused on the differences between the example and his own situation, implying that PD was clearly more challenging than a "lover's quarrel," but did accept that one's perspective has some impact on how one feels about a given situation.

At the end of the session, I expressed concern that Gary seemed uninterested in the content of the program. Gary stated that he "had a lot on his mind" at the moment, and was trying his best to be engaged, but felt that he was not learning anything new, and doubted that changing thoughts or behaviors could make much difference in his experience given the

challenges he was facing. I tried to validate the reality of his challenges, and his disappointment that the modules presented concepts that he was already familiar with. I said I thought his familiarity with these concepts was a great advantage, but that if he did not put these concepts into practice outside of session, it was unlikely that the program would be helpful to him. Gary agreed, and said he would try to spend more time on the program, but said he had "so many other things to do" that it would likely be difficult. I asked if he thought it was the right time for him to participate in the program, and assured him that if this was the case, he should not feel pressure to continue, and could return to the program in the future. Gary said that he was committed to the program, and would engage to the "best of his ability."

In the final third of the session, we discussed the central role of the Thought Log in the cognitive restructuring component of the program. Gary declined to practice generating Thought Log entries in session, and promised that he would make at least one entry each day over the course of the next week. Given how overwhelmed Gary said he had been feeling, I was concerned that this assignment would fall by the wayside if we did not do some planning around how he would incorporate making Thought Log entries in his schedule, but I elected not to raise this issue because I felt Gary had already made concessions to my recommended approach to the program, and deserved the benefit of the doubt. In addition to completing his Thought Log entries, I asked Gary to read Module 3.

#### Module 3

At the beginning of our third session, Gary rated his mood over the last week a 4/10 (10 = best), similar to the previous session's rating. Gary reported that his anxiety about his financial situation continued to be high, since he had decided he needed to sell his house, and it had become apparent that this would be more difficult than he had originally believed because some parts of the property had fallen into disrepair and might need to be fixed before the house could be put on the market. Additionally, he had not heard back from two potential employers after recent job interviews, and worried that his current income would soon be insufficient to cover his medical bills. On top of this, he had just been notified that his water would be shut off at the end of the month and a lien placed on his property if he did not pay his water bill, which he had delayed paying while he tried to determine why it had been several times its typical rate for the past few months. Gary described this situation as a major stressor, so we spent time discussing steps he might take to determine whether he would have to pay the bill (e.g. looking for a leak, asking the town to assess whether the meter was broken). Gary expressed gratitude for being able to discuss this issue in session.

Gary had not written out any Thought Log entries, but had made mental notes of some scenarios he thought were appropriate. The first had occurred one morning when Gary was feeling particularly stiff and achy while trying to prepare himself to head to the gym for a workout, and had the thought: "I don't know if I'm strong enough to handle this." Gary described the accompanying emotions as anxiety and depression. Although the thought was not formulated in an optimally challengeable way, I was encouraged that Gary had made an effort to keep track of his thinking and its impact on his feelings, and by the suitability of the example he

came up with. I tried not to praise him too effusively, as I had begun to suspect based on previous instances that he experienced this as condescending rather than reinforcing.

I suggested that we review Module 3's list of cognitive distortions to see if any of them applied to this thought. Gary had not reviewed Module 3 the previous week, and as we went through some of the examples of cognitive distortions, he seemed to assume that my suggestion that we assess the applicability of a given cognitive distortion to his thoughts indicated that I believed these thoughts were in fact distorted. Realizing that I had not framed the concept of cognitive distortions properly for him, I emphasized that the cognitive distortions list in Module 3 was meant to describe common ways in which negative thoughts *could* be distorted, but that the 'evidence for/against' approach to cognitive restructuring, which we would be reviewing in the next session, involved examining the evidence for and against a thought before deciding whether any distortion was present. This seemed to help Gary warm to the idea of cognitive distortions, and he showed curiosity about some of the distortions as we perused the list. With some assistance, he was able to identify Fortunetelling as a cognitive distortion potentially applicable to the thought we had discussed.

For homework, I asked Gary to read Module 4, to identify one more negative thought during the course of the week, and to try to identify an appropriate potential distortion.

#### Module 4

At our fourth session, Gary rated his mood over the past week a 5/10 (10 = best). He explained that an enjoyable weekend with his son had helped brighten his mood, and that he had been able to push himself to exercise despite stiffness, pain and fatigue. He stated that his financial situation and the prospect of living the rest of his life with PD continued to weigh heavily on his mind.

Gary had re-read parts of Modules 1 and 2 over the past week, and said that based on the sections describing the importance of activity goals, he wanted to focus on adding social activities to his schedule. Specifically, Gary was interested in reconnecting with old friends. Gary stated that after receiving his diagnosis, he had made less of an effort to connect with friends because he felt he needed to "focus on taking care of himself," but had realized that he missed having more social contact. However, Gary was concerned that his friends would be "pitying" or would be disturbed by his tremors, fatigue and bleak outlook. I suggested that these thoughts might be worth examining for potential distortions, as per Module 4, and Gary agreed, although there was annoyance in his tone, and I wondered whether I had jumped too quickly back to 'the program.' I did not mention my impression of his annoyance. While we were on the topic of scheduling social activities, I mentioned that I had heard from Dr. Dobkin about a Young Onset PD support group in Central New Jersey, and suggested this as an alternative to the support group Gary had previously been dissatisfied with. At this point, my sense was that Gary was still in the early stages of coming to terms with his diagnosis, and I hypothesized that if he could tolerate it, being around other PD patients that he could identify with might be enormously helpful. However, Gary said the location of the group was too far from where he lived. We

discussed when, where and with whom Gary might schedule a social event for the next week, and then shifted our focus to the previous week's homework.

Gary had read Module 4 and written several entries in his Thought Log. I suggested that we try practicing the 'evidence for/against' cognitive restructuring technique on his thought "I'm not sure if I am strong enough to handle this" from last week's session. As a way to preempt Gary's defensiveness, which I had gotten a hint of in Module 3, I reiterated that this process was meant to be exploratory, and that it was important to avoid a priori assumptions about whether a given thought was distorted.

Since Gary's thought as it had been originally stated expressed an unknown amount of doubt about Gary's ability to handle his situation, I asked him to give me a percentage estimate of the degree to which he *did not* believe he could handle his situation. Gary stated that he found the idea of trying to quantify the strength of his belief was "silly," and the most specificity he could muster was "more than half." I was more active and directive in this part of the session than I had been previously in our treatment, and I sensed that Gary might be feeling uncomfortable with this, but I decided to stick with this approach, as past experience indicated that Gary overestimated his grasp of the program concepts, and I had found the 'evidence for/against' technique to be the most difficult for most patients to understand. In comparing the evidence for and against his thought, Gary was able to come up with a number of pieces of evidence supporting the thought, though several of them were other negative thoughts (e.g. "I will be unable to work soon"). However, he drew a blank when I asked him to think of evidence that contradicted the thought. I suggested some possible pieces of counter-evidence (e.g. "so far, I have been able to hold down a job, maintain a relationship with my child, and maintain a home while coping with PD symptoms"). Gary did not believe that this evidence was accurate, and detailed the ways in which he felt his performance at work was poor and deteriorating, that he was dissatisfied with the amount and quality of the time he spent with his son, and that he was unable to maintain his home if he was in danger of having his water shut off. I tried to emphasize that my example was meant as a hypothetical example to demonstrate what counterevidence might look like, and that if Gary did not feel it was strong evidence, then it would not be helpful to include it. Gary was clearly quite upset, and went on to say that he trusted that I was trying my best to be helpful, but felt I was not fully comprehending the challenges he was facing, and was unsure about how helpful the program would be.

Realizing I needed to backtrack further, I emphasized that the 'evidence for/against' approach was one of several cognitive restructuring options, and although it had been helpful for many people, we could focus on other strategies if it was not helpful for him. I mentioned that some of these alternative strategies would be presented in Module 5, and referenced where in this module he could find information on these strategies. Gary agreed to give Module 5 "a look," but seemed cold and disengaged for the rest of the session, which I decided to end early.

#### Module 5

At the beginning of our fifth session, Gary rated his mood over the previous week as a 5/10 (10 = best). He said that he was feeling better than he had the previous week, and

apologized for being "cranky" at our last session. I thanked him for his apology, and said that I felt I had failed to hear his concerns fully, and hoped to do a better job adapting the program to his needs. Gary believed that his anxiety might be a bigger problem than his depression, and had recently made contact with a psychiatrist specializing in treatment of anxiety. I asked him to describe his anxiety, and he stated that he felt he was in a constant state of panic about trying to get things done "before it's too late," and that "staying as busy as possible" was the best way for him to deal with his anxiety. He estimated that he had "10 good working years left," and felt pressure to make as much money as possible during this time to ensure that he would be able to pay for his son's college education. Gary also said that he had so much on his plate that it was hard to decide where to start, and that he spent a lot of time "spinning his wheels." I mentioned that there were relaxation exercises and worry control techniques included later in the program, and that we could review these components earlier in the program if he was interested. Gary said that this was unnecessary, and that he wanted to see if the psychiatrist could help with his anxiety first. I was concerned because the terms of the research study request that patients abstain from altering their medication regimen if possible, but I felt concerned about how he would react if I brought this issue up, and since he did not yet have an appointment with the psychiatrist, decided to revisit the issue in the next session.

Gary said he had briefly reviewed Module 5, but again seemed unfamiliar with some of the other cognitive restructuring concepts described therein. I decided to focus on the 'cost/benefit analysis' and 'what would you tell a friend' techniques, since I worried that the 'worst case/best case/most likely scenario' approach might be frustrating to Gary given its similarity to the 'evidence for/against' skill. Wanting Gary to feel as much in control of the process as possible, I asked him to pick a thought he had recorded in the Thought Log to use in practicing these techniques. Gary chose the thought "I won't be able to work in 10 years." Gary reported feeling a mix of anxiety and helplessness in connection with this thought over the last week. When I asked him what the costs and benefits of focusing on this thought might be, Gary cited "motivation to make money now" as the primary benefit, and could not think of a cost. I told Gary that it had sounded to me like his anxiety might have been exacerbated when he attended to this thought.

Gary responded that it was his situation that made him anxious, and that he had no choice but to think about it and deal with it. I worried that Gary was again feeling like he was not being heard. I mentioned my concern to him, expressed my sincere desire to avoid a confrontation, and asked him how he would like to proceed. Gary stated that he did feel annoyed, because he felt that the interventions he had learned so far had been designed to ignore the negative aspects of his situation and force him to "just think positive." Focusing on the 'cost/benefit analysis,' skill, I said I entirely agreed with the need to be realistic about his challenges, I understood that he derived motivation from the challenges he was facing, and that the idea of this skill was not to ignore these benefits, but to check to see if there instances in which a given thought might be counterproductive, e.g. by making him feel more hopeless, or making him feel so anxious that it was difficult to actually take action. Gary seemed partially mollified, and stated that there were times when he did feel so anxious that his concentration was affected, but affirmed that for him, the motivating power of this thought outweighed its cost in anxiety. I framed our 'cost/benefit

analysis' of this particular thought as successful in that we had ascertained that the benefits of the thought outweighed the costs.

However, based on the fact that he had expressed interest in reducing his anxiety psychiatrically earlier in the session, and his description of his anxiety leading him to "spinning his wheels," I strongly suspected that there were moments when worries about his financial future led to unhelpful emotional consequences without providing him significant benefit in helping him handle these concerns. Looking back, I wish I had not acted on this hypothesis, as this could be seen as contradicting my message that it was acceptable to conclude that a given thought's benefits might outweigh its costs, even if the costs were significant. However, I was worried that I might not have many more chances to demonstrate the value of the program to Gary, and it felt important for Gary to derive benefit from this exercise. To this end, I introduced the concepts of rumination and effective problem-solving, and stated that while I understood that the thought "I won't be able to work in 10 years" was more beneficial than costly to him in general, I wondered whether there might be specific instances in which he was ruminating on this thought rather than using it to generate solutions to his financial challenges, and suggested that such instances might fit his description of feeling so anxious about getting things done that he was "spinning his wheels." Gary said such a scenario was possible, but that he could not think of any specific examples. I suggested that if he was able to identify situations in which he was ruminating on this thought and could not effectively problem-solve, he might maximize the benefit and minimize the cost of the thought, and suggested that he monitor his experience over the next week for such instances of rumination, which he agreed to. I asked once more if Gary wanted to move the program content focused on relaxation and worry control to our next sessions given his concern about anxiety, but Gary declined, so I asked him to read Module 6 in addition to his thought monitoring assignment for homework.

NOTE: Gary subsequently informed me that he was no longer interested in continuing his participation in the study, so session 5 turned out to be our final session.

# Discussion of Gary's Case

Gary was the most challenging patient I encountered during my work with Dr. Dobkin for a number of reasons. I believe much of our difficulties stemmed from an interaction between Gary's approach to coping with his recent PD diagnosis, the nature of the program, and my own biases and weaknesses as a clinician. In the following discussion, I will attempt to describe these factors, my interpretation of their interplay during treatment, and the lessons I took from the treatment that I hope may have applicability to treatments with similar features.

During the intake, I began to pick up on signs of what I now conceptualize as Gary's coping reaction to his diagnosis, and they made me concerned that maintaining our therapeutic alliance would be a significant challenge. He seemed particularly interested in evaluating the competence of his healthcare providers, and at several points he generalized his specific complaints about certain providers to criticism of the profession in general. Our first session gave me no reason to revise my initial assessment: at several points, I felt like Gary was assessing me for sufficient life and professional experience, and finding me wanting. He asked

how old I was, and after I responded honestly, he suggested at several points later in the session that I would likely have difficulty understanding his experience because I was "young." In the exit interview, Gary stated that my age and relative inexperience as a therapist led him to take a dim view of my potential to be helpful, and "not give the program a chance."

Additionally, when I asked him about his experience reading Module 1, he said that it "hadn't taken him very long to get through" because he had taken psychology courses in college, and the material was familiar to him. When I then suggested that we try to apply some of the concepts in Module 1 to Gary's own situation, he seemed uninterested, and made several comments to the effect that he was unimpressed with the complexity of the ideas in the Module 1, and felt it would be more helpful to him for us to "just talk." For example, I suggested that we review his current activity schedule with the idea of assessing what activities he might want increase, maintain or remove, he said that he did not have time for "nice activities," and that his schedule was already full of activities that he considered obligatory.

In addition, Gary was uncomfortable with the idea of a fixed session time, stating that it "stressed him out" to be scheduled in this way, and asked if I could call him whenever I was free, and should he also be free, we could have the session. I was puzzled by this request, but when I asked Gary about what exactly felt stressful about having a fixed session time, he reiterated that it just "stressed him out," and had trouble providing further detail. During our sessions, Gary was h or involved in other activities (e.g. watching TV in the background, cooking dinner), and he repeatedly mentioned feeling pressed for time and "all over the place." In talking to Gary during the exit interview, he said that at the time of our treatment, he felt like "the clock on his life was ticking" due to his PD diagnosis, and that he was coping with this by trying to get as much done as he could while he was still able. Gary further described this coping strategy as stemming from a "lack of acceptance" of his diagnosis and an unexamined fear of what life with PD would look like, and that throwing himself into frantic activity was a means of "running away" from this fear.

Gary coping strategy seemed to deny the reality of his diagnosis, and as a result, placed unrealistic expectations on himself and others involved in his care. For example, I think Gary's complaints about certain healthcare providers not responding to him in a timely manner were valid and understandable, but Gary suggested there was negligence, and perhaps even malicious intent, behind his neurologist's prescription of an antidepressant (nortriptyline) that Gary found unhelpful, saying "they just give you this stuff to numb you out," and "I feel like it's a big conspiracy." Based on what Gary said in the exit interview, I think this hostility came out of understandable anger at the injustice of his having contracted PD at such a young age, and a desire to hold someone accountable for the fact of his illness. I believe this meant that he saw providers who were unable to cure him of his symptoms as responsible for them, and I inevitably fell into this category. To me, this unrealistic expectation of a cure, or difficulty accepting his prognosis, explains his a priori suspicion of the program's usefulness, his resistance to attending support groups, and his relentless pursuit of herbal remedies and dietary solutions to his symptoms. In a brief conversation with Gary's mother, who served as Gary's caregiver for the study, but had relatively infrequent contact with him, she said that he had been quite irritable and

rejecting of her since his diagnosis, which leads me to believe that his anger was also directed at those who were not directly involved in his treating his PD.

In addition, Gary's difficulty in accepting his diagnosis also led him to place unrealistic demands on himself. In the exit interview, Gary explained that his discomfort with having a set session time, his tendency to be occupied with other activities during our sessions, and his reports that he often felt agitated and "all over the place" in the course of his daily life resulted from his attempts to accomplish what he hoped to achieve in life before his symptoms left him incapacitated (e.g. providing for his son's college tuition, moving to a more suitable home).

However, I believe these efforts created persistent worry that he was not getting enough done, led him to multi-task to the point of ineffectiveness (thus his sense of "spinning his wheels" and his frequent distraction during session), and made him hesitant to make time commitments that might interfere with his multi-tasking efforts (e.g. our sessions). I think the anxiety stemming from Gary's unrealistic expectations of himself and the treatment limited his ability to engage with the program in a meaningful way.

Additionally, I think the structured, change-focused nature of the TH-GSH-CBT protocol, and the fact that the treatment was delivered in the context of a research study, were not well suited to a patient still coming to terms with their PD diagnosis. This mismatch primarily manifested itself in an ongoing tension between Gary's stated desire that we "just talk," and my sense of responsibility to implement the treatment as intended. As treatment progressed, I found it increasingly difficult to maintain our focus on the materials presented in the modules. Gary indicated that he simply wanted me to listen to and empathize with his plight, and when I tried to validate his concerns and suggested that we refer to the module for ideas on how to address them, Gary experienced this as unhelpful, and would redirect our discussion back to further elaboration of his distress and the reasons behind it. When I mentioned this dynamic in the exit interview, Gary characterized it as a manifestation of his difficulty accepting his diagnosis, stating that at the time of our treatment, he "wasn't ready to think about what to do." My interpretation of this statement is that thinking about "what to do" in a realistic way required accepting the reality of the diagnosis in a way for which Gary was not prepared.

I did my best to strike a balance between validating Gary's experience and helping him develop the skills presented in the program, but I think that certain biases and weaknesses in my clinical approach contributed to the treatment failure. First, I feel most comfortable implementing structured treatments, and at that point in my training, I had little experience and even less confidence in delivering the kind of unstructured treatment that Gary seemed to be looking for. As mentioned above, given that Gary's treatment was part of a research study, I felt obligated to be as adherent to the protocol as possible. However, I was unclear on the amount and types of modifications allowed for by the program, and I felt hesitant to ask for input on this issue from Dr. Dobkin, as I worried that she might see this as a clinical skill deficit, and ultimately went through Gary's treatment feeling pressure to err on the side of sticking closely to the protocol agenda. In subsequent discussions with Dr. Dobkin, it became clear to me that the program allowed for much more flexibility than I imagined, and that Gary might have gotten more out of the treatment had I been willing to ask for help.

I suspect that the telephone format of the intervention also worked against my capacity to convey empathy for Gary's distress, because it precludes the use of body language, facial expressions, and at times tone of voice when the telephone connection is poor, all of which I have found to be essential in communicating respect, interest and care in face-to-face therapy sessions. I have found that for me, playing a directive therapeutic role over the phone (e.g. providing psychoeducation about depression symptoms or working through a cognitive restructuring exercise) is no more challenging than doing so in person, I think because the content of the conversation is central to this task. In comparison, I find empathic listening and reflection to be more difficult over the phone, since the therapist is speaking less, and must convey information in other ways. Of course, it is quite possible to convey empathy over the phone, and I certainly could have increased my emphasis on empathy relative to skill acquisition in Gary's treatment. However, with Gary, it would have been helpful to have as many empathic tools at my disposal as possible, and I have often wondered whether treatment might have gone differently had we conducted treatment in-person. Thus, in telephone-based treatments with patients in need of empathic support, I propose that this task may require more time and energy compared to in-person treatments, in which empathy can be conveyed through non-verbal channels.

In addition, at the stage of my training when I treated Gary, I think my skill in providing cognitive restructuring was unrefined, and I struggled to convey cognitive restructuring skills particularly the 'evidence for/against' skill—in a way that did not send the message that patient's thoughts or interpretations were "wrong," especially with patients like Gary, who were sensitive to feeling invalidated or condescended to. In particular, after listening back to our sessions, despite telling Gary that it is important to avoid making a priori assumptions about the strength of evidence supporting a negative thought, I think I indirectly sent Gary the message that I was making these assumptions. One example was in the hypothetical counterevidence I suggested might fit his negative thought "I don't think I'm strong enough to handle this" in Module 4. Although I did intend to provide hypothetical examples of counterevidence, I chose pieces of evidence that I suspected were actually applicable to this negative thought, which may have made it more difficult for Gary to see them as hypothetical, and more likely that he see me as imposing my evaluation of the validity of his thought. Given that cognitive restructuring is such an important part of the TH-GSH-CBT protocol, and can be such a powerful tool when used well, I think it is essential for clinicians to take care to be open-minded about the outcome of 'evidence for/against' approaches to negative thoughts when implementing these treatments with patients who are particularly sensitive to invalidation.

As we moved into the middle portion of the program, which focuses on cognitive restructuring, I found myself in a conundrum: on the one hand, I felt confident that Gary's mood was being negatively impacted by automatic thoughts ("I can't do anything," "my life is basically over") that were theoretically quite amenable to cognitive restructuring, and I felt an obligation to do my best to cover this material with him. On the other hand, at this point in treatment it was clear that Gary was sensitive to invalidation, and the more we worked on cognitive restructuring, particularly the 'evidence for/against' component, the more our already fragile rapport seemed in jeopardy. Despite the 'evidence for/against' skill's prominent place in the protocol, in Gary's case, there is reason to believe our treatment would have been more

successful if we had shifted our focus to other cognitive restructuring techniques (e.g. 'what would you tell a friend') earlier, or tabled cognitive restructuring temporarily, and focused on relaxation and worry control techniques.

There are several lessons I learned from my treatment with Gary that might usefully inform clinical decision-making in other treatments with similar features. First, I think that Gary quite understandably experienced his PD diagnosis as a significant loss, and in my experience, PD patients often describe undergoing a process of coming to terms with their diagnosis that resembles the 5 stages of grief outlined by Elisabeth Kübler-Ross in her book On Death And Dying (Edlich & Kübler-Ross, 1992). Gary was the first patient I came across who, in retrospect, seemed to fit in the second "Anger" stage, and if I had been thinking in terms of stages of grief, given his recent diagnosis, I might have further explored with Gary and/or Dr. Dobkin his appropriateness for the study, or pursued modifying the treatment in a more significant way, because, as Gary himself said in the exit interview, he was not ready to benefit from what the program had to offer. From the perspective of the 'Stages of Change' outlined in the Motivational Interviewing literature, I would describe Gary's perspective on coping with his PD and associated symptoms as fitting the "Precontemplation" stage, which is characterized by strong resistance to change, and denial of the feasibility or benefits of change (Miller & Rollnick, 2012). The MI approach to dealing with ambivalence involves an open exploration of the patient's reasons for desiring and resisting making a change, and aims to use the patient's own language and insights to emphasize the reasons for change while validating the importance of the reasons to resist change. It is possible that MI techniques could be used to supplement the TH-GSH-dPD protocol for patients demonstrating high levels ambivalence about engaging in treatment, either by including a course of MI prior to beginning the TH-GSH-dPD modules, or by encouraging the therapist to employ MI techniques as needed in the course of working through the TH-GSH-dPD material. In the future, it would be useful to develop a procedure for assessing treatment readiness, which might include measures like the Stages of Change Readiness and Treatment Eagerness Scale (SOCRATES) (Miller & Tonigan, 1996).

Thus, I would encourage clinicians working with patients who have recently been diagnosed with PD or other major medical illness, or who show signs of significant difficulty accepting a major medical diagnosis, to consider whether the patient's presentation indicates a ambivalence about pursuing treatment, and if so, whether the characteristics of the patient's ambivalence have implications for the treatment approach. In Gary's case, he received feedback from another provider that he "slow down," which for Gary came to mean: 'running from the diagnosis will not help,' and in the exit interview, he described this feedback as crucial to helping him move beyond his anger and denial of the diagnosis, and begin to take pragmatic steps to cope with it.

Secondly, I think being aware of the potential challenges to expressing empathy or rapport development that are imposed by a telephone-based treatment, and developing ways of maintaining or repairing rapport in this treatment modality are very important for clinicians doing this work. Although empirical evidence comparing therapeutic alliance in telephone-based and face-to-face treatments does not indicate significant differences (Dobkin et al., 2011; Stiles-Shields, Kwasny, Cai & Mohr, 2014), Gary stated that the telephone format of the treatment

interfered with our "one-on-one connection" and made it easier for him not to give me his "full attention." Aside from devoting more time and energy to validating Gary, I think I could have taken other approaches to strengthening or repairing our rapport within the telephone treatment format. For example, in our fourth session, when Gary became irritated with me when I provided possible counterevidence for his thought, I regret not putting the discussion of the skill on hold, sharing my experience of the interaction with Gary, and encouraging him to explore the source of his irritation. In the absence of visual information to use in tracking the clinical interaction, it may be more important for clinicians to directly address the therapeutic process in the moment, or to check in with the patient about their experience of treatment more frequently.

Lastly, given Gary's complaint that I was too young to understand the challenges he was facing and his doubts about the cognitive restructuring skills the program presents, and his desire for empathic support, I regret not making more of an effort to help Gary find peers within the PD community that he felt could relate to his situation, and might be able to help him work towards acceptance of his diagnosis. After Gary made clear that the Young Onset support group was too far away for him to attend regularly, I think I prematurely deemphasized the goal of finding social support within the PD community for Gary.

In his exit interview, Gary stated that what ultimately helped him come to terms with his PD diagnosis was feeling inspired by the stories of PD patients with whom he could identify. Specifically, Gary described reading the biographies of the college football coach Lou Holtz and the professional cyclist Davis Phinney—the latter of whom was diagnosed at an early age, like Gary—as central to his transition from anger and denial to acceptance and pragmatic coping. It is possible that we might not have been able to find another venue in which Gary could receive peer support, either due to a lack of options or Gary's unwillingness, but I believe more effort was warranted given the particular challenges of the case.

In seeking to understand why I did not focus more on enhancing Gary's connection to the PD community, two ideas come to mind. First, as discussed earlier, my awareness of the research context of treatment led me to feel a strong obligation to be adherent to treatment, which I believe I defined more conservatively than was necessary, which led me to focus on the skills and topics covered in the relevant module in each session. Thus, once the emphasis of the modules shifted toward cognitive restructuring techniques and away from goal settings and activity scheduling in Module 3, I focused on helping Gary learn cognitive restructuring skills rather than trying to refine and expand his activity scheduling, even as evidence mounted that he was not finding cognitive restructuring helpful.

Second, and more generally, I think the context of the treatment within a research study, the emphasis on cognitive skills within the modules, and my status as a trainee led me to conceive the "active ingredient" of change narrowly and rigidly. I tacitly assumed that the "meatier" cognitive skill components of the program should be the keys to improvement, and had a hard time revising this assumption despite significant evidence.

In retrospect, Gary gave me plenty of signals that what he needed was empathy and understanding, and that he was doubtful that I could adequately provide these things, and I wish I

had had the humility and flexibility to step back and try to help him find people who could provide this support. This speaks to a broader lesson that I continue to find applicable to many experiences implementing structured treatments: there is a great deal of flexibility and individual tailoring required even within the most structured treatment frames, and holding assumptions about the expected mechanism(s) of change lightly and in full view can help foster this flexibility.

# 7. THERAPY MONITORING AND USE OF FEEDBACK

Ongoing documentation of the therapy was captured in the recorded telephone sessions with the patients, and in my written clinical case notes and clinical impressions. After each session, these materials were used in clinical supervision that I received from Dr. Roseanne Dobkin, the principal developer and researcher of the TH-GSH-dPI treatment.

In addition to the qualitative data, the patients were quantitatively monitored on two depression measures (the HAM-D and the BDI), an anxiety measure (the HAM-A), and a measure of overall functioning (the CGI). Specifically, as shown in Table 2, the patients were administered these measures at intake (T1), in the middle of therapy (T2), at the end of therapy (T3), and at follow-up (T4 and T5).

# 8. CONCLUDING EVALUATION OF THE THERAPY PROCESS AND OUTCOME

In sum, above we have reviewed and discussed the individual course of TH-GSH-dPD treatment for four individual patients with Parkinson's disease and accompanying depression. These include two responders—Alice and her caretaker husband Bob, and Carl and his caretaker wife Doris; and two nonresponders—Ethan and his caretaker wife Fay, and Gary. As mentioned above, the quantitative results supporting the designation of "responder" and "nonresponder" are presented in Table 2.

A cross-case comparison of the four patients' treatments reveals, I propose, several factors that contributed significantly to treatment outcome in each case: a) the match between the worldview of the patient and that of the treatment program, b) the patient's cognitive functioning, c) caregiver involvement, and d) adherence to homework assignments. With each factor, I will consider the patients in the order in which their therapies were discussed above.

#### (a) Patients' Worldviews

Each of the four patients brought to treatment a worldview influenced by a host of factors, and the degree to which their worldviews matched the worldview represented by the program varied greatly. I hypothesize that the 'goodness of fit' between the worldview of each patient and the program imposed constraints and opened up opportunities in each treatment, and ultimately impacted treatment success.

Of the four patients whose treatments are profiled in this work, Alice's worldview was the most amenable to that of the TH-CBT program. The clarity and structure of the CBT

therapeutic approach fit well with Alice's concrete cognitive style, and unlike Gary, Alice had fully accepted her diagnosis, and was oriented towards active coping throughout our treatment. I believe that the good fit between Alice's worldview and that of the TH-GSH-dPD program was an important precondition for her outstanding homework compliance and engagement throughout treatment, and ultimately, her positive treatment response.

The degree of fit between Carl's worldview and the worldview of the CBT-based TH-GSH-dPD program was salient in two ways. First, my experience of Carl was that he found the TH-CBT program material to be dry, stuffy, and over-reliant on rationality. Over the course of our treatment, I came to believe that his tangents focused on the unconscious, mysterious and the occult, which at first seemed like non sequiturs, were in fact a means of expressing to me the discord between his way of seeing the world and the perspective offered by the program. As the evidence supporting this hypothesis grew, I began to experiment with managing these tangents by engaging Carl with program content on his own terms, rather than asking Carl to adapt to the style of presentation used in the modules. Ultimately, I believe that framing program concepts in language that was more consistent with Carl's worldview helped these concepts come to life for him, and helped him benefit from the program to the extent that he did. In support of this idea, Carl showed his greatest improvement at the end of the program when I began to find metaphors to help make cognitive restructuring more palatable to him.

As discussed previously, I hypothesize that Ethan's collectivist worldview led him to hold firmly to a set of beliefs about the meaning of "usefulness" that led him to view himself as "useless," and caused him significant distress. From my perspective, and the CBT perspective of the TH-GSH-dPD program, this belief constituted distorted thinking, but the importance of these beliefs within Ethan's worldview made it difficult to restructure his perception of himself by offering evidence that his criteria for "usefulness" were unrealistic. As a result, I shifted my restructuring approach and focused on the costs and benefits of maintaining his belief that he was "useless." I hypothesize that the moderate success of this approach was mediated by the same aspect of Ethan's collectivist worldview that had led to the negative thought in the first place, namely, the importance placed on the individual's impact on the community. Ethan's perceived uselessness was so distressing to him because it violated the collectivist value of contributing positively to the common good, and he drew motivation to restructure his thoughts because he did not want his low mood to detract from the common good of his family. Although Ethan did report greater success in cognitive restructuring as a result of his awareness of the "cost" of his low mood to family members and others, this development occurred at the end of Ethan's treatment, and I did not have a chance to fully assess the impact this development had on Ethan's mood. His 6-month follow-up evaluation indicated a return to pre-treatment symptom levels, and it is possible that the power of Ethan's perception of himself as "useless" outstripped his restructuring capacity. In addition, at the exit interview, Ethan reported that he felt his physical functioning had deteriorated significantly since the end of treatment, and it is possible that this process, in interaction with his collectivist worldview, contributed to the increase in his depressive symptoms.

I propose that Gary's worldview at the outset of treatment was profoundly colored by the recency of his diagnosis and the early onset of the disease. In the terms of the Motivational

Interviewing treatment's 'Stages of Change,' Gary could be said to have occupied the "Precontemplation" stage, characterized by resistance to change, and doubts about the benefits and feasibility of change, with change in this case entailing acceptance of his PD diagnosis and commitment to cope with the illness as effectively as possible (Miller & Tonigan, 1996). If Gary's PD diagnosis is conceived as a loss of a former self to be mourned, Gary could be conceptualized as occupying the "Anger" stage of Elizabeth Kubler-Ross's 'Stages of Grief,' characterized by anger about and denial of the loss (Edlich & Kübler-Ross, 1992). In either case, Gary perspective was in extreme opposition to the change-oriented perspective of the TH-GSHdPD treatment, which was predicated on an acceptance of the PD diagnosis and related psychiatric symptoms, and a commitment to working on mitigating these symptoms. I believe this mismatch significantly undermined Gary's engagement in treatment and working alliance, and ultimately led Gary to discontinue his participation in the program. Although I made some concessions to Gary's worldview, in retrospect, I believe the outcome of treatment may have been better if I had made a more significant adjustment of the program in order to accommodate Gary's perspective on his situation. Such an adjustment might have involved either (a) delaying Gary's initiation of treatment until assessment indicated his motivation for change had increased; (b) prefacing the TH-GSH-dPD treatment with another intervention designed to prepare Gary to engage in a change-oriented treatment, e.g. Motivational Interviewing; or (c) altering the TH-GSH-dPD treatment protocol in order to make it more conducive to the patient's worldview, e.g. creating space in the protocol for me to empathize with and validate Gary's anger and difficulty accepting his diagnosis.

## (b) Patients' Cognitive Functioning

I hypothesize that the cognitive functioning of the four patients discussed above also had a significant impact on treatment outcome.

## Alice and Bob

Although not clearly indicated by her MOCA score of 26, I experienced Alice's cognitive functioning to be relatively poor, particularly in the domains of abstract thinking and memory. She generally struggled to recall information from previous sessions, and had great difficulty generalizing from a concrete example to the underlying concept (e.g. when discussing cognitive distortions). The fact that Alice's mood improved substantially after she increased her activity engagement, and that we were able to restructure her negative beliefs through behavioral experiments, made her difficulty with more complex cognitive restructuring concepts less important to her overall treatment outcome. However, had she had a less supportive caregiver, or more difficulty finding rewarding or meaningful activities in which to engage, her cognitive deficits likely would have had a serious negative impact on the success of our treatment.

## Carl and Doris

Carl exhibited relatively strong cognitive functioning, demonstrating good short and long- term memory, and the ability to retain, generalize and apply abstract concepts. While many PD patients struggle with abstract thinking, Carl's strength in this area became an advantage in treatment once we were able to find a way to harness it by developing potent metaphors to help

Carl relate to program concepts. In addition, while it took Carl some time to accept the fundamental premises of the treatment and consistently comply with homework assignments, once he did, his superior cognitive abilities allowed him to absorb and put into practice a range of program concepts quickly. Without Carl's cognitive strength, it might have been more important to increase his caregiver's involvement in treatment, which I believe would have presented problems similar to those I encountered in Ethan's case, since when Doris was present early in treatment, she was frequently volatile and highly critical of Carl.

# Ethan and Fay

Ethan's cognitive deficits in the areas of executive functioning, abstract thinking and memory were a major barrier to treatment success, and maximizing his benefit from treatment required a number of modifications to my therapeutic approach, including increasing my focus on Fay's involvement in treatment, focusing on less complex cognitive restructuring interventions, trying to take advantage of concepts Ethan had already internalized whenever possible (e.g. 'cost/benefit analysis), and spending more time on the concepts we did cover in order to maximize Ethan's retention. Ultimately, I believe Ethan's cognitive deficits played a significant role in his non-response to treatment. It is possible that extending treatment, or providing more frequent and/or longer-term booster sessions following the completion of the program modules, might be indicated to maximize the benefit for patients with Ethan's degree of cognitive impairment. In addition, in light of Fay's involvement in Ethan's treatment and his significant cognitive deficits, and the positive correlation between caregiver involvement and treatment outcome (Dobkin et al., 2012), it would be useful for future research efforts in the PD population to examine the degree to which caregiver involvement can mitigate the effects of patients' cognitive deficits on treatment outcome.

#### Gary

I do not believe Gary's cognitive functioning had a significant impact on the outcome of his treatment. His cognitive functioning was assessed as slightly below normal (MOCA score = 25), but I experienced him as one of the more cognitively intact PD patients I treated, and I never felt that cognitive deficits played a role in the difficulties of our treatment. If anything, one might argue that Gary's relative cognitive strength made it easier for him to view program concepts as overly simplistic or childish, but I believe his attitude about the program had more to do with his emotional state than his cognitive capacities.

# (c) Caregiver Involvement

The degree and quality of caregiver involvement was also identified as an important factor in treatment success in the cases presented above.

#### Alice and Bob

Alice's caregiver, Bob, was highly involved in her care, participated in all of our treatment sessions, and read the modules along with Alice throughout the program. In addition, by all indications, he treated Alice with great kindness, patience, respect, and generosity, and

was able to help her articulate her thoughts and provide important bits of context during our sessions. Alice reported a very strong and loving relationship with Bob, and showed respect and gratitude towards him during our sessions. They managed their disagreements in a respectful, validating way. I believe the strength of their relationship, and the insight and investment Bob brought to the treatment, contributed enormously to Alice's treatment success. However, Bob's overprotectiveness also posed an initial barrier to treatment, because in his effort to safeguard Alice's welfare, he had reinforced her very low activity engagement, which I believed was contributing to her low mood. Luckily, Bob was very open to exploring and adjusting his interpersonal dynamics with Alice, and did a great job supporting Alice's behavioral activation, which I see as the key to her positive response to treatment. Thus, Alice's contribution to treatment was almost entirely positive, and given his important role in maintaining her disengagement, I think it would have been difficult to make significant progress in treatment without his involvement.

#### Carl and Doris

Carl's caregiver, Doris, was relatively uninvolved in his treatment after session 5, and overall, I think Doris's minimal participation benefited Carl's treatment. Carl's cognitive skills were quite strong, while Doris's seemed less so, and Doris showed minimal interest in and grasp of the program modules. Doris could not, and did not need to, provide the same support to Carl that Fay could for Ethan. In addition, like Fay, Doris demonstrated a penchant for harsh criticism of Carl, and was more volatile and difficult to redirect than Fay. Additionally, Doris had a strong accent, and I found it very difficult to understand her speech. She may have had a difficult time understanding me as well, because I often felt that her responses in our conversation indicated miscomprehension. I do think that Doris offered useful insights into Doris's thoughts and behavior at times, but for the reasons listed above, I think it was clinically indicated for Doris to play a small role in Carl's treatment, and I speculate that his treatment might not have been as successful had she been involved, although it seems equally possible that treatment would have been just as successful had Doris been more involved, because I think Carl had the cognitive and functional capacities to benefit from the treatment without much support, once the mismatch in his worldview and that of the program had been overcome.

## Ethan and Fay

Concerning Ethan and his caregiver Fay, Fay's contribution to Ethan's treatment was more complicated. Due to Fay's significant cognitive deficits, I believe it was very important that Ethan was present for most of our sessions and read the modules faithfully, since she became quite familiar with program concepts, and could help Ethan apply them. However, Fay was very frustrated with what she perceived as Ethan's irrationality and laziness, and the critical manner in which she delivered feedback to Ethan at least partially negated her positive contribution to treatment, as it seemed that both in and outside session, the hostility behind her communication made it hard for Ethan to take in her recommendations, and he often shut down or engaged her in an argument. I believe that my efforts to help Ethan and Fay develop skills to improve their interactions were partially effective based on my discussion with them in the second booster session and exit interview. However, since I spent very little time helping Ethan and Fay develop

these new skills, I hypothesize that their adversarial communication patterns continued after treatment concluded, and contributed to Ethan's poor response to treatment.

#### Gary

Gary was the only patient profiled in this work whose assigned caregiver (his mother) played no role in treatment aside from completing assessment materials. At intake, Gary stated that he did not have a particularly close relationship with his mother, but that she was the best candidate to serve as assigned caregiver for his treatment, while making it clear that he did not want her to participate in sessions, read the program modules along with him, or have any substantial role in his study participation. I see Gary's attitude of rejecting help as born out of Gary's feelings of shame and denial regarding his PD diagnosis, and exacerbated by the relatively distant relationship he had with his mother. It is possible that the participation of a caregiver, particularly someone closer to Gary, might have helped him overcome his denial and resistance, and engage in treatment more fully.

#### (d) Homework Adherence

Lastly, I believe that patients' degree of homework adherence, both in reading the program modules and putting program concepts into practice, played a meaningful role in the treatment outcomes of the patients described above.

#### Alice and Bob

Alice and Bob were highly compliant with module reading and other homework assignments throughout treatment. In part, I think this relates to the fit between the nature of the TH-GSH-dPD treatment and their worldview and outlook at the beginning of treatment: they were fully committed to treatment and appreciated the structured, problem-solving nature of the module material. In addition, unlike Gary, they had relatively few psychosocial stressors, and as retirees, had ample time to devote to reading the modules and practice program skills. Based on my treatment notes, it was extremely rare for Alice not to read the assigned module material or attempt to complete a homework assignment. In addition, Bob read the modules with Alice, which I strongly believe facilitated Alice's homework adherence and overall engagement with the program. In sum, I believe that strong homework adherence was an important factor in Alice's positive response to treatment.

#### Carl and Doris

Carl's homework adherence was fair for the first two-thirds of the program: read through the modules more than half the time, usually made an attempt at skills practice assignments (e.g. making Thought Log entries or doing cognitive restructuring practice) more often than not, and did a good job with activity scheduling. However, as discussed above, early in treatment, he had a difficult time relating to some of the program concepts, and did not seem fully engaged with the material until approximately sessions 8. However, once he did become engaged, he practiced cognitive restructuring skills (e.g. thought stopping) diligently, and reported significant benefit from them. While Carl's scores on quantitative measures of depressive severity did not drop in

correspondence with his increase in homework adherence late in treatment, my exit interview with Carl suggested that he used program skills after the end of treatment more often than most patients I spoke with, and I hypothesize that this ongoing adherence to program principles at least in part explains the fact that Carl maintained his treatment gains at the 6-month follow-up evaluation.

# Ethan and Fay

Ethan's adherence to module reading and skills practice assignments was quite poor, as he frequently forgot to do homework assignments or misplaced e-mails detailing these assignments, and Fay often complained that he procrastinated on program tasks. It was also difficult to tell how much of a given module he had read or the degree to which he had practiced a skill, because he retained so little of the information in the modules, and often misplaced homework assignments that he claimed to have completed. By the middle of our treatment, it had become clear to me that the majority of Ethan's engagement with program skills would happen within our sessions. I do believe that Ethan's poor homework adherence contributed to his nonresponse to treatment, but I also think his cognitive deficits were severe enough that it would have been hard for him to benefit significantly from additional practice without ongoing support from Fay. The difficulties in their relationship made it difficult for Fay to support Ethan in this way, but she did report an improvement in her ability to provide this support through the use of some of the interpersonal skills we worked on, and Ethan did report using the 'cost/benefit analysis' restructuring technique more effectively at the end of treatment. Ethan's 6-month follow-up scores indicate that he did not maintain the modest gains he made during treatment, and I hypothesize that poor homework adherence during the program and insufficient skill use after the program contributed to these results, although clearly, his cognitive deficits and contentious relationship with Fay were also major contributors.

#### Gary

In contrast to the other patients, Gary's homework adherence was quite poor. He reported not reading, or making cursory efforts to read, all modules aside from Module 4, and did not pursue non-reading homework assignments aside from making several entries in the Thought Log. In addition, Gary made clear that he did not have time for activity scheduling, and showed little interest in the cognitive restructuring skills we discussed, making it difficult to find appropriate homework to assign. At the exit interview, Gary acknowledged his resistance to homework assignments during the program, stating that he found the simplicity of the techniques off-putting. However, he also said he had made some efforts to identify and challenge negative automatic thoughts on his own during the course of the program, and found the process surprisingly helpful. He had not shared these efforts with me during treatment, and I suspect that doing so would have been taking a step in the direction of acceptance and commitment to change that he was not yet prepared to take.

#### Conclusion

After considering the lessons I learned in the course of the four treatments presented in this work, I believe the most important common factor underlying the treatment successes and

failures I experienced is the degree to which I was able to flexibly adapt the treatment to the needs of the clinical situation. In the case of Alice, I recognized and addressed the role Alice's caregiver was playing in reinforcing her disengagement from pleasurable activities; and in Carl's case, I was ultimately able to present the program materials in a way that he could relate to. On the other hand, I struggled to tailor treatment to sufficiently mitigate the negative impact of Ethan's cognitive and functional impairments and his combative relationship with Fay. Finally, I was unable to find a way to modify the treatment protocol to meet Gary's need for support and validation.

Overall, I am encouraged that the four case studies provide additional understanding of some of the processes that facilitate or inhibit progress in different patients' therapies conducted within the TH-GSH-dPD model. Such knowledge can be valuable in generating further empirical research questions and in improving clinical practice within the model.

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- Telephone-Based, Clinician-Guided Self-Help Cognitive Behavioral Therapy for Depression in Parkinson's Disease (dPD): The Responder Cases of "Alice" and "Carl," and the Nonresponder Cases of "Ethan" and "Gary"

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#### Table 1. Program Content Summary, p. 1

#### Modules 1 & 2: Behavioral Activation

- Review of depression symptoms
- Act according to goals and not feelings
- Act as if (not depressed/anxious)
- Schedule rewarding/meaningful activities each day
- Daily exercise

## Modules 2 & 3: Thought Monitoring

- Interpretations of events determines their impact on mood
- Thought Log helps understand relationship situation, thoughts, and emotions
- Catch and "press pause" on negative thoughts
- 'Cognitive distortions' help recognize and categorize negative thoughts

# Modules 4, 5 & 6 – Cognitive Restructuring

- Change mood by changing thinking
- Develop more realistic, balanced, accurate appraisals of situations
- Techniques:
- 'Evidence for/against,' 'Cost/benefit analysis'
- Behavioral experiments
- What would you tell a friend?
- Focusing on the most realistic outcome

#### Modules 7 – Stress and Relaxation Training:

- Complete Natural Breathing
- Guided Imagery
- Progressive Muscle Relaxation

#### Module 8 – Worry Control

- Scheduling and postponing worry
- Coping statements or positive affirmations
- Writing
- Problem-solving
- Cognitive restructuring

#### Modules 8 – Sleep Hygiene & Stimulus Control

- Maintaining a regular bedtime/wake-time schedule
- Establishing a bedtime/nighttime routine
- Using your bedroom for sleep and sex only
- Limiting naps
- Challenging negative thoughts that exacerbate insomnia

# Table 1. Program Content Summary, p. 2

## Module 9 – Simplified Restructuring

Practice moving directly from your negative thought to a more rational response

# • Module 10 – Program Review

- Review program goals, assess progress towards meeting goals, and troubleshoot obstacles to implementation of program concepts/skills in the future
- Review program concepts module by module, focusing on concepts and skills that were emphasized in treatment
- Review 'Tips for Post-Treatment'

Table 2. Quantitative Outcome Measures

		T1 (Intake)	T2 (6 weeks)	T3 (11 weeks)	T4 (15 weeks)	T5 (35 weeks)
HAM-D	Alice	19	12	7	7	N/A
	Carl	28	16	17	12	11
	Ethan	22	20	21	15	23
	Gary	18	N/A	N/A	N/A	N/A
BDI	Alice	23	14	5	8	N/A
	Carl	28	17	17	16	10
	Ethan	19	20	25	22	30
	Gary	20	N/A	N/A	N/A	N/A
HAM-A	Alice	19	15	17	16	N/A
	Carl	27	21	19	19	15
	Ethan	23	20	23	18	21
	Gary	13	N/A	N/A	N/A	N/A
CGI	Alice	Moderately III	Much Improved	Very Much Improved	Very Much Improved	N/A
	Carl	Markedly III	Minimally Improved	Minimally Improved	Very Much Improved	Very Much Improved
	Ethan	Markedly III	Minimally Improved	No Change	Minimally Improved	No Change
	Gary	Moderately III	N/A	N/A	N/A	N/A

#### Table 3. Exit Interview Questions

#### For Patient:

- 1. What were the primary difficulties you were facing as a result of your PD prior to participating in our study? How were you coping with these difficulties?
- 2. What was it like for you to participate in this treatment?
- 3. Which parts of this treatment did you find most helpful, and why? Which parts of this treatment did you find least helpful, and why? Which skills or concepts have you continued to use after completing the treatment?
- 4. What was it like to involve [name of caregiver] in your treatment? In what ways did you feel that caregiver participation was helpful/unhelpful in treatment? In what ways could the program improve the role of the caregiver?
- 5. What was it like to participate in a treatment that was delivered over the phone?
- 6. What was your experience of completing the evaluations involved in this program?
- 7. What was your experience using the written self-help materials provided to you for the program? In what ways were these materials helpful? In what ways were they unhelpful?
- 8. What do you see as the most important positive changes resulting from your participation in the study? How did those changes occur?
- 9. What were some things that did not get better for you during the program? Do you have suggestions for how the program might have better addressed these difficulties?
- 10. What are your primary difficulties related to PD at the moment? What strategies have you tried to address these difficulties?
- 11. Were there other significant obstacles to treatment success that we have not touched on? How might the program help eliminate these treatment barriers and better capitalize on treatment facilitators in the future?

#### For Caregiver:

- 1. What was it like for you to participate in this treatment?
- 2. In what ways do you feel [patient's name] benefited or did not benefit from the program?
- 3. In what ways do you feel you were able to help [patient's name] benefit from the program? In what ways was it difficult for you to help [patient's name] benefit from the program?
- 4. Which parts of this treatment were you most actively involved with? Which parts of this treatment were difficult for you to engage with? Are there parts of the program that you continued to help [patient's name] use after the program was over?
- 5. In what ways do you think the program could improve the role of the caregiver?