

# Cognitive behavior therapy: palliative care



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Individuals that have been deemed by their medical team to have serious diseases that are resistant, nonresponsive or have failed reasonable treatments are often referred to specialists for “ comfort measures only”. According to the World Health Organization, “ Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families” (WHO, 1990). The National Center for Health Statistics (1996) estimated that 20% of all deaths and 30% of the deaths of elderly individuals occurred in extended care facilities. Extended care facilities are but one place where end-of-life issues are a common fact of daily life. However, regardless of the setting, each individual faces the end of life with his or her own view of life, death and the dying process.

The estimated number of patients in palliative care varies due to the difficulty in capturing the actual numbers from hospitals, primary care practitioners, families and emergency rooms. The estimate of patients receiving the Medicare benefit for hospice and palliative care is approximately ½ million, and it is estimated that, in 2000, approximately 20% of patients dying in the United States received hospice or palliative care services. It should be noted that although many, if not most, individuals in hospice/palliative care settings are age 85 or older, this level of care is not limited to older adults. Motor vehicle accidents, post-traumatic incidents, drug overdoses and other physiologically devastating disorders may result in permanent damage to the younger body as well as the older body. Mortality

rates at a young age for those with mental illnesses is decreasing therefore it is estimated that by 2030 there will be 15 million individuals with mental illness residing in long term care facilities (SAMHSA, 2004).

This chapter will focus on the reduction or modification of autonomic, psychiatric, or sensory symptom experience of these individuals through use of cognitive behavioral therapy. Cognitive behavior therapy (CBT) uses a structured and collaborative approach while helping individuals to recognize, evaluate and restructure the relationships between their thoughts, feelings and behaviors. Through a process of targeted interventions, the therapist assists individuals to identify, monitor and cognitively restructure the dysfunctional thoughts and/or to modify behaviors that are maladaptive, useless or even harmful (Beck, 1976; Turk, Meichenbaum, & Genest, 1987; Freeman & Freeman, 2005). CBT includes a range of both cognitive and behavioral techniques such as relaxation, guided imagery/visualization, biofeedback, behavioral experiments, guided discovery, stress management, training in pain or stress management strategies, and cognitive restructuring for dysfunctional thinking and many others. Although there is a paucity of research on the use of CBT in palliative care settings, CBT is effective for many of the psychological issues that are prevalent in palliative care including, depression, anxiety, pain management, and insomnia. The purpose of this chapter is to provide an overview on the use of CBT for assessment and treatment of psychological distress in palliative care settings.

Assessment of Emotional Functioning in Palliative Care

There are many challenges to the assessment of mood disorders in palliative care settings. An initial challenge is the myth that psychological distress is a normal reaction to end of life. Despite expectations, most individuals in palliative care settings do not have symptoms of anxiety, depression or dementia. Many individuals arrive at this stage of their lives or illnesses with a sense of calm resignation, if not expectations of relief and of “going home” to God, heaven or family members waiting for them in the hereafter. Therefore those individuals that are experiencing symptoms that require intervention may achieve significant benefit from the interventions. The most common presentations are those of depression, anxiety, pain management failures with exhaustion and anguish, and sleep disorders. The healthcare provider requires tools necessary to differentiate major depression from anger, sadness, and anxiety associated with the symptoms of an untreatable or chronic illness.

Assessment of preparatory grief and depression. Another obstacle to the assessment process is simply overcoming the challenges of differentiating symptoms from normal grief of the illness itself. Differentiating between preparatory grief and depression is a key component to the proper assessment of depression in palliative care and has important treatment implications. Preparatory grief can be defined as what an individual must “undergo in order to prepare himself for his final separation from this world (Kubler-Ross, 1997).” Symptoms of preparatory grief include 1) Mood waxes and wanes with time, 2) Normal self-esteem, 3) Occasional fleeting thoughts of suicide, and 4) Worries about separations from loved ones (Periyakoil and

Hallenbeck, 2002). Preparatory grief is a normal, not pathological, life cycle event (Axtell, 2008; Periyakoil and Hallenbeck, 2002).

Major depression is defined as five or more of the following symptoms during the same two week period: depressed mood, marked diminish in pleasure, weight loss or gain, insomnia or hypersomnia, psychomotor agitation/retardation, fatigue/loss of energy, feelings of worthlessness or inappropriate guilt, lack of concentration/indecisiveness, and recurrent thoughts of death and suicidal thoughts or plans (APA, 1994). Table 1 provides a symptom list. The list is not intended to be all inclusive however it gives the clinician an overall view of symptoms that may be observed in the individual dealing with depression in a palliative care setting.

Although some symptoms of grief and depression overlap, there are ways to distinguish between grief and depression. Table 2 summarizes the ways to differentiate symptoms of grief versus depression according to temporal variation, self-image, hope, anhedonia, response to support, and active desire for an early death (Periyakoil & Hallenbeck, 2002).

The first step to proper recognition of depression involves the identification of possible risk factors (Wilson, Chochinov, de Faye, and Breitbart, 2000). Certain demographic characteristics, such as younger age, poor social support, limited financial resources and family history of a mood disorder, as well as a personal history of previous mood disorders place individuals at a greater risk for developing depression or anxiety in end of life situations. Risk for developing a mood disorder also is elevated with certain types of diagnoses, including pancreatic cancer and brain tumors, and particular

medical interventions such as radiation therapy (Hirschfeld, 2000).

Symptoms of the illness, including poor symptom control, physical disability, and malnutrition also place individuals at higher risk.

The second step to the proper assessment of depression includes utilization of appropriate assessment tools. Many times it is the degree and persistence of symptoms that provide the information necessary when considering major depression. Major depression, which is estimated to occur in fewer than 25% of patients in end of life care, may be best screened with targeted questions such as: " How much of the time do you feel depressed?" In addition, for those individuals that have a difficult time describing their symptoms or history, asking family members to provide information about a previous history of depression or a family history can be very useful.

Although studies validating assessment tools vary greatly, many of the self-report measures have been shown to be effective in palliative care patients. The most common utilized tools in palliative care settings frequently omit physical symptoms of depression. Many symptoms of depression overlap with the terminal disease process (Noorani & Montagnini, 2007). Examples of self-report measures that omit somatic symptoms include the Beck Depression Inventory II (Beck, Steer, and Brown, 1996), Hospital Anxiety and Depression Inventory (Zigmond & Snaith, 1983), and the Geriatric Depression Scale (Yesavage et al., 1983). The Hayes and Lohse Non-Verbal Depression Scale (Hayes, Lohse, and Bernstein, 1991) is a third party observational measure that can be completed by staff, family, or friends to assist with the diagnostic process. Terminally Ill Grief or Depression Scale (TIGDS), comprising of grief and depression subscales, is the first self-report

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measure designed and validated to differentiate between preparatory grief and depression in adult inpatients (Periyakoil et al., 2005).

Assessment of anxiety. The symptoms of anxiety may differ in individuals in the palliative care environment. Many times symptoms of anxiety have a physiologic component. For example in those individuals with chronic obstructive pulmonary diseases difficulty breathing, low oxygen levels and overall compromised respiratory function causes “ air hunger” which is experienced as anxiety and even panic. Table 3 lists some of the common anxiety symptoms seen in this population.

Family members are often at a loss as to what they can do to assist their loved one that is experiencing anxiety, and especially fearfulness. It is often useful to provide significant others with a checklist of items that are important to report to the healthcare provider. Involving the family has the benefit of giving them a structured guide for response which reduces their own anxiety in response to the patient. In addition the patient may relax more knowing that a family member is involved with their care in an approved, helpful manner. An example of a list of items for family members to watch for and report to the healthcare team is listed in Appendix 1.

### Cognitive Behavioral Interventions in Palliative Care

Psychological intervention in the palliative care setting includes those aspects of treatment that would provide relief from emotional distress while an individual is dying. Often this time period includes depression, anxiety, grief and organic brain dysfunctions such as dementia and/or cerebral vascular diseases. Individuals and their family members are both considered

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“ the patient” during these times. Many of these individuals are suffering from chronic, unremitting pain conditions which negatively impact their emotional health. Treatments for pain and chronic conditions also play a part in the individual’s mental status. The use of Cognitive Behavior Therapy (CBT) is extremely useful for these individuals. Cognitive Behavioral Therapy has the strongest empirical support of any psychological intervention for the management of symptoms typically seen in a palliative care setting.

The most common presentations of psychological distress in the dying patient include anxiety, depression, hopelessness, guilt over perceived life failures and remorse. Persistence of these thoughts and feelings interfere with functioning, makes the person generally miserable as well as those around them and can severely affect his/her quality of life. Medical treatments, such as antidepressants, anxiolytics and cholinesterase inhibitors, exist for these problems however supportive psychotherapy such as relaxation training, imagery, distraction, skill training, and negative thought restructuring improves the possibility of remission. CBT can also improve the symptoms of spiritual distress that may include feelings of disappointment, guilt, loss of hope, remorse, and loss of identity.

CBT for depression. Symptoms of depression are common in end of life care. It can be one of the most distressing groups of symptoms an individual can experience and may interfere significantly with daily tasks of life. Some experts have estimated that up to 75% of patients with terminal illnesses experience symptoms of depression. Amelioration of some of the symptoms of depression can increase the amount of pleasure and meaning in life, as well as add hope and peace. Treatment for depression can reduce the



experience of physical pain as well as general misery and suffering. In addition, reduction of the symptoms of depression may improve the treatment of coexisting illnesses more effectively. Most importantly, given that one of the most serious symptoms of depression is suicidal ideation, it makes sense to treat depression in order to prevent successful suicidal outcomes.

There is a paucity of literature in the area of the use of CBT with depression in Palliative Care, due to the high attrition rate resulting from physical morbidity and mortality (Moorey et al., 2009). Therefore, these factors pose significant barriers to conducting randomized clinical trials in Palliative Care to address these components. The following is a review of the sparse literature on CBT in Palliative Care with depression.

In an attempt to address this problem, Moorey et al., conducted a cluster randomized controlled trial in order to determine if it was possible to teach nurses CBT techniques in order to reduce anxiety and depression symptoms in patients with advanced cancer (2009). Eight nurses were trained in CBT by attending several 1- and 2-day workshops and then were rated on the Cognitive Therapy First Aid Rating Scale (CTFARS) for CBT competence. Seven nurses did not receive training and served in the control group. A total of 80 home care patients entered the trial; however most of these participants were excluded due to being too ill to participate. A total of 16 patients were in the CBT group and 18 patients were in the control group. The participants received home care nursing visits in which assessments were conducted at 6-, 10-, and 16-week intervals. The individuals who received CBT reported lower anxiety scores over time, but no effect of the training was found regarding depression. It was noted that both groups

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experienced lower rates of depression over the course of the study. The authors noted the heterogeneity of the sample and the high attrition rate due to physical morbidity and mortality presented several barriers to conducting the study and may have played in a role in the findings (Moorey et al., 2009).

Cole and Vaughan (2005), in their review on the feasibility of using CBT for depression associated with Parkinson's disease (PD), found that it is a promising option. The authors noted that depressed individuals with comorbid PD experienced a significant reduction in depressive symptoms and negative cognitions. In addition they experienced an increased perception of social support over the course of treatment (Cole & Vaughan, 2005). The recommended course of action for individuals in this setting included: stress management training, relaxation training, behavioral modification techniques for sleep hygiene, and cognitive restructuring. Modification of life stressors contributing to depressed mood should be identified and plans made to minimize stress and maximize quality of life. The use of thought restructuring is recommended in order to maintain a sense of purpose and fulfillment through meaningful activity and to adjust expectations of self and others. Individuals are also encouraged to return to previously enjoyed activities in order to maximize feelings of pleasure and happiness. Through systematic defocusing on physical conditions the person is able to experience more pleasant activities, which are also encouraged.

Similarly, Dobkin et al, conducted a study which explored the effects of modified CBT for depressed patients with PD, in conjunction with a separate social support intervention for caregivers (2007). The patients received 10-  
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14 sessions of modified CBT, while caregivers attended three to four separate psychoeducational classes. The modified CBT sessions were comprised of the same components of the previous Cole & Vaughan, (2005) study, such as, stress management training, behavioral modification techniques for sleep hygiene, relaxation training, cognitive restructuring, modification of life stressors, and increasing engagement in pleasurable activities. The classes were targeted at providing caregivers with ways to respond to the patients' negative thoughts and beliefs, as well as, strategies to offer appropriate support. As in the previous study, the modified CBT sessions were comprised of training in stress management, behavioral modification, sleep hygiene, relaxation techniques, and cognitive restructuring. Participants reported a significant reduction in their depressive symptoms and cognitions and increased perception of social support at treatment termination and one-month post-treatment.

CBT for anxiety. Along with depression, anxiety is a common mental health problem in palliative care settings and also appears to be alleviated with CBT interventions. In a small feasibility study examining the use of cognitive behavioral therapy techniques for mild to moderate anxiety and depression in hospice patients, four sessions of CBT techniques was found to significantly reduce anxiety and depression in a majority of patients (Anderson, Watson, Davidson, and Davidson, 2008). Overall, participants in the study found the CBT techniques acceptable, helpful, and qualitatively reported improved mood. A significant reduction in anxiety symptoms also was seen in a randomized controlled trial of CBT administered by home care nurses in patients with advanced cancer (Moorey et al., 2009).

CBT techniques are particularly effective to assist with the management of anxiety related to breathing difficulties commonly seen with pulmonary diseases, such as chronic obstructive pulmonary disease (COPD). In a group of individuals with COPD, six sessions of guided imagery, a CBT relaxation technique, was found to significantly increase the partial percentage of oxygen saturation, which is a physiological indicator signaling more effective breathing (Louie, 2004). In another study, as little as 2 hours of CBT group therapy yielded a decrease in depression and anxiety among older patients with COPD, but there was no change in physical functioning (Kunik et al., 2001).

CBT for pain management. Pain is not simply a biological response to unpleasant stimuli. It is a complex phenomenon that includes biological, psychological, behavioral and social factors that interact in complex ways to influence the pain experience. Some of the factors that can influence a person's experience of pain include: a) previous pain experiences, b) biologic and genetic predispositions, c) mood disorders such as anxiety and depression d) their beliefs about pain, e) fear about the pain experience, f) their individual pain threshold and pain tolerance level, and f) their skill with coping methods. Cognitive-Behavioral Therapy has the most empirical support for the management of chronic pain, especially when used as part of an interdisciplinary treatment approach to manage pain symptoms (Turk, Swanson, & Tunks, 2008).

Cognitive behavioral techniques can be used independently to assist with pain management or integrated into a comprehensive cognitive-behavioral case conceptualization framework to address pain (Turk, Swanson, & Tunks, <https://assignbuster.com/cognitive-behavior-therapy-palliative-care/>

2008). The three components to CBT for pain management are 1) Education and rationale for the use of CBT, 2) Coping skills training, and 3) Application and maintenance of CBT skills (Keefe, 1996). Useful behavioral interventions to assist with pain management include goal setting, relaxation strategies, such as deep breathing and guided imagery, and activities scheduling. Cognitive interventions would include increasing problem-solving skills and addressing an individual's maladaptive thoughts related to pain management. Examples of maladaptive thoughts include: 1) I've tried every pain management intervention with no success, 2) I cannot do any of the things that I used to do, 3) nothing will help manage my pain, and 4) no one can help me feel better. CBT for pain management has demonstrated efficacy in various diagnoses often addressed in palliative care. CBT has been found to be efficacious in the management of cancer-related pain in single studies (Syrjala, Donaldson, Davis, et al., 1995) as well as in systematic reviews (Abernethy, Keefe, McCrory, Scipio, & Matchar, 2006).

CBT for sleep hygiene. Insomnia, sleep duration and quality are major concerns for people with pain disorders such as osteoarthritis (Vitiello, 2009). Approximately 60 percent of individuals with chronic pain disorders report frequent nighttime awakening due to pain during the night. Disrupted sleep patterns exacerbate chronic pain intensity and experience which in turn causes more disturbance of the sleep/wake cycle. Successful treatment of interrupted sleep may reduce the pain experience as well as improve the overall quality of life for these individuals. Psychotherapeutic techniques that target sleep disturbances are easily incorporated within behavioral and cognitive management of other co-occurring disorders as well.

Sleep disorders are common in patients who suffer from Parkinson's disease (PD) (Stocchi, Barbato, Nordera, Berardelli and Ruggieri, (1998). Specifically, insomnia, nightmares, REM sleep behavior disorder, sleep attacks, sleep apnea syndrome, excessive daytime sleepiness, and periodic limb movement in sleep result from changes in sleep structure, movement disturbances in sleep, disturbances in neurotransmission and medications. Individuals who are sleep deprived are at risk to develop infections, cardiovascular disease, hypertension, diabetes, depression, and require increased time to recover from stress (Schutte-Rodin, Broch, Buysse, Dorsey, and Sateia, 2008). CBT improves sleep by addressing unhelpful beliefs regarding sleep and misperceptions about the amount of sleep that one obtains. Many misperceive the amount of time they are actually asleep. People who suffer from insomnia actually sleep more than they are aware of because they are only attentive of when they are awake. Furthermore, many people believe they require 8 hours of sleep in order to be able to function during the day and any amount of sleep that is less is insufficient and will result in reduced ability to function during the day. Therefore, these beliefs and misperceptions can increase one's stress level about sleep and a stress response may result when one thinks about going to sleep. Clearly, a heightened stress response is not conducive to sleeping. CBT increases one's control over their unhelpful and inaccurate beliefs and enables them to replace them with more helpful and accurate beliefs (Whitworth, Crownover, and Nichols, 2007).

CBT also addresses the behavioral components of one's sleep routine or patterns that interfere with one's ability to obtain restful sleep. Exercising,

smoking, or drinking caffeinated drinks just prior to bedtime can interfere with one's sleep. All of these activities are stimulants that energize the body. Also, not having a bedtime routine, a regular sleep-wake pattern, or taking naps may interfere with one's ability to get restful sleep. Increasing one's sleep hygiene by developing positive habits that influence sleep such as, having a bedtime routine to prepare one's mind and body for sleep, regular exercise several hours before one intends to prepare for sleep, and avoiding coffee, alcohol, and smoking in the evening, as well as, increasing activities that produce relaxation (e. g., taking a hot bath one to two hours before going to bed, meditation, deep breathing, or muscle relaxation) can increase the likelihood of obtaining restful sleep. Another behavioral strategy utilized in CBT is sleep restriction. This technique attempts to match one's actual sleep requirement with the amount of time one spends in his/her bed. The theory behind this approach is that reducing the amount of time spent in bed without sleep will increase one's desire to sleep (Harvey, Ree, Sharpley, Stinson, and Clark, 2007).

Results of a study by Vitiello showed that " treatment improves both immediate and long-term self-reported sleep and pain in older patients with osteoarthritis and comorbid insomnia without directly addressing pain control" (2009). This study included 23 patients with a mean age of 69 years were randomly assigned to CBT, while 28 patients with a mean age of 66. 5 years were assigned to a stress management and wellness control group. Participants in the control group reported no significant improvements in any measure while Individuals treated with CBT reported significantly decreased sleep latency (onset of sleep) by an average of 16. 9 minutes and 11

minutes a year after treatment. Interruptions in sleep after sleep onset decreased from an average of 47 minutes initially to an average of 21 minutes after one year. Pain symptoms improved by 9.7 points initially to 4.7 points. Sleep efficacy (how rested does the person feel upon awakening) initially increased by 13 percent and 8 percent a year after treatment. The improvements remained robust in 19 of 23 individuals at a one-year follow-up visit.

Furthermore, while many older adults experience insomnia, it is reported that up to two-thirds of those who experience these symptoms have limited knowledge regarding available treatment options. Sivertsen (2006), conducted a randomized controlled trial to compare the efficacy of non-benzodiazepine sleep medications with CBT. This study included 46 patients with a mean age of 60.8 years who were diagnosed with chronic primary insomnia. Participants were randomly assigned to either the CBT intervention (information on sleep hygiene, sleep restriction, stimulus control, cognitive therapy, and progressive relaxation), sleep medication (7.5 mg zopiclone each night), or placebo medication. Treatment lasted 6 weeks, and the CBT intervention and sleep medication treatments were followed up at 6 months. Data regarding total wake time, total sleep time, sleep efficiency, and slow-wave sleep was collected utilizing sleep diaries, and polysomnography (PSG; monitors physiological activity during sleep). Results revealed that total time spent awake improved significantly more for those in the CBT group compared to the placebo group at 6 weeks and the zopiclone group at both 6 weeks and 6 months. In comparison, the zopiclone group did not reveal significant results from the placebo group (Sivertsen, 2006). The CBT group



experienced a 52 percent reduction in total wake time at 6 weeks compared with 4 percent and 16 percent in the zopiclone and placebo groups respectively. A statistically and clinically significant finding was that participants receiving CBT improved their PSG-registered sleep efficiency by 9 percent at posttreatment, opposed to a decline of 1 percent in the zopiclone group. Total sleep time increased significantly between 6 weeks and 6 months for the CBT group. The zopiclone group showed improvements at 6 weeks and maintained these improvements at 6 months, but did not show further improvements. The CBT group showed significant improvements compared to the zopiclone group in total wake time, sleep efficiency, and slow-wave sleep; total sleep was the only area that did not yield a significant difference (Sivertsen, 2006).

## **ADAPTING CBT TO THE PALLIATIVE CARE SETTING**

### Overview of CBT in Palliative Care

Cognitive-behavioral therapy is effective for many of common mental health issues seen in palliative care and often augments the success of pharmacological interventions. In addition to the individual with the terminal illness, their family members, as well as multiple health providers are considered integral members to the success of the collaborative relationship. Use of a CBT case conceptualization framework and various components offer flexibility, which makes the CBT approach feasible to implement within a palliative care setting. The following section provides an overview of the components of cognitive-behavioral therapy and necessary adaptations to palliative care settings.

## Collaborative Relationship

As mentioned in previous chapters in this book, a collaborative relationship is a core component of an effective cognitive-behavioral intervention. In a palliative care setting, the collaborative relationship often involves more than just the client and the therapist. The interdisciplinary treatment team works with the individual to develop an individualized treatment plan that is central to the case conceptualization and goal setting of CBT. A variety of disciplines, such as nursing and social work, use CBT techniques in palliative care settings. Individuals receiving palliative care often need assistance with CBT interventions as their illness progresses. Individuals receiving palliative care often need assistance from the treatment team with practicing skills, such as relaxation techniques, and adapting CBT interventions as goals of care change.

Some individuals in the Palliative Care setting may not be facing death in the near future, and if they are facing impending death, they may not be aware of it. In these cases the primary patient may be the family member or significant other. It is also common practice for most individuals to seek help for mental health problems from their family practitioner even though the typical family practitioner has very little training in psychiatric/mental health assessment, diagnosis and treatment. In cases where the family is relying on an under-trained health care provider it may be incumbent upon the mental health provider to negotiate the gap between family and medical care.

## Case Conceptualization and Goal Setting

Therapy with the dying person should begin with having the person identify, explore and determine outcome goals regarding the issues at hand. Similarly to the primary care setting, case conceptualization and goal setting need to occur almost immediately. The therapist uses the Socratic Dialogue to explore the person's concerns and worries. This gives the individual more of a sense of control over what will be happening in the therapy session. Once this sense of control is established it becomes easier to explore other, more emotion laden topics.

Goals should be small, obtainable and proximal to the session to be most effective. For example, " Mrs. Jones I will be back to see you tomorrow. One of the things you have decided to practice is your deep breathing at least twice tonight and again in the morning. When I return I will check with you to see how you are doing with the practice." In palliative care setting, it may be necessary to discuss how other people involved in care can assist with reaching goals. For example, nurses might remind individuals to practice relaxation strategies during wakeful periods, as well as talk an individual through the relaxation technique when experiencing a high level of pain.

### Behavioral Interventions

Pleasant Events Scheduling. Activities scheduling is a useful intervention to assist with mood disorders, pain management, and sleep hygiene issues seen in a palliative care setting. Engaging in pleasant events distracts an individual from negative thoughts and provides experimental evidence to support more adaptive thinking styles. Often times in palliative care the first barrier to overcome is identifying pleasant events that can occur in a

palliative care setting due to health limitations. Pleasant events need to be person-centered, meaningful, and feasible activities that can be built into a daily routine.

Meaningful pleasant events can be identified through both clinical interview and self-report methods. Clinical interview queries should include taking a history of an individual's daily schedule and identify activities the individual enjoyed engaging in on a routine basis prior to their illness. From the generated list of previously enjoyed pleasant events it needs to be determined which activities the individual can continue to enga